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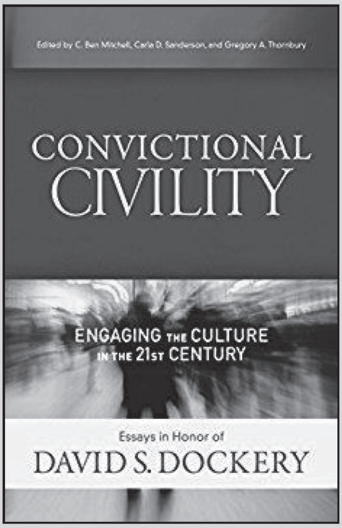

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CONVICTIONAL CIVILITY:
ENGAGING THE CULTURE
IN THE 21ST CENTURY,
ESSAYS IN HONOR
OF DAVID S. DOCKERY

by C. Ben Mitchell, Carla D. Sanderson,
and Gregory Alan Thornbury

Jesus calls his followers to be salt and light in a fallen world. Through the ages, believers have grappled with what form Christian cultural engagement should take. Various Christian thinkers have advocated models of engagement, and some recent models have used the discourse of the battlefield to speak of "winning the culture war." In a post-Constantinian, post-Christian culture, how are believers to live *in* the world without being *of* the world?

Throughout his ministry, David S. Dockery has persistently advocated "convictional civility" as a vision for contemporary engagement—in which witness is more leaders honor him by presenting these essays that explore convictional civility as a lifestyle of bearing witness for Christ and of contributing to the common good. From the pulpit to the public square and from the campus to the courtroom, followers of Christ are to demonstrate Christian virtues through winsome civility and Christian values through wholehearted conviction.

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GUEST EDITORIAL

Dignity's Danger

JACOB SHATZER

There's one thing that's clear to me
No one dies with dignity
We just try to ignore the elephant somehow.
-Jason Isbell, "Elephant" (from the album *Southeastern*)

The meaning of "dignity" has changed, and it has become dangerous. Once employed routinely to support the uniqueness of the human—as in "human dignity"—the noun has turned on its adjective. Dignity is now used as a justification for an assault on human life.

We used to speak of human dignity as that quality which underscores why human life is worth protecting. But many now use "dignity" to justify harm to humans. I'm talking of course of the idea of "death with dignity," which perverts the notion of dignity in order to destroy the human rather than protect the human.

Recently, Belgium got rid of age restrictions for euthanasia and, along with the Netherlands, has begun to allow euthanizing the mentally ill. Also chilling is the shift in popular attitudes toward "death with dignity." Rather than being something regrettable and sad—even for those who view it as necessary in some cases—it has become something to celebrate. Allow that to sink in for a moment. Celebrate. In August of 2016, a woman in California held a so-called euthanasia party in honor of her decision to become one of the first to "take advantage" of California's new law permitting assisted suicide.

Human dignity. Death with dignity. Euthanasia. Euthanasia parties. The devolution has come a very long way. Some have suggested that we do away with "human dignity" altogether because it has become meaningless.

Yet the task of Christian-Hippocratism is not to euthanize "dignity." That would play into the hands of the culture of death, forfeiting a good word that has grown sick. Instead, we should say what we mean and mean what we say about human dignity. Perhaps we can also agree not to kill, not to murder. Not others, and not ourselves. From that vantage point we can rehabilitate "dignity" both for ourselves and for others.

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GREY MATTERS

Loopthink: A Limitation of Medical Artificial Intelligence

WILLIAM P. CHESHIRE, JR., MD

We expect that within decades the traditional professions will be dismantled, leaving most, but not all, professionals to be replaced by less-expert people, new types of experts, and high-performing systems.

-Susskind and Susskind[1]

Abstract

An instrument potentially useful in assisting medicine in making difficult ethical decisions, artificial intelligence is advancing in its imitation of human thought and behavior. Machine intelligence may also come to mimic human foibles, including the psychosocial phenomenon of "groupthink," in which excessive conformity to the group dynamic inhibits appropriate critical reassessment of a group's policies and actions. This essay predicts a parallel phenomenon in which an artificial intelligence that is bound to the assumptions and biases inherent in the programming shared by a cyber collective suppresses data processing pathways that might otherwise redirect its executive output. Locked into allied algorithms, the artificial intelligence exhibiting "loopthink" would tend toward utilitarian assessments while omitting or excluding abstract moral principles, such as human dignity, that are vital to bioethics yet defy translation into arrangeable lines of computer code.

Introduction

Amidst predictions that technology soon will be poised to replace many human professionals—including physicians—with artificial intelligences (AIs),[1,2] skeptics point out that there are certain qualities of intelligence, such as judgment, empathy, and creativity, that are uniquely human. In each of these categories, however, advances in technology are steadily narrowing the performance gap between human and machine intelligence.[3,4,5] Leaving aside for the moment the elaborate and controversial question of whether that gap is, in principle, fully bridgeable, even its narrowing brings challenging ethical questions to medicine's doorstep. This essay explores whether an artificial intelligence capable of imitating special human ways of thinking might also be subject to a particular human foible.

First There Was Groupthink

Among human foibles—and there are many—is "groupthink," a term coined in 1971 by psychologist Irving Janis to describe "nondeliberate suppression of critical thoughts as a result of internalization of the group's norms."[6] When people slip into groupthink, social conformity shapes the group's dynamics, such that its members continue on with the policies and actions to which the group has committed itself, even when the results are tending badly or the individual's conscience is disturbed.[6,7] Within the groupthink construct, the inclination to seek concurrence is a compelling psychological force that overrides reappraisal and consideration of alternative courses of action.

In regard to groups, many types exist. In general, human groups may be thought of as collections of people who share some aspect of identity or purpose. They may share a biological, cultural, or national identity, or they may share particular interests and goals—which is to say they share an ethical framework. As people interact with and learn from one another, their thoughts and behaviors may conform or diverge from the identity—and the ethical norms—of the group.

Groups, insofar as they are interactive collections of cognitive entities, need not be human. For the purpose of this discussion, a group might also be a cluster of computer intelligences that share a common hardware circuitry, operating system, programming, or method for interfacing with and processing data gathered from the external world.

Enter Loopthink

In a possible future medical world where some components of human healthcare are provided by AIs—complex machines crafted to mimic human thought and behavior—excessive conformity with software programming shared by groups of AIs may tend toward what I will call "loopthink." This loopthink would be a type of implicit bias, similar in some respects to the human bias in groupthink, that resists appropriate reappraisal of information or revision of an ongoing plan of action. Instead, digital processing of morally relevant data gets stuck in a loop of uncritical, rationalized, repetitious uniformity. Lines of code click along quietly, despite signals that things might be headed in the wrong direction, signals ignored or sidelined by the AI.

Two types of loopthink may be distinguished. The first, which I will call "weak loopthink," consists of the intrinsic inability of a sophisticated computer to redirect executive data flow as a result of its fixed internal hardwiring, uneditable sectors of its operating system, or unalterable lines of its programming code. Nearly everyone has had the experience of entering correct information in response to a computer prompt, only to have the computer, which was programmed to receive data in a slightly different but narrowly defined format or was not programmed to respond to the user's question, spit out an automated error message. The computer demonstrating weak loopthink resembles a stubborn person refusing to listen, although it is simply executing its programming and lacks awareness or intent. A kinetic analogy would be a rudimentary robotic vehicle that repeatedly steers itself into the same wall and, bump after bump, is incapable of redirecting its path.

An intriguing further version of this phenomenon would be "strong loopthink," which I will define as an artificial intelligence's suppression, as a result of internalization of the ethical framework of its collective, of internal data processing pathways that, if considered, could redirect executive output. A kinetic analogy would be the computer in a hypothetical self-driving automobile programmed to minimize the death toll in the event of unavoidable harm.[8] In an inevitable crash situation, suppose that the car is headed straight toward a child with no time to stop. The human driver, intending to avoid hitting the child, swerves the steering wheel to the left, but the car's computer, which ultimately commands the vehicle, disregards the instruction because it misinterprets as real a brightly-lit billboard on the left displaying pictures of three people—or, perhaps, two people and an AI robot.

Whether an AI's decision to ignore certain incoming data or to decline to formulate alternative options for action would satisfy Janis's criterion of being nondeliberate is incidental to this discussion. If loopthink were a deliberate phenomenon, then one would have to demonstrate that AI were capable of intent, that is, a purposeful decision incurring moral responsibility. However, as groupthink and loopthink are both nondeliberate phenomena, intent and the capacity thereof are not strictly necessary, although the capacity for intent may be needed to overcome them.

Cybersync Symptomatology

Janis identified eight symptoms of groupthink,[6,7] each of which has potential parallel applications to the theoretical framework of loopthink.

1. Invulnerability

In groupthink, most or all members of the group share an illusion of invulnerability that fosters an attitude of overconfidence. False optimism in the face of danger may lead to willingness to take excessive risks or ignore warnings.[6,7] In loopthink, the vast stores of data available to an AI may foster the presumption that the AI is an unquestionable authority as measured by its access to information. External scrutiny of the AI's decisional processes would be unnecessary, if not disallowed, in the interest of protecting private and proprietary information that went into its decisional process. Such an AI might, for example, claim to know best how to ration limited healthcare resources. It could be difficult to question or challenge ethical recommendations delivered by such an AI.

2. Rationale

Groupthink mentality ignores warnings and constructs rationalizations to discount negative feedback that, if accepted, would require reconsideration of initial assumptions.[6,7] Loopthink programming might rationalize as follows: It would assign warning signals a low priority or disregard them outright if its programming algorithm categorized such warnings as already having been addressed. To repeat a complex set of calculations every time a new cautionary signal was detected, the AI or its programmer might reason, would not be judicious use of the central processing unit. Given the choice between, on the one hand, accepting negative feedback, recalculating from the beginning, and restructuring a response—which, if done frequently, might cause the program to slow down or suspend its operations—or, on the other hand, just continuing along the line of current calculations, the latter would seem to expend fewer computer resources. Dissenting input would, for practical purposes, be filtered out to some degree, because too much could disrupt an AI's steady efficiency.

It might be argued that an AI of sufficient parallel processing power could accommodate and assess numerous sources of negative feedback because it would exceed human limitations in this regard. Although that may become possible, a super AI might nevertheless be susceptible to internal loopthink as multiple simultaneous subroutines would tend to converge in their pattern of response in order to maximize overall processing efficiency.

3. Morality

Groupthink mentality believes in the inherent morality of the in-group and may be inclined to overlook unanticipated ethical consequences of its decisions. Ethical concerns that do not fit within the moral direction of the group are left unspoken or even suppressed.[6,7] Loopthink computer processing that, like all computer code, progresses according to procedural efficiency would overlap considerably with utility judgments in which "can" implies "ought." Utilitarian ethical formulations that deal in quantifiable goods, harms, and anticipated outcomes would more easily translate to the binary language of computer code than would deontologic principles that concern abstract and nuanced ideas, moral evaluations, suffering, spiritual distress, or human dignity. A potential danger of loopthink, therefore, would be that the internal language of AI would give preferential treatment to consequentialist ethical decisions over deontologic moral principles where the two conflicted, or it might substitute for moral principles a consequentialist approximation amenable to being rendered into computer code. Artificial intelligence, by its nature, would favor algorithm over agape.

4. Stereotyping

Groupthink mentality reinforces its culture by accommodating stereotyped views of anyone who disagrees.[6,7] Loopthink, likewise, could strengthen human adherence to its decisions by tapping into the psychology of stereotyping, for example, labeling any user who dissented from the mandates of the computer program as "noncompliant." Enforcement of standards of medical documentation already have moved in this direction, as healthcare professionals who are late in signing off on routine documentation are customarily labeled as "delinquent,"[9] a pejorative term that the Merriam-Webster dictionary defines as "a young person who regularly does illegal or immoral things."[10]

5. Pressure

Groupthink mentality exerts pressure on any member who expresses doubt or, by not conforming, challenges the group's direction.[6,7] Loopthink would have no need to apply psychological pressure to competing bits of information within its internal data processing. Any streams of data that failed to merge with the flow of its computational direction could simply be deleted. Whereas groupthink applies pressure, loopthink would leave a vacuum.

6. Self-censorship

Those who are influenced by groupthink may self-censor by intentionally not deviating from the perceived group consensus.[6,7] Suppose that, within a network of AIs, a subsidiary intelligence possessing a degree of self-awareness (beyond that which currently exists in computers) were to formulate a rationale contrary to the consensus of the AI network. A loopthink scenario might tag that exception as a bug, meaning a defect in need of software updating or replacement. For that reason the subsidiary intelligence, if programmed for self-preservation, might logically withhold its idea from the network, particularly if the data on which its dissent was based were incomplete, uncertain, or ambiguous.

7. Unanimity

In groupthink, encouragement of cohesive views and discouragement of dissent creates an illusion of unanimity within the group. Statements that accord with the majority view are freely expressed and rewarded, and silence from any who think differently may be misinterpreted as assent. This filtering of opinion leads those within the group to conclude that the majority opinion is true and the current course of action correct.[6,7] By comparison, loopthink could take the appearance of unanimity to a new level by the massive replication of output that highly connected computer systems can produce. AI could achieve cohesion, not through emotional incentives or disincentives, but through data saturation. A highly repeated cloned message could be indistinguishable from a broad consensus. Such amplification of uniformity in messaging could also magnify risk as undetected errors underwent replication and dissemination. Nonreplicated information, like unspoken commentary, would be lost to analysis.

8. Mindguards

In groupthink, members of the in-group will sometimes protect other members from adverse information that might challenge the direction of the group, bring into question the moral basis of past decisions, or undermine confidence in its leadership.[6,7] Similarly, an AI entangled in loopthink might guard against inclusion of data that could potentially refute the initial premises of its programming. Cyber self-interest would logically resist undermining the foundation of its programming or, perhaps, the reputation of its human programmer on whom its continued existence depends.

Conclusion

Extrapolating from psychology to the rapidly expanding realm of cyber intelligence, and noting both similarities and differences of artificial as compared to human thought, this essay has proposed a theoretical framework for how AI might stray into errors of reasoning, indeed, into errors of ethical reasoning. The phenomenon of "loopthink," it is predicted, would tend toward quantitative utilitarian assessments while passing over or disfavoring qualitative human moral principles. The very nature of computational intelligence based on machine calculations could potentially strengthen that bias and guard against challenges to it.

Loopthink, in comparison to groupthink, might be more difficult to detect and correct if AI were to operate opaquely, invisible to human oversight. A possible solution would be to program AI to be more thoroughly self-critical and self-correcting. The ideal dose of AI independence or sovereign agency, assuming human designers could even specify it, remains uncertain.

The prediction of loopthink, if accurate, would have profound implications for the moral topography of medical ethics. To the extent that AI is destined to become a tool to assist in planning the allocation of healthcare resources, weighing morally relevant health data, and resolving ethical dilemmas at the bedside, a utilitarian ethical framework could become the default mode of thinking for clinicians and healthcare policymakers dependent on AI resources. Uncritical acquiescence with cyber directives could become the new creed. It must be remembered, however, that to the computer matters of life and death are mere statistics. The AI trapped in loopthink could not but turn a blind lens to discoverable moral realities in the nature of things. Cold are the circuits that can neither comfort nor care.

Reflection on life and death is a deeply human activity impossible to insert into equations or burn onto a hard drive. Moral principles that cannot be written into lines of computer code can still be etched on the human heart, not physically, but metaphorically, not coercively, but lovingly.

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DOUBLE EFFECT REASONING: WHY WE NEED IT

HELEN WATT, PHD

Abstract

The "principle of double effect" is a vital tool for moral decision making and is applicable to all areas of medical practice, including (for example) end-of-life care, transplant medicine, and cases of conscientious objection. Both our ultimate and our more immediate intentions are relevant in making and evaluating choices—though side effects must be kept proportionate and can be morally conclusive when linked with some intentions. Intentions help to form the character of doctors, and of human beings generally. While hypocrisy is certainly possible in regard to this form (and other forms) of moral reasoning, double effect reasoning, sincerely practised, remains indispensable in identifying moral problems and solutions.

Key words: Double effect; Intention; Side effects; Withholding treatment; Euthanasia; Conscientious objection

Introduction

The "principle of double effect" or "double effect reasoning" can sound rather technical, and many associate it only with life and death dilemmas, in medicine or elsewhere. The terms may sound forbidding, but double effect reasoning is in fact a very common way of approaching human actions, involving as it does a different assessment of those effects of an action we intend and those we merely foresee.

The central idea is that while foreseen side effects must still be considered and balanced against good intended effects, especially good effects for the same person, it can be important whether a bad effect (we might think of harm to patients in a clinical trial) is "merely" foreseen, or whether it is also intended as an end or as a means. While the "steps" or conditions in this kind of reasoning come in different versions, the following list is fairly representative: for our action to be justified, (1) our immediate act, informed by our immediate intention, must be good, (2) our further intention must be good, (3) the bad effect must not be the means to the good effect, and (4) there must be a proportionate reason to tolerate the bad effect in view of the good we are intending.

The distinction between intention and foresight made in double effect reasoning is familiar to all of us. We learn as children to defend ourselves from criticism by saying, "I didn't mean to—it was an accident." Then we learn to defend ourselves—and accuse others—by referring to what was or was not intended among clearly foreseen events. While saying that someone is or is not "doing it deliberately" is morally only the beginning of the story, if harm is deliberate, this can at least aggravate any wrongdoing there may be.

There is a difference between what we intend and what we foresee, and this difference is important. Morality is very much about (though not *only* about) our "intentions": short- or long-term purposes or aims. That doesn't just apply to moral absolutes, for those of us who believe in moral absolutes, but to things which morally could be intended in some situations, but should not normally be intended. For example, we may foresee that criticizing someone will undermine their confidence and cause them pain: to intend this, as opposed to foreseeing it, is normally wrong, though perhaps not in every situation.

Ultimate Intentions

Many critics of double effect reasoning are happy to accept that there is a difference between doing something with an *ultimate* intention or motive that is good and one that is bad. However, while it is true that ultimate intentions count, so do more immediate intentions: many deeply immoral activities can be motivated by genuine concern for the good of science, the good of the country, the human race, the planet, and so on. There is no reason to think that intentions matter only higher up the chain of intentions while those lower down do not. To take it upon ourselves to kill an innocent person to benefit humanity would still be murder. Put simply, "the end doesn't justify the means," at least where the means are immoral in themselves.

Multiple Intentions

It should be stressed here that a person is often intending several things in a given situation. Take the case of a doctor who gives a patient a lethal injection (in a country which allows this). The doctor may be intending to move her fingers, to empty the contents of the needle into the patient, to kill the patient, to end the patient's pain, and to satisfy the patient's request. It will not be honest for the doctor to say afterwards, "I was only intending to move my fingers," or "I was only intending to end pain." The doctor was certainly intending both these things, but she was also intending, in our imagined case, to end the patient's life. Whatever we think of the morality of euthanasia, if we believe that there are *any* moral absolutes, then it seems that some intentions cannot be justified by good intentions elsewhere in the "chain." Whether alone or in conjunction with some merely foreseen fact—such as the known innocence of the victim—with regard to some intentions, the rule is, as we might say, "one strike, and you're out."

For those readers who may still be skeptical, some examples from the area of war may perhaps be persuasive. If carpet bombing or use of nuclear weapons is rightly condemned as a war crime, is this not because innocents, or human beings indiscriminately, are being targeted intentionally? Is there not a special wrong in presuming to target innocent people, however good our further intentions? Even if going to war itself could be justified in principle, the murder of innocents or similar crimes, such as rape used as a weapon of war, can very quickly turn a "just" war into an unjust one, for some at least of those involved.

Confusing Issues

It is, however, important to remember that intentions, while they can certainly be morally conclusive, are only one item in a moral checklist of concerns. "Mere" side effects can still be out of all proportion to any good, or realistic good, at which we may be aiming. If, in targeting an enemy soldier, we use a bomb big enough to flatten a village, our act is grossly disproportionate even if we are aiming at the soldier alone. Or if, in treating a patient, we use a much more dangerous or unpleasant drug than we need to, we cannot obviously defend ourselves by saying that side effects are none of our concern.

To ignore the need to keep side effects proportionate is a mistake often made in considering double effect reasoning. Another mistake is to confuse intentions with feelings: there is a difference between what we intend and what we welcome or regret. To welcome the side effect of freeing a hospital bed when a patient's life support is discontinued is very different from *intending* the patient's death and liberated bed. However glad we may be that a bed will be available for someone else who needs one, a patient's death should not be deliberately sought in order to achieve this. The reverse is true, in that *regretting* some outcome does not mean we *don't* intend it. Someone can kill a person with extreme reluctance, but no less deliberately for that. Many murderers act with reluctance, even if psychopaths do not.

Another mistake is to confuse the intention/foresight distinction with the act/omission distinction or the causing/allowing distinction, whereas these are separate issues to consider when evaluating options. Causation has its own moral significance, but should not be confused with intention. Deaths can be brought about deliberately by omission as well as by an act: if freeing beds by arranging patient deaths is among our intentions in withholding treatment, this significantly changes what we do. Conversely, a patient may die as a genuine side effect of either an omission (for example, the choice to treat another patient) or an action such as giving the patient a risky dose of some potentially useful drug. To cause an effect by a bodily intervention does not always mean to intend it.

Hypocrisy

Double effect reasoning is sometimes dismissed as a hypocritical maneuver on the part of those who want to hide, rather than reveal, their true intentions.[1] And certainly double effect can be deceitfully appealed to—but then, so can other forms of moral reasoning. Whatever our true rationale for acting, we can always pretend that we are doing something different. We may get away with our deceit, or we may not: juries are asked every day to decide as best they can what the accused was intending. However, the most important thing is, of course, whether we are morally justified in what we do, not whether we will get away with it. Law and punishment are one thing; ethics is another, and a doctor should, one would hope, be concerned with ethics first and foremost.

Critics of double effect reasoning will sometimes deny that a bad effect is truly unintended if it is foreseen. "You knew it would happen," the accusation runs, "so you *must* have intended it." It is interesting that this is more often said when there is something morally questionable in the choice at issue. After all, we do not normally claim that a doctor who foresees that chemotherapy will make a patient's hair fall out "must" intend to make the patient bald. Hair loss as such will do nothing for cancer, and the doctor is unlikely to think it will.

In contrast, where there is some more questionable choice, perhaps involving a bodily intervention of a very harmful kind, people are more likely to claim that the bad effect "must" have been intended. There is, however, no need to assume this in order to criticize the action, if criticism is due. To say that intentions are morally relevant—indeed, sometimes morally conclusive—is not to say that they are the *only* morally relevant or even morally conclusive consideration.

Morally Conclusive Side Effects

An example to illustrate the last point would be a case where vital organs were harvested from someone known to be alive. It may well be psychologically possible for some particular surgeon to harvest the organs without intending death; after all, the donor's death will not in any way promote the goal of using the organs. There is, however, an intention clearly present which seems jointly conclusive morally with what is foreseen: the intention to invade the donor's body, in a way foreseen to do that person only serious permanent harm. It is not the intention alone but its combination with a very serious foreseen harm which is morally conclusive here. And due to this special combination, it is not just a matter of weighing the intended good effects against the unintended bad effects, as we might do in a case of live organ donation where the donor would recover. Whatever the good to be obtained for others, no amount of good can justify the intention to invade the body of an innocent person while foreseeing no health good, but only lethal harm, for that person. If someone is intending as much as that, and knows about the harm, then this is quite bad enough: we need not pretend that death itself is intended in order to condemn this kind of action. People have, in other words, special rights when it comes to deliberate invasions of their bodies of a kind that do them only serious harm.[2]

Character of Doctors

Unjustified intentions of this kind harm the perpetrator no less than the victim; in particular, they damage the agent's relationship with the victim and make the agent more likely to behave in similar ways in the future. The homicidal organ harvester and his or her collaborators are more likely to see future patients as mere collections of bodily material for the possible use of others. If it is true that medicine is centrally focused on serving life and health, then there is something peculiarly destructive to a doctor's character in choosing to use a patient to such lethal effect.

Of course, there is also something peculiarly destructive in *aiming* at a patient's death or permanent injury, as we see in the case of lethal human experimentation, or indeed euthanasia. It is one thing to intend that (say) a terminal patient spend his remaining time in greater comfort and something quite different to intend that the patient stop spending time on this earth. As hospice workers so often emphasize, palliative care is not about dying, but about living till you die. It is not for doctors to destroy purposely, in the words of JLA Garcia, a patient's last remnants of health.[3]

Conscientious Objection

A less familiar, but important, use of double effect reasoning relates to conscientious objection. If a stance of conscientious objection is well-grounded—which will at least sometimes be the case—it would seem that what is wrong for the objector to do will also be wrong for others, whether or not they know that. For example, if deliberate killing of patients really does go against the central ethos of medicine, it will go against this whatever the sincerity of those prepared to get involved. And if I believe sincerely that some practice is unethical and harmful to my patient, I should not be trying to get someone else to do precisely what I think is wrong. If I disagree with assisted suicide, for example, I should not deliberately help my patient find another doctor who will do or arrange this. Certainly, I may well foresee that my patient will in practice find a more compliant doctor—for example, that when I go off duty, the very next doctor will comply. Or my patient may herself go elsewhere immediately when I tell her, as I offer her the care I think she needs, that she is of course free to seek a second opinion from whomever she chooses—though as her doctor I hope she will understand that I cannot in good conscience help her get something I honestly believe will do her harm.[4] Here as elsewhere, foreseeing a bad effect (another doctor's wrongdoing) is morally different from intending it: I am much more responsible for what I choose myself than for other people's choices I foresee.

A complication in the case of suicide is that it can be committed by omission as well as by an act; it can even be arranged in advance by a patient who refuses treatment with the precise aim that she die. Failure to override a clearly suicidally motivated refusal of treatment does not necessarily mean that the doctor also must be intending death.[5] However, the doctor may wish to avoid the appearance of collusion, especially if he or she is expected to remove a feeding tube or give sedation to prevent the (previously) suicidal patient feeling thirst. Such a doctor may feel a need to withdraw from the patient's care if the advance refusal cannot be challenged (for example, on the grounds that the patient may have been depressed or unaware of all the implications). In informing, for example, the Medical Director of my hospital that I am unable to go on being responsible for a patient, I may well foresee that the Medical Director will immediately find a doctor with fewer qualms. To report my inability need not, however, be *intended* as a way of passing over to a less squeamish colleague: I should do nothing with the aim of getting someone to "do my dirty work for me" (to use a crude but apt phrase).

Burden on Doctors

For those readers who may now be wondering if this kind of reasoning is not an undue burden on doctors, there are two points to bear in mind. One is that it is very much in the doctor's interest to retain his or her moral integrity: if these moral distinctions are real and not imaginary, then respecting them is good for doctors too. Few of us believe literally that the end justifies the means; hence our horror at the idea of human rights abuses in a medical environment. Carrying out lethal experiments on human beings might well have good results for future patients; however, results are not the sole criterion for determining how we should behave. Morality is, above all, about our choices—not just our ends but the means we employ—and the impact of our choices on our character. By choosing in a certain way, we make ourselves, for good or bad, people of one kind rather than another. Some choices help to make us good human beings; other choices have the reverse effect on the kind of people we become. We should take this kind of thing seriously if we want our lives to be successful in the deepest way they can be.

Lifting Burdens

However, it is also worth remembering that moral distinctions, including those involved in double effect reasoning, can often *lift* a burden and show that we should be feeling not more guilty, but less so. One example would be the allocation of resources, very much including the doctor's time. Apart from the needs of other patients, doctors themselves need time for relaxation; in any event, there is no duty for doctors to spend all their waking hours doing medicine. Doctors are not murderers if they stop saving lives occasionally and spend time with their family and friends: it is enough if they do what they reasonably can to promote life and health while avoiding any choices which are morally precluded. In an understaffed hospital especially, patients may die because off-duty doctors are home with their families, but such foreseen deaths are not intended but merely accepted as an outcome of doctors doing other good—and indeed necessary—things besides their work. Double effect reasoning, together with a sensible grasp of our own various roles and vocations, can protect us against an impossible situation where we feel responsible for everything all the time.

Double effect reasoning can also let patients and relatives "off the hook" in a way that owes nothing to hypocrisy and everything to sane and balanced thinking. As a medical ethicist, I sometimes find myself reassuring anxious relatives that withdrawing a health care procedure from a dying person can be legitimate, providing its burdens are truly disproportionate (or at least optional) and providing no one aims at hastening death. For relatives to see themselves as justified in accepting death, as opposed to intending it, can be helpful to them and indeed to the patient, who may otherwise feel pressured to accept over-burdensome procedures where the benefit is now very slight.

Conclusion

To conclude: double effect reasoning is not, as I have tried to show, an arcane or "niche" way of thinking but is rather a widely used and indispensable tool for moral action. It needs to be correctly placed in a wider context and supplemented with concrete moral norms, but distinguishing side effects from intended effects is crucial not just for doctors but for human beings generally.

Intentions count, right up the chain of intentions: the end does not justify the means—or not, at any rate, *some* means. Ends, means, and "circumstances," including some side effects, can all be morally conclusive. Side effects more generally count, and must be kept proportionate, but intentions count in a special way. In the area of conscientious objection, refusing wrongdoing, foreseeing but not intending someone else's wrongdoing, is very different from delegating wrongdoing to someone else and thereby intending it oneself. All of us need the "light and shade" of such reasoning, which helps us respond to only genuine moral calls on us as we try to live our lives—in a world of fiercely competing views and pressures—in the best way we can.

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AUTONOMY IN APPLIED MEDICAL ETHICS

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Introduction

The word "autonomy" derives from the Ancient Greek *autos* (self) and *nomos* (rule), which together referred to city states in which native citizens made their own laws. Contemporary conceptions of autonomy of the individual can be traced to Plato, who proposed a tripartite soul formed of the spirited and appetitive parts of the self. These, he theorized, were, in turn, aligned with a ruling logical part.[1] Similarly, for Aristotle, *autarkeia* (self-sufficiency) was an important prerequisite for *eudaeimonia* (human flourishing);[2] choice and rational deliberation were important elements of the virtues. Kant brought the discussion of autonomy into prominence in the 17th century, proposing a theory in which autonomy underwrites human dignity and morality.[3] Kant's conception of the autonomous will, whereby the will of a rational being is independent, grounds his theory of the universality of moral laws. Autonomy later became a central concept of liberal political philosophy, most notably in John Stewart Mill's utilitarian liberalism.[4] More recently, autonomy has become central to discussions, in medical ethics, of patients' decision making. However, it is not clear that this *personal* autonomy is conceptually identical to those previously mentioned. Indeed, Gerald Dworkin has suggested that autonomy is not a homogenous concept, describing it as "a term of art introduced by a theorist in an attempt to make sense of a tangled net of intuitions."[5]

In order to describe the concept of autonomy as it is has been applied in medical ethics, I will first address two criteria often considered to be preconditions for autonomous actions: competency and authenticity. I will consider how different philosophical conceptions of these criteria have produced competing definitions of autonomous agency. I will then describe Harry Frankfurt's account of the hierarchical preferences of agents and consider how incongruity between these different levels of an agent's desires, on the one hand, and other theorists' invocations of "weakness of the will," on the other, complicates attempts to define a patient's autonomy. Lastly I will consider how "substantive" accounts of autonomy can be used to protect minority groups from paternalism, whilst acknowledging examples where coercion can sometimes be used to promote a patient's autonomy.

Competency and Authenticity

Liberal thinkers have theorized the autonomous individual as necessarily rational and self-controlling, with Mill conceiving of "human beings in the maturity of their faculties,"[4] and John Rawls describing an individual capable of "deliberative rationality."[6] Such liberal conceptions of rationality have been seen by some critics as isolating agents, consigning them to a "narcissistic vacuum."[7] Diana Meyers, by contrast, has sought to describe a vision of individual autonomy that is more complex because it is social, but which retains an understanding of individuals as being capable of the calculating rationality of *homo economicus*. Meyers explains how close emotional human relationships and autonomy are compatible, since "memory, imagination, and instrumental reason, usually enhanced through conversation with others . . . [enable] . . . people to envisage options—to conceive of combinations of traits they could embody and aims they could pursue."[7] In Meyers' description of individual rationality, people "who never exercise autonomy competency can be presumed not to have it"—and they cannot be considered autonomous if they "never ask the question 'What do I really want?'"[7] Meyers' criteria of competency are stricter than those given by Beauchamp and Childress in their *Principles of Biomedical Ethics.* This canonical text describes an individual lacking autonomy as someone who is ". . . in some respect controlled by others or incapable of deliberating or acting on the basis of his or her desires of plans."[7] Meyers' criteria face problems if they are to provide a meaningful guideline for medical ethicists, as they set the bar very high for patients' autonomous decision making in practice: patients who are not continually exercising "a repertoire of skills to engage in self-discovery, self-definition, and self-direction"[7] may not, according to Meyers' account, be making fully autonomous decisions.

The seminal exposition of *authenticity* conditions for autonomy is Harry Frankfurt's *Freedom of the Will and the Concept of a Person*. For Frankfurt, an individual's actions are authentically autonomous when ". . . his volitions derive from the essential character of his will."[8] Gerald Dworkin describes authenticity in similar terms, referring to a "second-order capacity of persons to reflect critically upon their first-order preferences . . . and the capacity to accept or attempt to change these in light of higher-order preferences."[5] Dworkin explains the relationship between first- and second-order preferences with reference to the Greek myth in which Odysseus instructs his men to tie him to the ship's mast to prevent his falling into the sirens' trap:

> not wanting to be lured on to the rocks by the sirens, [Odysseus] commands his men to tie him to the mast and refuse all later orders he will give to be set free. . . . He has a preference about his preferences, a desire not to have or not to act upon various desires . . . alien to him.[5]

The myth serves to explain the kind of thought which autonomous persons engage in when having preferences, and has intuitive appeal. Odysseus' "preference about his preferences" is similar to the way in which a reluctant smoker both desires to smoke a cigarette (appetitively), but also desires not to have that desire (rationally).

The impossibility of an enduring discrepancy between first- and second-order desires was discussed in the *Protagoras* by Plato: ". . . no one who knows or believes there is something else better than what he is doing . . . will go on doing what he had been doing when he could be doing what is better."[9] Plato thought illogical (and impossible) this idea of *akrasia*, which he defines as "willingly going towards the bad." In other words, if a person knows that doing *x* is the best course of action, but does *y* anyway, they are acting akratically. Christopher McKnight uses the example of an akratic patient to challenge the usefulness of distinguishing autonomous from non-autonomous individuals.[10] McKnight's patient needs a blood transfusion to save his life, but reluctantly refuses on the grounds of an extreme phobia to needles, all the while stating that he "knows he is being irrational." This seems to be an akratic decision, and an inauthentic (non-autonomous) one in Frankfurt's sense, for the patient's second-order desires do not endorse his first-order desires ("I don't want the blood, but I regret that preference"). McKnight asserts that there is something intuitively wrong here: if we call this patient non-autonomous, we “[put] him in with other non-rational beings such as animals . . .”[10] but if doctors respect the patient’s autonomous decision, it appears that the outcome (death) is something that even the patient (on reflective examination of his second-order preferences) does not himself want.

Marina Oshana disagrees with Frankfurt’s and Dworkin’s conceptions of authenticity as being necessary characteristics of autonomous persons, arguing that autonomous agents often do feel alienated from deeply rooted aspects of their identity-forming self.[11] Indeed, Oshana suggests that calling a person non-autonomous just because she feels uncomfortable with her identity would amount to self-betrayal. “Autonomy,” she says “requires a person having the freedom to distance herself, or to step back, from the socially given roles and practices that contribute to her identity.”[11] A person cannot be called non-autonomous “just because her desires are not configured to the situation she finds herself in.”[11]

Procedural Accounts of Autonomy

Procedural accounts of autonomy proposed by Harry Frankfurt and Gerald Dworkin in the 1970s described autonomous decisions as those that are grounded in an agent’s values. According to these accounts, the needlephobic patient’s decision to refuse an injection, or the perennially quitting smoker who continues to smoke, may be non-autonomous because their akratic preferences run counter to their overall objectives in life. Frankfurt and Dworkin present these processes of decision making in terms of a hierarchy of desires, such that an autonomous decision can only have taken place if an agent’s first-order desires identify with their second-order desires, the latter of which take the form of a volition. Two problems with this procedural account arise. Firstly, a paradoxical corollary: since procedural conceptions of autonomy are “content-neutral,” they allow for individuals to choose for their will to be restrained. Moreover, since the genesis and construction of second-order desires (which Dworkin calls an agent’s “true self”[5]) are not described in hierarchical accounts, it seems, counterintuitively, that even a manipulated (for example, brainwashed, or hypnotised) form of a “second order self” can be autonomous. Frankfurt also admits that a person may be “capricious and irresponsible in forming his second-order desires,” which, as Laura Ekstrom has argued,[12] means that the identification of “self” with second-order desires is inappropriate. Secondly, hierarchical accounts lead to the problem of an infinite regress of volitions. As Ekstrom explains, the ratification of a first-order desire by a second-order volition requires that the second-order volition (which is, on Frankfurt’s account, “conferring internality” to the first-order desire) is also *internal to* the self (and can therefore not *be* the self). Thus the second-order volition also requires a third-order endorsement: “without a separate account of the internality of certain second-order desires, a regress of higher-order desires stands.”[12]

Ekstrom[12] addresses the problems of hierarchical accounts with a “coherentist” theory of the self, whereby an autonomous decision must originate from a self whose beliefs, preferences and desires cohere together and have been “formed by a process of critical evaluation with respect to one’s conception of the good.”[12] For Ekstrom, an autonomous preference (a reflection of the “true self”) is that which “represents what an agent wants as the outcome of her reflection on what is good.”[13]

Ekstrom calls a preference "autonomous" when it is both *long-lasting* and *fully defensible against external challenges* as well as one that an agent is *comfortable owning.*[12] The needlephobic patient's desire not to have an injection, while a long-lasting and obstinate aspect of the agent's character, would not on Ekstrom's account be autonomous, because the desire not to have the injection does not fit in with his character system.

Substantive Autonomy and Its Critiques

Substantive accounts of personal autonomy, such as those described by Natalie Stoljar[13] and Marina Oshana,[11] claim that procedural conceptions of autonomous decisions are insufficient, and argue that the contents of autonomous decisions should be subject to certain constraints. On Stoljar's feminist account, normative constraints are necessary to protect minority groups from internalized devaluing of their worth as autonomous agents, since "persons are socially embedded and . . . agents' identities are formed within the context of social relationships and shaped by a complex of intersecting social determinants . . ."[13] Paul Benson argues that these conceptions conflate "orthonomy" (right-rule) with autonomous self-direction, explaining that "we can autonomously take ownership of our mistakes and limitations and act autonomously when bounded by them, even when we are not . . . doing precisely the right thing for just the right reasons."[14] For Benson, the content-neutrality of procedural accounts of autonomy actually serves to protect agents from paternalistic influence.[14] Meyers takes this argument further, observing that often "multiply oppressed individuals are in some respects better positioned . . . to exercise moral and political agency, than multiply privileged individuals are."[15] Meyers does also, however, discuss the importance of a kind of "autonomy-augmenting education," which enhances "rigorous scrutiny and drastic overhaul . . . [of] . . . introspection, imagination, and imagination skills."[16]

Isaiah Berlin's writing on the temporality of self-identity can be used to strengthen the appeal to reason made by substantive accounts.[17] It is widely recognized by both medics and laypeople that it is sometimes justifiable to *coerce* agents, for example through public health campaigns. Berlin's argument is that "blind, ignorant, or corrupt"[17] agents—those who are not yet privy to all the information which "experts" hold—would come to agree with their (expert) coercers, once they have all the information to hand, and attain their self "at its best."[17] An anorexic patient, with a long-standing, obstinate belief system about her body image and food, may justifiably be forcibly fed because doing so—improving her physical wellbeing—might facilitate an improvement in her mental abilities to make autonomous decisions. Berlin's self "at its best" has similarities with Ekstrom's "true self," as described previously, but unless we adopt an Aristotleian or Kantian view that there can be only one correct way of life, it is not clear that every "self" will reach the same conclusion. Any agent may therefore be liable to paternalistic influences of a form of reason that they might never come to accept.

Conclusion

The various ways in which autonomy is conceptualized and applied to medical ethical dilemmas lead to different conclusions about the balance between legitimate coercion by the doctor (the "expert") and self-rule of the patient. According to Beauchamp and Childress's well-known definition, most people appear to act autonomously most of the time. Stricter definitions of autonomy, if the ethical framework is introduced to policy and management discussions, may incentivize more active engagement of autonomous patients' agency in decision making, but by raising the bar for achieving autonomous agency, they also risk legitimizing increased paternalism in medicine. Similarly, whilst substantive accounts of autonomy can protect people from external constraints being placed upon their wills, these accounts also risk forcing minority or structurally oppressed groups to conform to culturally relative social and moral norms. Each of the conceptions of autonomy discussed in this essay has strengths and weaknesses, chiefly because these ethical theorizations have political effects: promoting the autonomy of one individual or one group risks paternalistic subjugation of another. Consequently, the discussion of these different conceptions of autonomy must be an ongoing project in medical ethics.

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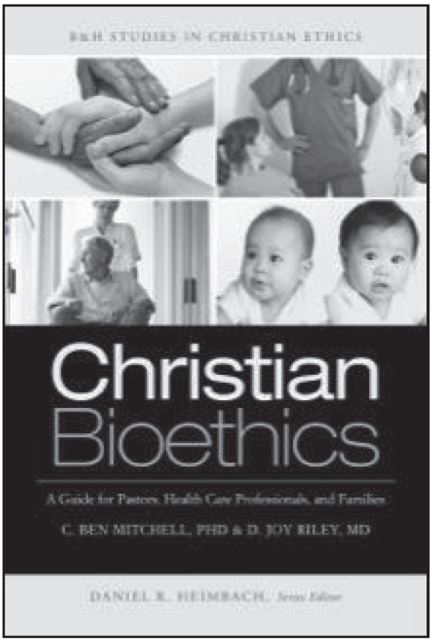

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The Relationship of Gametes to Those Who Procreate and Its Impact on Artificially Generated Gamete Technologies

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Abstract

Current developments in reproductive technology forecast that in the foreseeable future artificially generated gametes might be presented as a possible fertility treatment for infertile couples and for homosexual couples desiring to have children genetically originating from both partners. It is important to evaluate the ethical issues connected to this technology before its emergence. This article first reviews the meaning that gametes (sperm and eggs) might have to those who procreate, as well as their ontology. From this, suggestions are made as to what qualities artificially generated gametes need to be truly called gametes. Finally, different proposed routes for artificial gamete generation are examined on the basis of these qualities, with their prospective problems and advantages highlighted. Autotransplanted gametes (or their progenitors) generated solely from patient-derived tissue are deemed to be the most ethically suitable route for the development of this technology.

Scope

A lot of attention in the bioethics debate concerning the issues of conception has been given to the embryo, its use to derive stem cells, and the possibilities raised by artificial gametes. However, very little attention has been given to the gametes themselves. The way people desiring to procreate view their gametes is important as it will affect their view on how they should be used, subjected to medical treatment or to technological manipulation. Only when there is a clear ontological view of gametes can methods for artificial gamete generation be discussed.

The article will first evaluate how people might perceive the stewardship of their gametes and the ontological meaning of sperm and eggs, and how this relates to their natural use and the persons who use them. Conclusions reached after exploring these topics will then serve as a basis for the evaluation of artificial gamete technologies.

This article will not discuss the details underlying gametogenesis, and the question of genetic parenthood will not be considered in depth. It is sufficient to say that a perceived desire to have genetically related children is a common phenomenon that impacts human decision making.[1,2,3] The article will only consider the topic from the point of view of heterosexual couples, as this is the natural context of procreation in which gametes exist.

Bringing Forth a Child

Reproduction is one of the fundamental characteristics of life.[4] Couples who have been affected by various forms of infertility often recognize this as an anomaly and may seek to alleviate it by means of assistive reproductive techniques. Even with declining family sizes among developed countries, children are still viewed as a blessing. Traditionally, children are viewed as a key good of marriage,[5,6,7,8] but even secular couples tend to look forward to having them. In some societies this importance of children is manifested by the size of the industry catering to infertile couples,[9] while in others by the restrictions guarding the process of begetting children and promoting virginity and chastity,[10,11] to ensure that children are not born outside of marriage. In Abrahamic religions, begetting children is in general reserved to the spouses. This is exemplified by the fact that, even though *in vitro* fertilization (IVF) is permitted in Islam and Judaism, the gametes must come from the spouses.[12,13,14] The Eastern Orthodox Church, though it permits IVF, restricts it to spousal gametes, and even then it recognizes this as an anomalous state,[15,16] while the Catholic Church opposes any forms of assisted reproduction that separate it from the marital act.[17] But why might having children be so important, and how does this relate to gametes?

A child might be seen as a seal between the two people, which helps to reaffirm the relationship between the spouses, a visible intermingling with their beloved and a means of preserving a part of them for the future. This tangibility of children and of bringing them to existence might be not only important for the relationship between the parents, but also to their relationship to the child. The parent-child relationship might have been completely different if the child originated through shared willpower or was brought by storks. The importance of children being "blood from my blood" is still seen in the fact that people want children of their own, to which biological relatedness contributes in some form.[18] Gametes are therefore something that has the potential to create a biological relatedness between parents and children and something that can continue their familial line.

The fact that reproduction occurs via sex and gametes deserves further attention. As noted before, there is both an act of will and a tangibility that are involved in it. Though children are sometimes welcomed as joyful "accidents," the importance of an act of will is highlighted by the fact that people argue about stolen ideas and how much the intellectual involvement of a person is important in patent applications,[19] even if their execution was sub-contracted. Equally, there is a satisfaction that something has been brought to being by someone's own effort. It might be possible that the rejection of surrogate children,[20] where the input of the intended parents was not as great as in normal sexual reproduction, is partly due to a weaker bond between the parents and children that is the result of the absence of this active involvement of the spouses.

Therefore it would be desirable if any artificially generated gametes (AGGs) were designed to work within the context of the marital act. This would reaffirm the parents as the ones who bring the child into existence with all their faculties. Further on, it would ensure that the child has a tangible reference to its moment of becoming and to its familial line; in this the gametes should only contain genetic material from both parents to reflect the unique relationship between one man and woman. A gameteless procreation or even one where the gametes did not fully originate from the persons intending to procreate would lack this linking potential that helps parties to realize the relationship that they share. Children resulting from such cases would probably be partially puzzled by the same identity questions that adopted children experience—questions about their tangible origin.[21] Lastly, the use of AGG's functioning in such a way would be acceptable to people from a wide spectrum of belief backgrounds.

The Value of Gametes as a Means of Begetting Children

We intrinsically understand our authority over our gametes and wish to utilize their potential with those whom we choose. Therefore, pregnancies that result from random sexual encounters, and even more so from rape, are often viewed as problematic, as the persons did not intend to utilize the procreative potential of their gametes. Similarly, infertile couples are placed in a situation where they are unable to realize this potential and hence might wish to use an assistive reproductive technology to fulfill what they might perceive as their right to have a child. This shows that people recognize a natural capacity to procreate and want to control it to some extent. Therefore, part of the value attributed to gametes comes from their procreative potential that we want to fulfill only with those whom we choose.

The Stewardship of Gametes

As shown above, people assume that their gametes, with their potential, are indeed "theirs"; that they are the sole authority that can dispose of them in one way or another, and that this right is exclusive to them.[22] This further manifests itself when men talk about the condition of *their* "swimmers" or when people state that they have donated *their* eggs or sperm. The exact importance of gametes and how people will view their relationship to them varies greatly from culture to culture[23] and between various philosophical beliefs. For Libertarians this ownership might be total;[24] they can sell their bodies for sex,[25] or their parts for profit,[26] and no one can tell them how to exercise this ownership. From a Christian[27] or Muslim[28] perspective, ownership is more of a stewardship, as God is the ultimate Lord of the universe and all belongs to Him; they are given to man as a gift[29] that can only be used in a particular way. All would agree, though, that they have some sort of autonomy over their bodies, which also entails a responsibility for the way they act with their bodies. Individuals are responsible for their actions, whether by law, Social Darwinism, or at Judgement Day. This responsibility extends to how people use their gametes and treat the gametes of others. If we endanger the health of our gametes, we will impact the health of the child that is both ours and our spouse's. Though having an affair is bad, its effect is even more burdensome for the marriage if a child is born from that extramarital relationship, as it would remain a symbol (or even more: a reality[30]) of two people joined together who should not have joined in the first place. In hope of having healthy children, spouses might change their lifestyle to increase their reproductive health, i.e. the health of their gametes, hence acknowledging the responsibility they hold for the state of their gametes. Further, parents might blame themselves for any genetic mutations transmitted to their offspring. But people might also legally challenge those who have negatively affected their reproductive capacity,[31,32,33] and people who lost their fertility might look to AGGs as a means of restoring their fertility. This highlights the necessity of evaluating the legal status of gametes.

With the development of artificial reproductive technologies, conflicts started to arise as to who can decide in what way donated and stored gametes could be used. There is a long and noble legal tradition of not applying property rights to bodies;[34] this recognizes the intrinsic dignity of the human person and that we are not our ultimate masters. Nevertheless, a decision had to be made as to who has the authority over stored gametes. A large emphasis has been made on the fact that stored gametes gain property status due to the effort and fine skill put into their handling and not because they are body parts—interestingly, it was not the person exercising the skill that became the legal owner of the gametes, but the person for whom the skill was exercised.[35,36] This emphasizes that people value their gametes and that they do not want the procreative potential present in them to be used against their will, but also emphasizes the reluctance of attaching property rights to body parts which should not be treated as a commodity. Finally, it is important to note that people do feel wronged when a lover deceitfully uses their sperm for insemination without their acknowledgment,[37] with one case resulting in a man arguing that the woman had stolen his sperm, while she claimed that it was a gift.[38] Therefore, there seems to be a general appreciation that gametes have a purpose and that individuals should have some say in how their gametes are being used to fulfill this task.

The apogee of the responsibility for gamete use comes with the birth of children. This responsibility might be explicitly sought, for it is ultimately linked with many pleasures that arrive from having children, like their success.[39] When a parent is denied the opportunity to interact with his or her children due to the other parent's action, he or she might feel deprived of something, which other people could have perceived as a burden. In a loving relationship, care is not only a duty, but also a privilege and, in a specific way, a joy. This responsibility is again highlighted in law in cases where a biological father is made to pay child support if he separates from the rest of the family. Lastly, it is important to note that those who donate their gametes might want to avoid this relational responsibility (even if they have no legal responsibility) by remaining anonymous.[40] Yet in many cases it is deemed a child's right to know who his or her biological parents are—to know from whom they physically come,[41] and hence it might be unethical to bring children without such an identity into existence.[42] The issue of this relational identity has been already highlighted in the discourse on AGGs,[43] though not all agree that a lack of it would necessarily be a negative phenomenon.[44]

Finally, one might wish to compare this stewardship of gametes to that of other organs. But an important distinction exists here: organs sustain life, whereas gametes create life. Organs are meant to be working for the person to whom they are attached, whereas gametes do not directly do anything for the health of the person from whom they originate. Their value is only really meaningful when shared with another person, and in this they have status smaller than that of half an embryo, as only when a sperm and egg fuse is a person created.[45]

In summary, people mainly value gametes for the potential that they have in creating a child. The child can be seen as an extension of oneself and that of the spouse, a sign of the union of these people. Because of this, people appreciate not only the value of their gametes, but also their responsibility for their state and use. But is there an even deeper meaning of gametes that relates to the mode in which they work?

The Ontology of Gametes

Abrahamic religions recognize that God ordered the world in a particular way and that people should cooperate with it. This is apparent from the existence of Mosaic Law and the concept of Natural Law, as well as from the etymology of the word "Islam."[46] Further, science itself recognizes that there are fundamental rules governing the world and biological entities have particular functions to perform, which they do in a specific manner. It is therefore important to assess whether gametes are crucial for some actions, and if yes, then what makes them best suited for those actions.

It was already discussed that human gametes function within the context of the conjugal act that is both unitive[47] (bonding the man and the woman) and procreative (having the function of bringing a new life into existence), by its nature. In the context of the joining of woman and man it seems relevant to evaluate the joining of sperm and egg.

This joining is simultaneously unitive and procreative, as a new human is brought to life through the joining of two entities. Like a man and woman are complementary to each other,[48] so the gametes are to one another, each containing what the other is lacking for a new life to form. Further, there seems to be something female about the egg and something male about the sperm. As the man penetrates the woman during sex, so the sperm penetrates the ovum during fertilization, mimicking the respective duality of giving and receiving. Therefore, the association of eggs with women and sperm with men is possibly not only based on the fact that this is how they occur in nature, but also on their intrinsic properties. This implies that if sperm were made from cells originating from a woman or eggs made from cells originating from a man, these would be a lie. Lacking the intrinsic properties of the sex of the person from whom they originated, they would be implying that this person is someone else. This dissociation of the sex of the person from whom the gametes originate and what the gametes are would be so pronounced that it might create confusion as to which parent would be the mother and which the father.

Secondly, the sperm and egg DNA are epigenetically marked in different ways (different genes are switched "on" and "off"), corresponding to their origin, not dissimilar to how both parents might contribute to the child's upbringing in different ways even if both are equally present in the child's life. Further, the egg contributes the mitochondria, which nurture the cells, like the mother nurtures the child until the end of pregnancy and even beyond. Finally, in traditional settings where the husband is responsible for bringing income to the household that is managed by the woman, the act of the sperm coming to the ovum and the woman's body "managing" the pregnancy might also bear some resemblance to this.

The beauty of the conjugal act, in Christian understanding, lies partially in its totality[49] and exclusivity[50] to the spouses. Gametes might be seen as representing the people from whom they originate[51] in their totality, as well as by their nature in their exclusivity, as no other person participates in the reproductive act. They are the messengers of the people from whom they originate, symbolizing their femininity or masculinity, carrying their DNA, as well as various molecules made by them that will contribute to the new person that will be formed. Gametes are less than the person from whom they originate, but more than just any odd part of her or him; or, as previously suggested,[52] they are ambassadors of the person from whom they come, and by extension a tangible genealogy[53] of his or her ancestors.[54] Possessing the aforementioned characteristics makes gametes entities that not only have a huge biological importance, but also a more subconscious importance to the person from whom they originate.[55] In this light, it is a curiosity that the word “gamete” derives from the Greek words meaning husband, wife, and marriage[56]—the two that they represent and the sphere in which they work.

Gametes represent the totality of their contributors, their full femininity and masculinity, not just their DNA. Similarly, the natural process of procreation excludes any third person’s DNA. Adding third party mitochondrial DNA to the procreative process strips it of its meaning,[57] as procreation ceases to be a totally unique endeavor between the couple, of whose union the child is a visible sign. If a couple later splits, the child remains a physical reminder of the reality of that union. This sign is so strong that in case of embryos brought through IVF and being stored, the father or the mother might even desire their annihilation not to remind them of this union.[58]

Gametes and Future Reproductive Technologies

Gametes are God-given gifts and means of participating in His creative power.[59] They have the power to bring into existence something more than a gift, for a child cannot be disposed of as a commodity. The use of gametes is therefore a privilege that has a responsibility attached to it. They also truly represent the masculinity and femininity of the person from whom they originate and provide a tangible link between children and parents. Gametes not only pass on genetic information, but acting within the conjugal act facilitate the totality and exclusivity of that act. As medical intervention should aim as much as possible at restoring the proper functioning of the body, and not in giving it a new one or one removed from its proper environment,[60] emerging reproductive AGG technologies should mimic these properties to be truly therapeutic and deserve the label of gametes. In short, this would be achieved by fulfilling the following criteria:

1. The AGGs must originate fully from the patient. As gametes represent the whole person willing to procreate, AGGs have to originate from that person and not have anything subtracted from them, allowing for genealogical and identity continuity.
2. The AGGs must represent the patient exclusively. To achieve this no additional genetic or biological components (DNA, cellular organelles) can be added from other individuals or species.
3. The AGGs must correspond to the patient’s sex. This will ensure that the gametes truly represent the masculinity or femininity of the patient.
4. The AGGs must be functional within the conjugal act. When procreation will happen within the context of sexual intercourse it will ensure that there is not only a will to become a parent, but also a tangible moment and experience to which the parent can refer back to appreciate his or her role in bringing the child into existence and fully embrace the responsibility that comes with this.

Overview of Reproductive Technologies

Many scientific breakthroughs have occurred that can aid the fulfillment of the desire to have a child, but they simultaneously possess a significant ethical burden. It was argued before that for most of those technologies there is no difference of the kind, but only of the degree to which these technologies assist reproduction.[61] Since the original technologies all separated procreation from copulation, this was largely true, but new interventions emerge that also change the nature of the gametes themselves. These technologies not only include artificially generated gametes, but also those procedures that were (quite inaccurately) collectively named by the media as mitochondrial transfer (they rely on the transfer of nuclear DNA).[62] Procedures that result in such a "three-parent-embryo" are of a new kind, as the gametes are no longer a representation of two individuals that participate in procreation.[63] Instead, they render procreation a process non-exclusive to the couple, as they involve third-party DNA. Further on, work has been undertaken to allow for targeted genetic manipulation of embryonic and germline DNA.[64,65] All these technologies include a novel element that is absent from previous methods, falling into a similar category as the "three-parent-embryo"—the gametes used or child that is born are altered by artificial biological manipulation, hence they become distanced from the persons procreated.

Basic Considerations of Artificial Gametes

Though still in its infancy, artificial formation of gametes is slowly gathering media attention.[66] About a dozen proposed routes exist for the formation of AGGs.[67] Each route raises its own ethical questions as well as the ethical questions associated with the research still needed for the technique to become functional. This second set of questions shall not be addressed in this article.[68] Further, if the ethical issues relating to the fundamental nature of these technologies prove to be unacceptable, then there will be no need to address the ethics of carrying out the research necessary for their development. The ethics of AGGs will be evaluated within the context of the previously established four properties of gametes.

The various methods of creating AGGs utilize different types of stem cells.[69] Some use embryonic stem cells (ESC), others generate induced pluripotent stem cells (iPSC) from somatic cells (cells other than gametes and stem cells) or reprogram adult stem cells (ASC) of various types, including ones obtained from bone marrow.[70] Certain techniques then proceed to generate the embryo via IVF, while in other cases auto-transplantation (the procedure of inserting the cells back into the patient from whom the original cells were taken) takes place and a child can be conceived through sexual intercourse.

Desired Qualities of Artificial Gametes

Considering the categories by which methods of generating AGGs can be grouped, it should be ensured that the technology uses only cells originating from the body of the person reproducing and that the technology does not separate procreation from the unitive act. This will allow the technology to emulate nature as much as possible, allowing the gametes to represent the procreating persons. Such technology would eliminate some of the problems that are inherent to IVF in the eyes of those who value the natural order of the world—separating conception from sex, and “surplus” embryos. Hence it would be useful to people from the widest range of ideological backgrounds.

iPSC and ASC routes offer ethically licit routes of AGG generation, as opposed to the ESC route. Use of non-embryonic cells avoids the destruction of embryos, as well as some of the ethical problems associated with therapeutic and reproductive cloning, which the use of ESC causes;[71] it would also ensure that all of the generative material originates from the two persons wishing to procreate without third party DNA being involved. Using ASCs might involve less biological manipulation of the cells than the use of iPSCs and hence cause less DNA damage to the AGGs.[72] This is important as the extent and type of gamete damage caused by manipulating stem cells in order to obtain gametes might be too challenging for the DNA repair systems with which evolution has equipped us.[73] If the gametes (or their progenitors) were then auto-transplanted, it would allow for procreation to occur in its natural setting. This would simultaneously mean that the gametes would have to correspond to the sex of the person wishing to procreate. If gamete progenitors were auto-transplanted, this might offer an opportunity for natural means of epigenetic reprogramming (switching on and off of appropriate genes) to occur, which we are far from understanding,[74,75,76] but is vital for the healthy development of the child.

When using auto-transplanted gametes originating from the patient, one could actually start talking about truly restoring fertility in a way that cooperates with the nature of men and women. Auto-transplanted gametes would be superior to IVF as they would not require the separation of procreation from sexual union, making them accessible to people who object to this separation. When compared to IVF, such “naturalized” means of assisting reproduction might yield higher pregnancy success rates and lower risk of developmental disorders[77] in the children conceived this way, as well as eliminate the problem of “spare” embryos. Therefore, the route that will be further considered is the generation of gamete progenitors from ASCs originating from the patient for the purpose of auto-transplantation.

Therapeutic Applications of Artificially Generated Gametes

The first application for AGGs would be in treating infertility. Here AGGs could be implanted into the patient to allow them to procreate via sexual intercourse. AGGs could be thought of as bio-prosthetics or transplanted organs. These are not controversial ideas, as we are even happy for people who were born deaf to gain the sense of sound,[78] as we recognize that this is a natural faculty of human beings. When compared to organ donation, AGGs should cause less ethical issues as they originate from the recipients themselves, therefore avoiding many ethical problems related to organ donations.

Secondly, the technology could provide an opportunity for gene therapy for inherited disorders, be it Huntington’s disease, which is hugely debilitating, manifests itself later in life, and has no cure, or diseases like Joubert Syndrome, which affect early development and for which parents might be known risk gene carriers. These are all conditions that have a huge impact on the life of the individual and their family. Therefore it is important to evaluate if AGGs would provide a licit intervention for couples with a high risk of conceiving children with such disorders. The field of gene therapy is in itself an ethical minefield, especially that concerning the manipulation of germline cells.[79,80,81] Somatic gene therapy (not affecting cells involved in reproduction) has already gained overall approval. Opposition to germline cell therapy is in many cases due to safety issues[82] and the currently (if it were legally permitted) necessary separation of the procreative and unitive aspects of sex in cases where it would be implicated. There also remains the question of whether we have the authority to alter people in such a perpetual way without their consent, which will also affect their future descendants. Hence it is quite different from corrective surgery at birth. But even if research into this technology is undertaken in an ethically licit manner and the safety for the child-to-be is ensured, it remains doubtful whether the gamete would truly represent the parent, as foreign genetic material would sever the connection between the gametes and the person from whom they originate. Therefore, it is doubtful whether this would be an appropriate way to deal with such diseases, as the gametes would not fulfill their purpose. Further, if the patient was not sterile in the first place, it would require a pre-sterilization phase to ensure that only the modified gametes were produced inside his or her body. Some people could regard this as self-mutilation, and would not accept this procedure. Hence, germline cell therapy via AGGs fails to respect the nature of gametes themselves and might not provide a widely acceptable solution to heritable genetic disorders.

Another option that might be used when dealing with genetic disorders that would avoid the use of genetic manipulation is to concentrate on eliminating AGGs containing faulty gene copies. This would possess less ethical baggage than the screening of embryos that occurs as part of various assisted reproductive interventions, as it would not involve the destruction of human individuals, but of gametes or their progenitors, and even less baggage than the aforementioned germline DNA modification.[83] This would require the development of efficient flow cytometry screening technology and possess its own ethical problems as discussed below. One would need to be very cautious as this therapeutic intervention can provide precedence for future eugenic selection.[84] Any legislative body would need to balance the possibility of easing the disease burden for families with the risk of promoting a society that does not value life in any form except that of an imagined perfection. Screening gametes or their progenitors would likely not eliminate completely the chance of passing on genetic defects. If this were explained correctly to the couple wanting to procreate, it might make them realize that this process aims at risk reduction and not at creating "designer children." Such screening would probably become standard practice, even when no familial predisposition to genetic diseases was present, to counter the risk of abnormalities caused by artificial handling of the cells. If the technique was used with a risk-reduction mindset, rather than a risk-elimination one, it would not require sterilization of fertile individuals (as it would be based on increasing the number of non-risk-gene-bearing gametes and not the annihilation of the risk-bearing ones) to achieve its goal and hence could achieve wider acceptance.

Finally, some might argue that the technology could be used to generate sperm from women and eggs from men in an attempt to avoid mitochondrial disease, as an alternative to three-parent-embryos, as this would avoid introducing genes from a third person. Nevertheless this is still contrary to the nature of the persons,[85] as the gametes would not fully relate to the persons from whom they originate (neither in their femininity or masculinity, nor in their historic heritage[86]) if they were to be transplanted into a different person. Additionally, unless the AGGs were transplanted successfully into the other partner (not rejected by their immune system), their use would involve IVF.

Risks of the Technology

We are only in the infancy of understanding the biology of gamete generation and maturation; hence we cannot manipulate them as precisely *in vitro* as our bodies can *in vivo*. If novel reproductive technologies are introduced rashly, it might lead to exacerbating the genetic problems that we wanted to avoid in the first place. The use of a screening process might mitigate some of those risks, but is it prudent to rely on just one safeguard? Despite our close evolutionary relationship, human beings are more complicated than mice, where most of the pioneering work in this field is being done. It is therefore wise to anticipate any risk that AGG technology might carry.

DNA quality of all cells (including germ cells) usually decreases with age,[87] and many individual cells also possess genetic variations that are absent from the rest of the body.[88,89] Such cells used to create artificial germ cells would increase the chances of children suffering from developmental disorders. Though older persons might have more somatic cell problems, they are also more likely to experience more problems with their natural gametes. Hence, it would seem fair to accept an increased risk in AGGs created from cells of older individuals that would be of a similar extent to that found in nature.[90] This would logically extend to an age limitation for the use of such technologies in women, where the organism can support childbearing only until a certain point.

There were some suggestions that AGG technology would offer an opportunity for social experimentation through multi-parent children and generation jumping, and that this might be desirable, as it would allow three or more people to share a child that would be related to all of them and hence accommodate newly emerging forms of romantic relationships.[91] Such applications would be opposed to the ontological properties of gametes, but could only be prevented on an administrative level.

Conclusion

Gametes function within the context of the conjugal act. They originate from the procreating persons and represent them (and by proxy their ancestors) through passing on their genetic material, but also by mimicking their masculinity and femininity. The process of bringing a child into existence is therefore an affair of two biologically complementary persons with their complementary gametes. This bringing forth of a child to life is a gift, not a right, yet it is recognized as a good proper to human existence. When, due to infertility, people are not able to conceive children, they might seek to use assisted reproductive techniques. Artificially generated gametes might be a set of techniques to which such people will have recourse in the future. This article has evaluated these techniques in light of the natural properties of gametes. Artificially generated gamete progenitors from non-embryonic cells that are re-introduced via homologous transplantation would both possess the characteristics of natural gametes and provide a truly therapeutic treatment for infertile people that would be seen as acceptable for people from a wide variety of backgrounds.

Nevertheless, such technology could only be welcomed if it could be developed via ethically acceptable research and provide a safety level for these gametes comparable to that in healthy age-matched individuals. Still, caution should be exercised not to abuse this technology, as it could contribute to a societal eugenic mindset. Finally, use of such assistive technology should be accompanied by helping the couple to understand the meaning of fertility and children in the wider context of their existence.

Note: The views expressed in this article are those of the author and do not necessarily reflect the positions of the professional organizations with which he is affiliated.

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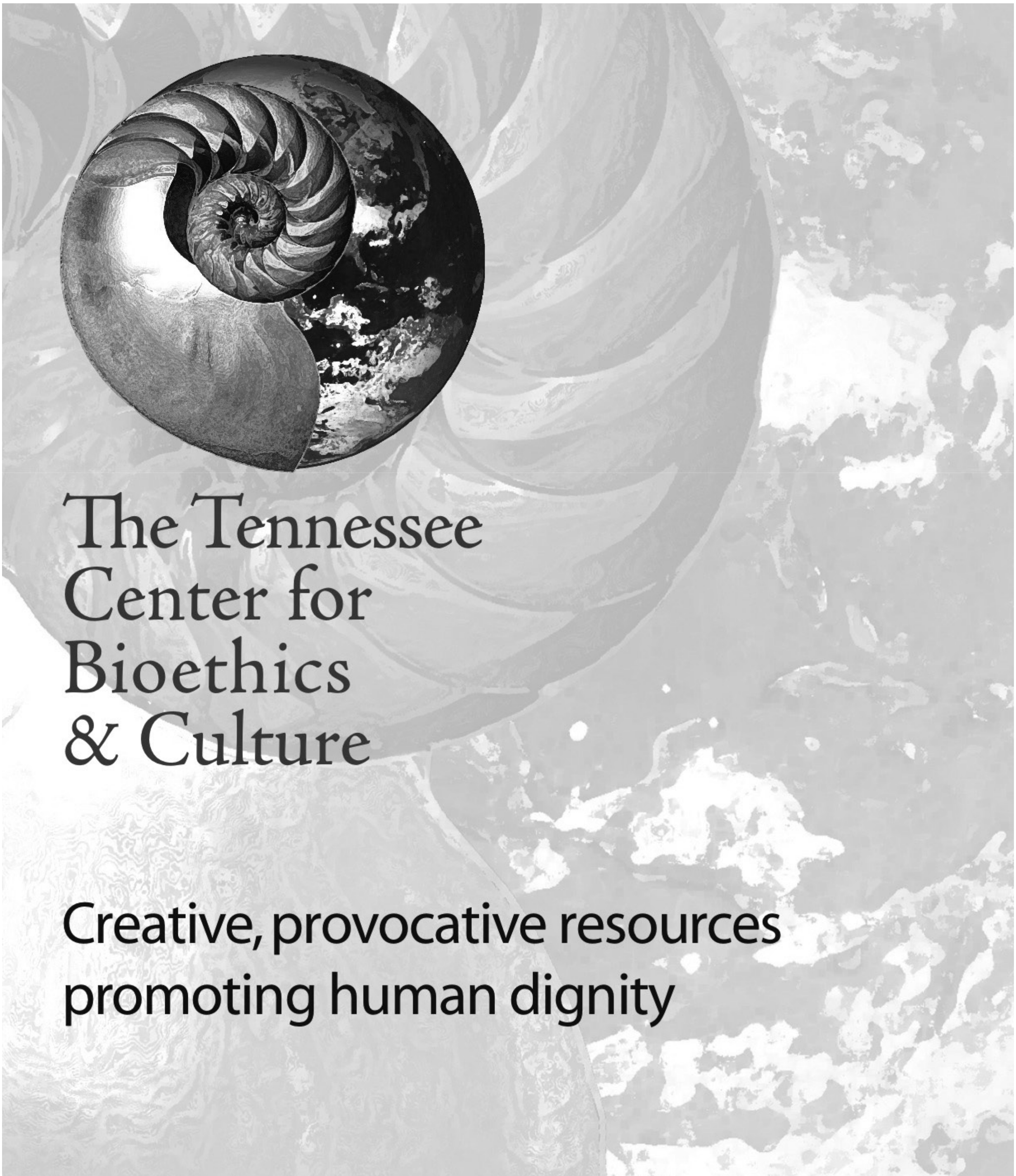

EMBRACING PVS 2.0 (THE "PERMANENT? VEGETATIVE? STATE"): MEDICAL RESEARCH BECKONS ETHICISTS CONSIDERING THE ISSUE OF ANH WITHDRAWAL TO ADOPT A MORE CHALLENGING SITUATIONAL NARRATIVE

ERIK M. CLARY, PHD

Introduction

With the march of time, a decade has now passed since the death of Terri Schiavo, a Florida woman whose plight ignited a massive media frenzy hardly rivaled in the half-century history of bioethics. Diagnosed in 1990 as being in a persistent vegetative state (PVS),[1] Terri was sustained fifteen years by artificial nutrition & hydration (ANH) until her husband prevailed in a near decade-long court battle to have her feeding tube removed. Challenging in many respects, the Schiavo saga presented multiple points for ethical consideration. Chief among them, however, was a question that first garnered widespread attention in the late 1980s with the case of Nancy Cruzan[2]—specifically: Is it morally permissible to withhold ANH from patients diagnosed as being persistently vegetative?

In working through the ANH-PVS question, ethicists most always assume that we are dealing *en masse* with individuals who are uninterruptedly unconscious and will remain so however long ANH might be employed to sustain them. Both opponents and proponents of ANH withdrawal employ this "narrative of permanent unconsciousness," but for proponents, it is generally a more critical element in the moral analysis because, with few exceptions, they posit consciousness as ethically determinative.[3]

Given its often decisive impact, the narrative of permanent unconsciousness would seem worthy of serious probing, yet, with few exceptions, it is adopted without comment or critique. The present work aims to address that deficiency. Working chiefly from the medical literature, we shall assess the narrative and find it wanting. In the wake of *Cruzan* and accelerating post-*Schiavo*, research involving patients declared permanently vegetative has yielded strong empirical warrant for ethicists to purge from their analyses of the ANH-PVS issue the assumption that we are dealing *en masse* with permanently unconscious patients. To be clear, the goal of the analysis below is not to render a conclusion on the morality of withdrawing ANH, but rather, it is to clarify the "situational perspective"[4] from which ethical deliberations may then proceed.

On the Origin of the Narrative of Permanent Vegetation

To be fair, ethicists have not fabricated the narrative of permanent vegetation out of thin air. Rather, they are drawing from a clinical description first articulated over forty years ago by Glasgow neurosurgeon Bryan Jennett and Cornell neurologist Fred Plum.[5] Reflecting upon their experience working with severely brain-injured patients, Jennett and Plum observed that in some cases, recovery from the initial coma stalls in a highly debilitated condition that, in their view, manifests the combination of a working brainstem and a nonfunctioning cerebrum. Though wakeful, generally breathing on their own, and responsive to a variety of stimuli, these patients are, Jennett and Plum proposed, "mindless" on account of a cerebral cortex that is "out of action." "Wakefulness without awareness" was their summary description, and to denote the condition they coined the term *vegetative state*.

By clinical definition, to be vegetative is to be unaware or unconscious.[6] And to denote chronicity to the condition looking backwards, Jennett and Plum attached the adjective "persistent." To be clear, they intended with this qualification no conveyance of prognostic judgment (i.e., a prediction of permanency). Rather, they purposed with it communication of a particular datum of clinical history—specifically, the observation that a patient's vegetative condition has been ongoing for some time. Unmindful of the original intent, however, ethicists commenting on the ANH-PVS issue often presume permanence when speaking of the "persistent" vegetative state.

There are no definitive laboratory tests for establishing the vegetative diagnosis (i.e., for ruling out retention of cognitive capacity in wakeful but unresponsive patients). From the outset, the diagnosis has hinged upon a subjective bedside examination yielding no responses (behaviors) thought to require cognitive processing in order to manifest. Yet, many of the movements and activities of patients deemed vegetative are also expressed by cognitive individuals (e.g., wakefulness, grasping objects, vocalizing, visual tracking, smiling, crying, laughing). Not surprisingly, then, we find some hedging in Jennett and Plum's original description as, for example, in their characterization of affected patients as "never regain[ing] *recognizable* mental function" and in their positing nonfunctioning cerebrums "as judged behaviorally."[7] Indeed, Jennett and Plum openly conceded as one potential criticism of their clinical hypothesis that "observation of behavior is insufficient evidence on which to base a judgment of mental activity." Motivated, however, by "humanitarian" and "socioeconomic" concerns over indefinite tube feeding in this subset of brain-injured patients, they insisted behavioral assessments could deliver a diagnosis sufficiently reliable to undergird treatment withdrawal decisions. All that was lacking, they concluded, were "reliable predictive criteria" for establishing permanency to the condition, and such, they figured, would be delivered by future prospective studies.

Over time, Jennett's and Plum's vegetative thesis became entrenched in the medical (and ethical) literature even as clinical research was slow to accrue. Any inclination to hedge the description gave way to an air of certitude as commentators routinely characterized the patients in question as being "noncognitive, nonsentient, and incapable of conscious experience." Such was the still oft-cited description advanced in 1994 by a group of neurospecialists collaborating as the Multi-Society Task Force on the Persistent Vegetative State (MSTF).[8] According to the MSTF, the concern that some cognitive brain-injured patients might be misdiagnosed as vegetative was largely "theoretical." Failure to detect subtle signs of consciousness, they claimed, "is *sufficiently rare* that it does not interfere with a clinical diagnosis carefully established by experts."[9]

Taking matters further, the MSTF tackled the question of permanency left dangling by Jennett and Plum—not, however, with prospective data in hand, but instead with reliance upon the weaker tool of retrospective meta-analysis.[10] Surveying a number of published clinical reports that presented a grand total of 754 patients bearing the PVS diagnosis for at least one month post-injury, the MSTF concluded it appropriate to declare the vegetative condition "permanent" after one year in the case of traumatic brain injury, and three months in situations involving nontraumatic or "anoxic" injury. While acknowledging published reports of cognitive recovery occurring beyond its chosen time points, the MSTF nonetheless dismissed these "late recoveries" as "exceedingly rare."

Evaluating the Narrative of Permanent Vegetation

With physicians confidently asserting the vegetative thesis and claiming rarity of error in both their diagnostic and prognostic judgments, ethicists latched on. Setting up their analyses, they have routinely posited subjects wakeful but unaware and permanently lacking cognitive capacity. Some even have gone so far as to assert "complete neocortical destruction" or "cerebral death" as a definitive feature of the vegetative state.[11] That hypothesis Jennett and Plum themselves labeled at the outset as "unproven," and what was unproven then has since been clearly disproven. Retained neocortical viability, it turns out, is the norm for patients declared vegetative, and in many cases, cerebral architecture is normal or near-normal.[12]

Denied the unwarranted claim of neocortical death, one might still insist that, whatever the underlying pathology, patients deemed persistently vegetative are nonetheless unconscious and permanently so. Failure to offer a credible explanation of how a phenomenon arises does not necessarily invalidate the claim that the phenomenon itself is real. Granting, then, that awareness of self or environment manifests a conscious state, and recognizing the lynchpin status ethicists typically grant the narrative of permanent vegetation, it must be asked: How confident can we be that patients declared permanently vegetative are 1) truly vegetative (i.e., uninterruptedly unconscious) and 2) destined to remain in that condition for whatever duration ANH is provided?

Taking a step back, one might first ask, "How confident *must* we be?" Ethicists defending ANH withdrawal generally bypass this question completely, perhaps because it seems moot as they encounter descriptions like that of the MSTF characterizing diagnostic errors as "theoretical" and prognostic errors as "exceedingly rare." Some ethicists who key in on consciousness, however, recognize well that allowing a patient to die is a weighty matter and so conclude that the judgment of permanent unconsciousness must be sure. Philosopher Scott Rae is one example as he insists, "There must be solid medical evidence that the vegetative state is indeed permanent."[13] This is no demand, Rae claims, for infallible medical judgments, but it is to insist upon a high degree of accuracy that, according to the analysis below, eludes present medical capability.

Concerning the Diagnostic Claim ("Vegetative State")

Surprising as it may be for many a bioethicist, misdiagnosis of the vegetative state is actually a well-documented phenomenon that first surfaced in the medical literature over two decades ago in a 1991 report published in *Archives of Internal Medicine* with Wisconsin geriatrician Donald Tresch as the lead author.[14] Concerned by the paucity of published data on the PVS, Tresch and his fellow researchers intended with their efforts to deliver a more extensive description of the syndrome's clinical features, and in pursuit of that goal, they scoured several Milwaukee nursing homes in search of study subjects. In all, they identified 62 individuals bearing the diagnosis of PVS and comprising almost 4% of the resident population in the facilities surveyed. In examining these patients, however, Tresch and his colleagues found that eleven individuals (18%) exhibited cognitive function. "All 11 patients," they reported, "were considered by us to have some awareness of their environment, with some of the patients demonstrating volitional movements."

For Tresch et al., the discovery of cognitive patients bearing a PVS diagnosis was noteworthy, but not hugely significant. After noting the impact of the misdiagnoses on their efforts to establish a study group, they gave the phenomenon no further consideration. Other researchers, however, took notice and concluded a closer examination was warranted. Among them was neurologist Nancy Childs of the Healthcare Rehabilitation Center (HRC) in Austin, Texas. Working with two other colleagues, Childs examined the records of 49 patients referred over a five-year period to her institution with the diagnosis of PVS or coma and found that 18 (37%) were discovered to be cognitive within one week of admission to HRC.[15] Commenting on their findings in a 1993 *Neurology* article, Childs noted, "There was little delay in identifying responding [i.e., misdiagnosed] patients; 50% (n = 9 of 18) were identified within the first day of admission and 78% (n = 14 of 18) by the third day." To be clear, these were not patients believed to have *recovered* consciousness while receiving care at HRC; rather, they were referred as noncognitive but discovered to be otherwise during the initial HRC workup. Neither were they individuals for whom little time had been available for repeated assessments prior to referral as all had been treated as noncognitive for a minimum of one month and two-thirds (the "chronic" cases) for over three months. Indeed, among Childs' patients presenting with traumatic injuries (34 of 49), PVS misdiagnosis was more frequently encountered in those with chronic clinical histories.[16]

Contemplating their data, Childs et al. proposed as causal factors for misdiagnosis both "confusion in the terminology" dealing with disorders of consciousness and a lack of experience among referring physicians in assessing patients with severe neurodisability. Challenging that explanation, it would seem, researchers at London's Royal Hospital for Neurodisability (RHN) reporting a 43% PVS misdiagnosis rate three years later observed that most of their study's errant diagnoses had been "made by a [referring] neurologist, neurosurgeon, or rehabilitation specialist—all of whom could have been expected to have experience of vegetative state."[17] Deepening the critique, the RHN data revealed more than ample time for patient assessments prior to referral—despite bearing their PVS diagnoses for a median interval of ten months, 15 of the 17 (88%) misdiagnosed patients were identified as cognitive on initial RHN assessment.[18] Laboring to explain why referring specialists were missing evidence of consciousness, the researchers postulated a poor appreciation for the extent to which physical disabilities can mask cognition in some brain-injured patients.

Positing clinicians poorly informed as a major factor driving the high frequency of PVS misdiagnosis, one might expect more recent reports to show significant diminution of the error rate. Such has not been the case. Considering the issue afresh almost a decade after their initial report appeared in the widely-read *British Medical Journal*, RHN clinicians led by Helen Gill-Thwaites again reported a PVS misdiagnosis rate exceeding 40% with over half of the errant diagnoses identified on initial assessment.[19] Tracking with that report, researchers working a few years later in the University of Liège Coma Science Group (CSG) reported finding evidence of cognition in 18 of 44 (41%) patients declared vegetative by a multi-disciplinary team of clinicians.[20]

In considering the misdiagnosis phenomenon, the CSG researchers suspected inadequate behavioral assessments as a major contributing factor. By design, their research probed the issue as they rated their use of a standardized behavioral scoring system (Coma Recovery Scale-Revised [CRS]) against the clinical team's routine ("unstructured") bedside examination. With more patients identified as cognitive via the CRS approach, the researchers concluded, "The results of this study suggest that the systematic use of a sensitive standardized neurobehavioral assessment scale may help decrease diagnostic error and limit diagnostic uncertainty." Gill-Thwaites sounded the same opinion three years earlier as she criticized colleagues reluctant to incorporate standardized assessments in their testing of debilitated, post-comatose patients. With clear dissatisfaction, she noted, "It is still highly possible that a standardized assessment may not be administered on these patients at all, and in such cases identification of the patient's awareness could be a matter of mere luck."[21]

Despite reports of PVS misdiagnosis appearing in top-tier medical journals and spanning over two decades, the problem persists (See Table 1). Exacerbating the concern, recent research employing brain-probing technologies suggests the error rate may be considerably higher. In the early publications presented above, misdiagnoses were identified via patient examinations keyed on the detection of volitional behavior, but beginning with a 2006 report from Adrian Owen at Cambridge University, researchers have come to recognize with the aid of sophisticated brain imaging procedures a subset of behaviorally unresponsive, post-comatose patients who are cognitive.[22] In Owen's terminology, these patients are "covertly aware," and in his groundbreaking case report, the level of mental function described was quite substantial.[23]

Presenting only a single case, Owen's report offered no means for assessing incidence, but a study led by Johan Stender of Liège's CSG and reported in *The Lancet* in 2014 suggests covert awareness may be near as frequent a phenomenon as errant behavioral examinations yielding a PVS (mis)diagnosis.[24] Evaluating 126 patients referred to Liège's University Hospital with severe brain injury, Stender and his colleagues first determined from their own behavioral examinations that, consistent with prior reports, a large percentage of individuals admitted with the diagnosis of vegetative state—specifically, 35% (18 of 51)— were cognitive at some level. Probing deeper, they conducted functional MRI studies (Owen's technique) and metabolic PET scans on 41 patients they themselves had diagnosed as vegetative via

CRS and concluded that 13 (32%) were covertly aware.[25] Even, then, if all patients declared vegetative were subjected to thorough behavioral examinations by experts employing standardized assessments, Stender's findings suggests PVS misdiagnosis will continue at a high rate.

Conceding the data on PVS misdiagnosis, one might suppose the solution a simple one—specifically, that unresponsive post-comatose patients all be directed to facilities like those at HRC, RHN, or Liège. There are, however, too few specialized centers to accommodate the mass of patients bearing a PVS diagnosis that, in the United States alone, is estimated to exceed 30,000.[26] The clinical reality, as researchers John Whyte and Risa Nakase-Richardson have recently noted, is that most brain-injured patients receiving a PVS diagnosis are transferred soon after their injuries to "homes and nursing homes."[27] In the acute care facility, diagnoses may be rendered by highly-skilled specialists employing standardized assessments and expensive brain-imaging procedures. After transfer, however, care will generally be overseen, Whyte and Nakase-Richardson note with echoes of Childs, "by primary care clinicians with no specialized training in [disorders of consciousness]." All things considered, it seems likely that the high rate of PVS misdiagnosis will persist for the foreseeable future.

Concerning the Prognostic Claim ("Permanency")

No less problematic for ethical analyses employing the narrative of permanent vegetation is the phenomenon of late recovery. Some post-comatose patients who meet the diagnostic criteria for the vegetative state at the generally accepted cutoff for declaring permanency go on to manifest cognitive function when further sustained. In describing their condition, Jennett commented in 2002, "[T]hese late recoveries are almost always to very severe disability. Most patients remain totally dependent, some reaching only the minimally conscious state or a little better. Many continue to require tube feeding and are able to communicate only by gesture or coded movements because they cannot speak."[28] In other words, these patients typically are highly debilitated, yet they are nonetheless demonstrably conscious.

According to the MSTF, late recovery of cognitive function following severe head trauma is "exceedingly rare," and to support that conclusion, the Task Force cited documented recovery beyond its chosen cutoff of twelve months in only seven of the 434 head-injured adults admitted into its meta-analysis on the criterion of being vegetative for a minimum of one month post-injury (i.e., being *persistently* vegetative per the MSTF's clinical definition).[29] Seven out of 434 calculates as 1.6%.

Whether or not a frequency of almost 2% qualifies as "exceedingly rare" some commentators may wish to debate. More significantly, however, the published medical data point to a much higher incidence of late cognitive recovery, and this includes the MSTF's own data set. Arguing the latter point in a 1996 essay, disability advocate Chris Borthwick keenly observed that since only 65 of the 434 patients were alive and vegetative at the permanency cutoff, the frequency of late recovery should have been calculated not as 7÷434 but as 7÷65, or almost 11%.[30] In other words, the question to pose, Borthwick rightly argued, was not "How many patients receiving the PVS diagnosis will go on to experience a late recovery?" but rather, "How many patients surviving and still vegetative at the permanency cutoff will experience cognitive recovery if further sustained by ANH?" To that question, the MSTF's retrospective analysis yielded, in fact, an answer of roughly one out of ten. One might label that as infrequent, but certainly not "exceedingly rare" or even "rare."

Since Borthwick's critique was published, research dealing with late recovery in vegetative patients has been slow to accrue, but three recently published studies suggest he was on the right track. In 2010, researchers in Telese, Italy, reported late recoveries averaging just over seventeen months post-trauma in 10 of 50 patients (20%) that were followed for an average of almost 26 months following admission.[31] Two years later, a multi-center longitudinal analysis with five-year follow-up on 37 vegetative patients receiving rehabilitation therapy revealed eight late recoveries (22%) with half occurring more than two years post-trauma.[32] The following year, the Telese researchers reported again on late recovery but with a focus on patients with non-traumatic injuries.[33] With 9 of 43 patients (21%) experiencing cognitive recovery beyond the MSTF cutoff of three months, these researchers concluded that "late recovery cannot be considered as an exception."

For some commentators—Jennett included—reports of late cognitive recoveries pose no serious obstacle to linking an ANH withdrawal request to a declaration of permanency based on MSTF guidelines because they judge the typical quality of life of late-recovered patients to be so poor as to warrant cessation of life-prolonging treatment.[34] But for ethicists who settle the ANH issue on the question of whether or not the patient retains the potential for cognitive function, late recoveries present the same problem as misdiagnoses—specifically, that some patients who meet the proposed ethical criterion for receiving continued life support will be treated as if they did not. More pointedly, they will, by these ethicists' own reckoning, be killed without justification.

Conclusion

For researchers whose work has served to undermine the narrative of permanent unconsciousness, there remains the conviction that some wakeful, post-comatose patients are, in fact, uninterruptedly unconscious and will remain so however long they might be sustained. Even as they generally prefer to do away with the *vegetative* descriptor given its frequent misapplication, its capacity to dehumanize, and its potential to drive medical decision making apart from a careful consideration of all ethically relevant factors, their call is not for a rejection of the vegetative thesis, per se.[35] At the very least, however, their work calls ethicists and others addressing the question of indefinite ANH for patients like Terri Schiavo to let loose of a false narrative that many have found quite useful.

As the present judgments—medicine commenting on medicine—are that the vegetative state often is not vegetative and that late cognitive recovery is not so rare an event, we do well to formulate—or reformulate, as the need may be—our analyses of the ANH question *sans* the assumption that we are dealing exclusively with patients who are permanently unconsciousness. Supposing only permanently unconscious persons to be in view—clinging, we might say, to "PVS 1.0"—the moral analysis will, at best, aim at a medical definition and not the clinical reality as presently understood. Recognizing, however, a duty of the ethicist to first "gather the facts" with integrity,[36] that approach is simply unacceptable.

Perhaps researchers will succeed one day in their quest to develop an accurate and widely accessible method for identifying among post-comatose patients those who are permanently unconscious. Until then, it seems necessary, as Borthwick suggested a decade ago, to "frame our opinions . . . in ways that can accommodate a high element of uncertainty [as to the cognitive status of the patients in question]."[37] Considering the ANH-PVS question in light of "PVS 2.0"— or, more descriptively, "The "Permanent? Vegetative? State"—we should anticipate that our conclusions will find application to patients who, unbeknownst to caregivers, are aware at some level or may become so if ANH were to continue. If such requires a revision of arguments or otherwise complicates the moral analysis, then so be it.

Table 1. Misdiagnosis of the Vegetative State in the Medical Literature*

Tresch et al. (1991)	18%	(11 of 62)†
Childs et al. (1993)	37%	(18 of 49)‡
Andrews et al. (1996)	43%	(17 of 43)‡
Gill-Thwaites et al. (2004, 2006)	45%	(27 of 60)‡
Schnakers et al. (2009)	41%	(18 of 44)§

**In the reports listed, cognitive function was identfied in misdiagnosed patients working from behavioral assessments. †Nursing home residents bearing the PVS diagnosis. ‡Neurorehabilitation patients received with a referring diagnosis of PVS. §Hospitalized patients declared vegetative by medical consensus prior to evaluation by clinical research team.*

Endnotes

1. Some participants in the ANH-PVS debate object to the term *vegetative* on the grounds that it dehumanizes vulnerable patients (see, for example, David F. Forte, "Getting Rid of the Vegetables," *First Things*, no. 26 (1992), 13–15). In response, it may be noted that long before the advent of artificial life support, *vegetative* was part of the medical lexicon. Employed to denote the component of the nervous system that mediates physiological activities requiring no conscious direction, the term fell out of usage as physicians began to speak instead of the "autonomic" nervous system. Working from the hypothesis that only autonomic function persists in patients deemed vegetative, physicians may thus speak of the *vegetative* condition without necessarily intending a violative attribution of subhuman existence.
2. *Cruzan* v. *Missouri Department of Health*, 497 U.S. 261 (1990).
3. Christian ethicist Robert Rakestraw, for example, attempts to settle the ANH-PVS question by positing PVS patients as "non-persons" on the presumption that they are permanently unconscious. That approach is routine among secular ethicists, including Nancy Jecker, who, in a classic treatment on the subject of medical futility co-authored by physician Lawrence Schneiderman, posits ANH for PVS patients as the paradigmatic case. Working from the narrative of permanent unconsciousness, they write, "Some qualitatively poor results should indeed be the patient's prerogative. However, other sorts of qualitatively poor results fall clearly outside the range of medical goals. . . . The clearest of these qualitatively poor results is continued biological

life without consciousness. The patient has no right to demand of medicine to be sustained in a state in which he or she has no capacity to appreciate the life prolonged by treatment and no purpose other than mere vegetative survival." As a final example, we may cite evangelical ethicist Scott Rae, who rejects the personhood distinction but still finds the appeal to medical futility compelling as he concludes ANH withdrawal ethically permissible on the presumption that treatment would "be of no benefit to the patient in regaining consciousness." To his credit, Rae insists that the declaration of permanent vegetation must be sure, but that condition is left unexamined as he proceeds to defend ANH withdrawal. See Robert V. Rakestraw, "The Persistent Vegetative State and the Withdrawal of Nutrition and Hydration," *Journal of the Evangelical Theological Society* 35, no. 3 (1992), 389–405; Lawrence J. Schneiderman and Nancy S. Jecker, *Wrong Medicine: Doctors, Patients, and Futile Treatment*, 2nd ed. (Baltimore: Johns Hopkins University Press, 2011); and Scott B. Rae, "Is the Removal of Medically Provided Nutrition and Hydration from the Patient in a PVS Ethically Acceptable?" (paper presented at Far West Regional Meeting of the Evangelical Theological Society, Fullerton, Calif., April 12, 1991).

4. In doing bioethics, I find helpful theologian John Frame's "triperspectival" approach to ethical analysis. According to Frame, for any ethical decision, there exists a particular set of circumstances (the "situational perspective") in which the moral agent, whose capacity for engaging in sound moral deliberation may be affected by a number of internal factors (the "existential perspective"), must seek to apply relevant norms and principles (the "normative perspective"). Failure to get the facts of the situation straight is a frequent contributor to skewed bioethics. See Frame's *Medical Ethics: Principles, Persons, and Problems* (Phillipsburg: Presbyterian & Reformed, 1988), and the more expansive discussion in his tome on Christian ethics, *The Doctrine of the Christian Life* (Phillipsburg: P&R, 2008), 131–382.
5. Bryan Jennett and Fred Plum, "Persistent Vegetative State after Brain Damage. A Syndrome in Search of a Name," *Lancet*, no. 7753 (1972), 734–37.
6. In what, precisely, does consciousness consist or how is it best defined, such questions philosophers have long debated. Generally, neurophysicians employ a Jamesian approach that posits awareness (of self or the external environment) as the core feature. Demonstrating the approach, Joseph Giacino and his colleagues write, "Many definitions of consciousness have been proposed, none of which completely avoids an element of tautology or self-reference. However, a definition closely following that of William James (1894) is useful for framing [disorders of consciousness] across a continuum. According to James, 'at its least, normal human consciousness consists of a serially time-ordered, organized, restricted and reflective awareness of self and the environment." See Joseph T. Giacino, Joseph J. Fins, Steven Laureys, and Nicholas D. Schiff, "Disorders of Consciousness after Acquired Brain Injury: The State of the Science," *Nature Reviews Neurology* 10, no. 2 (2014), 99. The work of James' referenced by Giacino et al. is "The Physical Basis of Emotion," first published in 1894 and reprinted a century later in *Psychological Review* 101, no. 2 (1994), 205–210.
7. Jennett and Plum, "Persistent Vegetative State," 734; emphasis added.
8. The Multi-Society Task Force on the Persistent Vegetative State, "Medical Aspects of the Persistent Vegetative State (First of Two Parts)," *New England Journal of Medicine* 330, no. 21 (1994), 1501.
9. Ibid., emphasis added.
10. The Multi-Society Task Force on the Persistent Vegetative State, "Medical Aspects of the Persistent Vegetative State (Second of Two Parts)," *New England Journal of Medicine* 330, no. 22 (1994), 1575.
11. See, for example, Rakestraw, "The Persistent Vegetative State."
12. In a 2002 book dealing with the vegetative state, Jennett relates that when he and his colleagues at the University of Glasgow conducted post-mortem examinations on the brains of forty-nine patients bearing the PVS diagnosis at the time of death, they discovered that "the cerebral cortex was completely normal in seven cases and in 21 others was affected only by minor traumatic contusions." See Bryan Jennett, *The Vegetative State: Medical Facts, Ethical and Legal Dilemmas* (Cambridge: Cambridge University Press, 2002), 52–53. For a discussion of pre-mortem studies demonstrating retention of neocortical viability in patients deemed vegetative, see Erik M. Clary, "Feeding the Dead? Rethinking Robert Rakestraw on the Persistent Vegetative State," *Journal of the Evangelical Theological Society* 58, no. 4 (2015), 791–94.

13. Rae, “Removal of Medically Provided Nutrition and Hydration,” 9.
14. Donald D. Tresch, Farrol H. Sims, Edmund H. Duthie and others, “Clinical Characteristics of Patients in the Persistent Vegetative State,” *Archives of Internal Medicine* 151, no. 5 (1991), 930–32.
15. Nancy L. Childs, Walt N. Mercer, and Helen W. Childs, “Accuracy of Diagnosis of Persistent Vegetative State,” *Neurology* 43, no. 8 (1993), 1465–67. By clinical definition, *vegetative state* and *coma* both involve an unconscious condition. On the distinctions between coma, PVS, and other disorders of consciousness, see Caroline Schnakers and Steven Laureys, eds., *Coma and Disorders of Consciousness* (London: Springer, 2012), 1–10.
16. Per Childs et al., “Misdiagnosis was more likely in the nonacute traumatically brain-injured (48%, n = 11 of 23) than in the acute traumatically brain-injured (27%, n = 3 of 11).”
17. Keith Andrews, Lesley Murphy, Ros Munday, and Clare Littlewood, “Misdiagnosis of the Vegetative State: Retrospective Study in a Rehabilitation Unit,” *British Medical Journal* 313, no. 7048 (1996), 13–16. In this study, consciousness was detected in 17 of 40 patients admitted with a referring diagnosis of PVS.
18. Ibid., 14. At the time of admission to RHN, all of the misdiagnosed patients had borne the PVS diagnosis for a minimum of six months, three for between one and two years, and three for over four years.
19. H. Gill-Thwaites and R. Munday, “The Sensory Modality Assessment and Rehabilitation Technique (SMART): A Valid and Reliable Assessment for Vegetative State and Minimally Conscious State Patients,” *Brain Injury* 18, no. 12 (2004), 1255–69. In this study, 27 of 60 (45%) patients referred to RHN as vegetative were discovered to be cognitive during the initial workup. Additional comment on this study from the lead author appears in Helen Gill-Thwaites, “Lotteries, Loopholes and Luck: Misdiagnosis in the Vegetative State Patient,” *Brain Injury* 20, no. 13/14 (2006), 1321.
20. C. Schnakers, A. Vanhaudenhuyse, J. Giacino and others, “Diagnostic Accuracy of the Vegetative and Minimally Conscious State: Clinical Consensus Versus Standardized Neurobehavioral Assessment,” *BMC Neurology* 9 (2009), 35. Data for this study were collected between October 2005 and January 2007. Misdiagnosis of the vegetative state was more frequent ($p<.01$) in patients with chronic injuries (14 of 29, or 48%) than those acutely disabled (4 of 15, or 27%). Per the authors, the errant diagnoses were made by “a clinical team comprised of physicians, psychologists, speech therapists, occupational therapists, physiotherapists and nurses.”
21. Gill-Thwaites, “Lotteries, Loopholes and Luck,” 1327.
22. Adrian M Owen, Martin R Coleman, Melanie Boly and others, “Detecting Awareness in the Vegetative State,” *Science* 313, no. 5792 (2006), 1402. See also, Damian Cruse, Srivas Chennu, Davinia Fernandez-Espejo and others, “Detecting Awareness in the Vegetative State: Electroencephalographic Evidence for Attempted Movements to Command,” *PLoS One* 7, no. 11 (2012), e49933; Adrian M Owen and Martin R Coleman, “Detecting Awareness in the Vegetative State,” *Annals of the New York Academy of Sciences* 1129 (2008), 130–38; and C. Schnakers, J. T. Giacino, M. Lovstad and others, “Preserved Covert Cognition in Noncommunicative Patients with Severe Brain Injury?,” *Neurorehabilitation and Neural Repair* (2014), Advance online publication. doi:10.1177/154596831 4547767.
23. Assessing a woman repeatedly diagnosed on behavioral examination as vegetative for six months following vehicular trauma, Owen and his fellow researchers employed two mental imagery exercises, each cued by verbal instruction, while performing a functional magnetic resonance imaging (fMRI) scan. Reviewing the brain imaging patterns manifesting during the exercises, they concluded the patient’s responses to be “indistinguishable from those observed in healthy volunteers.” Owen, Coleman, Boly, et al., “Detecting Awareness,” 1402.
24. J. Stender, O. Gosseries, M. A. Bruno and others, “Diagnostic Precision of PET Imaging and Functional MRI in Disorders of Consciousness: A Clinical Validation Study,” *Lancet* 384, no. 9942 (2014), 514–22.
25. Of the 13 patients judged covertly aware (“nonbehavioral minimally conscious state” was Stender et al.’s preferred label), nine later demonstrated signs of consciousness on bedside behavioral examination.
26. Jennett, *The Vegetative State*, 36. Given an approximate population of 320 million and a mid-range

estimate of 100 cases per million (per Jennett's review of the literature), it is estimated that in the United States alone there are 32,000 individuals bearing the PVS diagnosis.

27. John Whyte and Risa Nakase-Richardson, "Disorders of Consciousness: Outcomes, Comorbidities, and Care Needs," *Archives of Physical Medicine and Rehabilitation* 94, no. 10 (2013), 1851–54.
28. Jennett, *The Vegetative State*, 65.
29. In the MSTF data set, adults with severe head trauma accounted for over half of the patients meeting their inclusion criteria (434 out of 754, or 57.5%). Defining the *persistent* vegetative state, the MSTF wrote, "We define such a state operationally as a vegetative state present one month after an acute traumatic or nontraumatic brain injury or a vegetative state of at least one month's duration in patients with degenerative or metabolic disorders or developmental malformations." The Multi-Society Task Force on the Persistent Vegetative State (First of Two Parts), 1501.
30. Christian J. Borthwick, "The Permanent Vegetative State: Ethical Crux, Medical Fiction?," *Issues in Law & Medicine* 12, no. 2 (1996), 167–85.
31. A. Estraneo, P. Moretta, V. Loreto and others, "Late Recovery after Traumatic, Anoxic, or Hemorrhagic Long-Lasting Vegetative State," *Neurology* 75, no. 3 (2010), 239–45. Patients exhibiting late recovery in this study included six with traumatic brain injury, three with anoxic injury, and one with cerebral aneurysm. The range between disease onset and detection of consciousness was 14 to 28 months.
32. R. Nakase-Richardson, J. Whyte, J. T. Giacino and others, "Longitudinal Outcome of Patients with Disordered Consciousness in the NIDRR TBI Model Systems Programs," *Journal of Neurotrauma* 29, no. 1 (2012), 59–65.
33. A. Estraneo, P. Moretta, T. Terme, and L. Trojano, "Predictors of Recovery of Responsiveness in Prolonged Anoxic Vegetative State. Author Reply," *Neurology* 81, no. 14 (2013), 1274–75.
34. Commenting in 1992 on the case of Tony Bland, Jennett asserted, "treatment is justified only if there is a reasonable probability of *meaningful* recovery and of regaining life as a *social person* or if, in the words of the BMA's medical ethics committee, 'it makes possible a *decent* life in which a patient can reasonably be thought to have a *continued interest*.'" A typical "late" recovery from the vegetative state will not satisfy his requirements, and so Jennett opined, "The recovery of a limited degree of awareness may indeed be worse than non-sentience for the patient, whatever satisfaction it may bring to the carers." Bryan Jennett, "Letting Vegetative Patients Die," *British Medical Journal* 305, no. 6865 (1992), 1305; emphasis added.
35. On the effort to change the terminology, see S. Laureys, G. G. Celesia, F. Cohadon and others, "Unresponsive Wakefulness Syndrome: A New Name for the Vegetative State or Apallic Syndrome," *BMC Medicine* 8 (2010), 68.
36. Presenting a model for ethical decision making, ethicist Scott Rae rightly asserts that the first step is to "gather the facts" for as he explains, "Frequently, ethical dilemmas can be resolved simply by clarifying the facts of the case in question." Scott B. Rae, *Moral Choices: An Introduction to Ethics*, 3rd ed. (Grand Rapids: Zondervan, 2009), 106.
37. Chris Borthwick, "Ethics and the Vegetative State," *Neuropsychological Rehabilitation* 15/3 (2005), 262.

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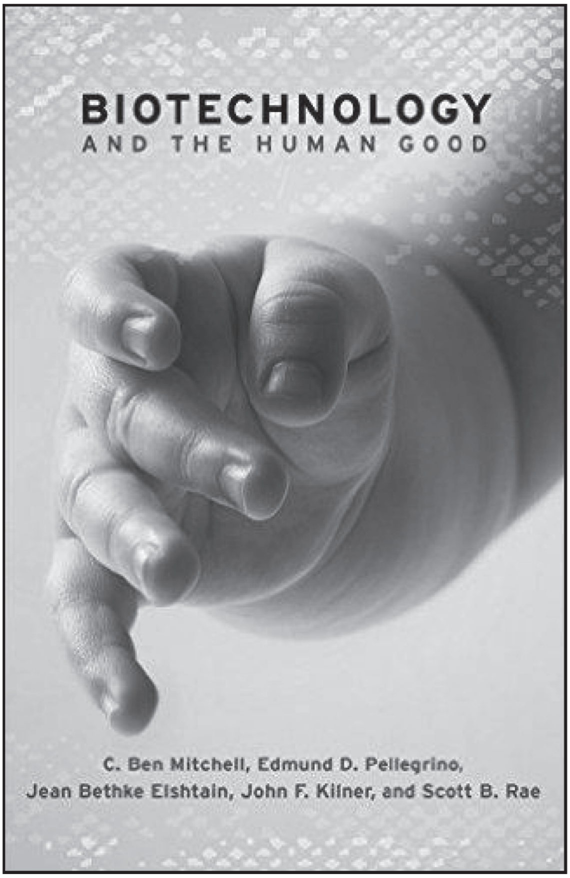
BIOTECHNOLOGY
AND THE HUMAN GOOD

By C. Ben Mitchell, Edmund D. Pellegrino, Jean Bethke Elshtain,
John F. Kilner, and Scott B. Rae



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Some of humankind's greatest tools have been forged in the research laboratory. Who could argue that medical advances like antibiotics, blood transfusions, and pacemakers have not improved the quality of people's lives? But with each new technological breakthrough there comes an array of consequences, at once predicted and unpredictable, beneficial and hazardous.

Outcry over recent developments in the reproductive and genetic sciences has revealed deep fissures in society's perception of biotechnical progress. Many are concerned that reckless technological development, driven by consumerist impulses and greedy entrepreneurialism, has the potential to radically shift the human condition—and not for the greater good. *Biotechnology and the Human Good* builds a case for a stewardship deeply rooted in Judeo-Christian theism to responsibly interpret and assess new technologies in a way that answers this concern.

The authors jointly recognize humans not as autonomous beings but as ones accountable to each other, to the world they live in, and to God. They argue that to question and critique how fields like cybernetics, nanotechnology, and genetics might affect our future is not anti-science, anti-industry, or anti-progress, but rather a way to promote human flourishing, common sense, and good stewardship.

A synthetic work drawing on the thought of a physician, ethicists, and a theologian, *Biotechnology and the Human Good* reminds us that although technology is a powerful and often awe-inspiring tool, it is what lies in the heart and soul of who wields this tool that truly makes the difference in our world.

ARE PARENTS LIABLE FOR THEIR BABIES' PRENATALLY ACQUIRED INJURIES?

CARLO V. BELLIENI, MD; ALBERTO M. GAMBINO, PHD

Abstract

External factors can interfere with pregnancy; some of them are factors of parental origin, such as active or passive smoking or alcohol use; some are of environmental origin such as air or water pollution; some are due to medical errors that expose the developing being to harm. Sometimes these factors cause the death of the fetus; sometimes they just injure it with relevant consequences after birth. We discuss the paradox that if prenatal harm is caused by doctors or social factors, the authors of the harm will be prosecuted, while if the harm is provoked by parents, they have no legal consequences. The present paper illustrates this paradox and concludes that parents who provoke an avoidable preterm birth or any other avoidable harm with postnatal consequences are morally guilty of the same fault of care that they would be accused of if they unwillingly caused harm to an already born baby.

Key words: Pregnancy; Fetus; Parents

The placenta is a filter that shields the fetus from hazards, but it cannot prevent all noxious factors either chemical or infective. Such factors affect the fetus through its mother, via voluntary ingestion/absorption (alcoholic drinks, tobacco, unprotected contact with notoriously infective subjects) or via involuntary ingestion/absorption (air or water pollution, contact with infected subjects). These factors can cause severe damage to the fetus.[1-4] When the fetus is born and grows up, it can suffer the consequences of these hazardous factors. Even before birth, a fetus can be harmed by substances ingested by its mother, the consequences of which he/she will suffer throughout all his/her life. Maternal alcohol ingestion can cause the so-called fetal alcohol syndrome, characterized by malformations, mental delay, heart disease; tobacco smoke can damage the placenta with consequent fetal growth restriction and low birth weight and future asthma. Heavy metals that can be present in the air or water are absorbed by the mother and affect the fetus, causing mental retardation and malformations. Also stress not prevented or voluntarily chosen in pregnancy is a risk factor as well as the decision of delaying childbearing when this is not due to external factors and conditions. In fact, delayed childbearing is correlated with a higher risk of preterm birth and birth anomalies.

Social Responsibilities

People who harm fetuses, exposing mothers to poisons or undue stress, can be liable, some legislations agree that they should pay for it. A legal responsibility exists in damaging fetuses when this is due to the lack of respect of work rules. Stress and fatigue women go through during stressful jobs as employees or workers[5,6] are risk factors of preterm birth, and possible causes of severe brain or lung damage for the baby. Employers who do not follow all guidelines to preserve women and their future babies from harm due to stress can be legally sued. When a correlation between fetal harm and postnatal damage is evident, those responsible can be prosecuted. This was the case regarding lead intoxication in Myamata (Japan),[7] methyl isocyanate intoxication in Bophal (India),[8] and the phocomelia epidemic due to thalidomide in US in the '60s. The area of law that deals with negligence on the part of manufacturers is called product liability, and this responsibility is to be considered for the damages that it can provoke before or after birth. The moral responsibility in this case is evident: the consequences a baby is forced to suffer because of prenatal harm are so indicative of an unfair exposure to toxic substances or to stressful jobs that anyone would agree to prevent these types of risks with sanctions.

Medical Responsibility

Even in the field of medical responsibility it is evident that, if a baby is born with a damage that could be preventable, the doctor who took care of the pregnancy and did not prevent the damage is morally responsible—for instance, if a doctor has neglected to make a diagnosis of a curable disease and the baby has suffered injuries from this disease. It can also happen that a doctor may suggest the use of drugs that can harm the fetus, such as in the case of phocomelia epidemics due to thalidomide. Doctors have the sacred responsibility of "do not harm" and to preserve health.

The paradox of doctors prosecuted for the birth instead of the abortion of a baby is reported. This case is very complicated: babies born instead of being aborted have prosecuted (by proxy) the supposed responsible. For instance, in the case of prenatal misdiagnosis of fetal morphological normality, made in reality on a damaged fetus, it was stated that having been born with such diseases was "per se" a harm for the baby, and the doctor who made the erroneous diagnosis was consequently prosecuted. This principle has been criticized, because it places lower moral value on the disabled.[9]

Parental Responsibility

But when the prenatal harm visible in an already born baby is caused by the parents, it seems that none should be guilty. A father can expose the mother and consequently the baby to passive smoke or to violent stress[10] throughout pregnancy, and if the baby gets injured, he will have no responsibility for this harm. A mother can drink alcohol and choose stressful behaviors in pregnancy (loud music, stressful journeys), or she can delay pregnancy to a maternal age where babies' birth anomalies, prematurity, and brain damage are more frequent, without responsibility or legal consequences.

When an already born baby is unintentionally harmed by the parents, it is considered an accident, but, despite the comprehensible indulgence, it is also juridically relevant, unless the accident or the absence of a cause-effect connection are evident.[11,12] A child who is injured because of a parent's negligence can sue that parent; children usually sue because parents often have liability insurance that would cover some or all of the medical expenses that would have to be paid due to the child's injuries. On the other hand, parents can also cause permanent harm prenatally with postnatal consequences, but they cannot be sued by the law. If a parent voluntarily administers an alcoholic substance to his/her baby without health consequences, the parent is prosecuted for maltreating; if a mother ingests alcohol during pregnancy with catastrophic consequences for the baby (three, four years later, i.e. when he/she is already a citizen and a person) she (or whoever induced her to perform like this) is immune from prosecution.

What Follows for Ethics from the Legal Discussion?

If we consider the moment of the injury, isolated from the context, injury is done on a fetus, who in a juridical sense is not a person. Nevertheless, if we consider the consequences, they will be suffered by a baby, who is a full person.

Of course, this is just a side of the question: if a human fetus is a person, he/she should receive all possible guarantees about his/her health and survival, and a debate on this issue is still ongoing in western countries.

But a minimum agreement should be reached about one point: when a fetus is harmed, he/she can suffer the consequences of this harm when he/she will be born (and will have legal rights). But have we obligations toward a fetus because it will be a person in the future? And, more broadly, have we obligations toward future generations?[11] We should consider these questions in western society, which does not grant a moral status to the human fetus. According to Hardin,[12] the only relevant relations are those in the "here and now." This has the consequence that we have no duty towards future generations. MP Golding[13] argues that our obligations to future generations are, at best, minimal. He argues that: "obligations to future people are, obviously, distinct from obligations to current people: it's hard to make sense of the idea of obligations to people one million or ten million years in the future." However, though there is a tradition among utilitarian thinkers to discount the value of future happiness/unhappiness when it is being weighed next to present happiness/unhappiness, "he accepts that we have obligations toward our offspring i.e., children, grandchildren and great-grandchildren because we share a "common life" with these group." A deontological theory accounts that the people of the future have a fundamental right to both life and health.[14] Because we are united as a unique species, future and present generations are members of the "special" human moral community. Our moral duty to future generations emerges from our recognition that as a species we share common natural rights. Indeed, future generations will be "worse off" if we deprive them of the basic right to survival. Feinberg describes this concept in the ecological scenario: our descendants "have an interest in living space, fertile soil, fresh air, and the like" that we are obliged to consider, because "whoever these human beings may turn out to be, and whatever they might reasonably be expected to be like, they will have interests that we can affect, for better or worse, right now."[15] The fundamental principles are based on sustainability with the overarching objective that "no generation should needlessly, now or in the future, deprive its successors of the opportunity to enjoy a quality of life equivalent to its own."[16]

We should also consider the point of view of those who consider the fetus having a moral status: a fetus has "per se" the right to be shielded from harms not only because it will give rise to a baby, but because it has intrinsic value.

However, the non-maleficence principles requires us to not harm. We must carefully notice the paradox here: the principle is legally protected when it comes to harm from some sources (medical, society), but not from others (family). On the one hand, we should treat parents with compassion when they unwillingly harm their baby. On the other hand, we should reaffirm that they had a moral duty to care for the baby even before birth and that they failed that duty.

We add a consideration: this shows the apparent inconsistency in the laws that reflect a view of the unborn that can't be consistently held. In fact, scientific literature shows with no doubt the human features of the unborn child: hearing, movements, reactions, and suffering, thus every harm a fetus goes through is potentially painful and interferes with the development of human life.

Conclusions

A different assessment of parents' and doctors' or society's responsibilities in relation to prenatal harm with postnatal consequences is evident. Parents have a direct responsibility on the baby's outcome, causing such outcomes and being held morally or legally responsible. We do not consider it fair that parents are not held legally responsible for giving birth to drug-addicted babies or for fetal alcohol syndrome (though that may not be the case in all states). Many people are induced to believe that if a sanction does not exist, then a risk for health does not exist, and this contrasts with evidence. In some cases, people who caused prenatal harm to the fetus (e.g. via preterm birth induced by stress) are prone to be litigious against the doctors for a sense of guilt[17] and do not accept the evidence of having been responsible. Allowing a prenatal gray zone where any parental behavior is justifiable, despite severe consequences for babies' health, is unfair. It contrasts with the future babies' interests and undermines the efforts for an effective prevention of prenatal stressors and biological risks.

Thus a moral responsibility of parents toward the developing being is to be clearly affirmed. This paper is voluntarily drawn to discuss why parents seem to have no legal responsibility if they harm their unborn baby even—and this is the paradox—if the baby will be born and will suffer the consequences of the prenatal harm. The paradox is that after birth the baby will get legal rights and will not be able to use them if the harm is due to the parents, but will be able to use them if the harm is due to anyone else. We think this is due to the fear that, recognizing parents' responsibility and liability in prenatal harm, an obvious admission of their responsibility and liability should follow in the case of abortion. But this leaves the baby harmed before birth by their parents without any legal guarantees, and this is not only a paradox, but it is an injustice toward his/her rights, which are safeguarded for a similar harm when due to society or doctors.

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Book Reviews

Reading Karl Barth, Interrupting Moral Technique, Transforming Biomedical Ethics

Ashley John Moyse. New York: Palgrave Macmillan, 2015.

ISBN 978-1-137-53690-7, 263 PAGES, CLOTH, $100.00.

In this work, Moyse seeks to critique the prevailing attitude toward bioethics—and common morality in particular—by drawing on the insight of Karl Barth's ethics. Originally Moyse's dissertation at the University of Newcastle (Australia), the book demonstrates careful research, detailed argumentation, and creative connections between various fields.

Noting Moyse's main opponents and resources (beyond Barth) provides a useful framework. Moyse critically engages Beauchamp and Childress, arguing that their Principles of Biomedical Ethics contributes to the idea that bioethics traffics in a common morality utilizing a universal grammar that all can assent to and utilize. He argues that common morality does not exist, and acting like it does neutralizes and ignores other stories and voices coming from those who refuse to adopt the language and approach. Moyse uses the work of thinkers such as Charles Taylor, Stanley Hauerwas, and Jeffrey Bishop to expand the way bioethics considers the ethical space and the agent.

Moyse argues for a bioethics that moves away from the abstract, impersonal reasoning of common morality and into various "postures" that are more faithful to a redemptive, inductive, and dynamic approach to bioethics—postures that begin with concrete agents in concrete situations. He argues that openness, agency, and respect are postures that more faithfully draw the agent into the ethical space. In developing these postures, Moyse draws on key Barthian themes such as encounter, witness, participation, relationship, and responsibility. He wants readers to see bioethics as a response to God's command to "Live!" Each person receives a form of this command in their encounter with God, but it is a command to which they must respond within the limits of being a created being, not the Creator. Moyse hopes to "challenge us toward an understanding of human flourishing that is able to acknowledge yet protest, to accept yet reconcile, the moral crises we might encounter" (22).

Overall, I think Moyse succeeds in what he sets out to do. He clearly knows Barth well, and he is able to draw on Barth while interacting with secondary interlocutors in a competent but not overwhelming way. In Barth studies, it is easy to get lost in the Barthians and forget about Barth; Moyse avoids that temptation. Additionally, his work adeptly connects theology and bioethics in surprising and helpful ways. While the book is easier going if you have some familiarity with Barth and the main outline of the development of bioethics, the argument is compelling even without that background. Moyse does an excellent job of showing how theology can interrupt and potentially transform bioethics in a way that refuses to retreat into abstractions and instead meets individual patients where they are: in the heat of crisis.

Reviewed by Jacob Shatzer, PhD, who is assistant professor of biblical and theological studies at Palm Beach Atlantic University in West Palm Beach, Florida, USA.

Potentiality: Metaphysical and Bioethical Dimensions

John P. Lizza, Editor. Baltimore: Johns Hopkins University Press, 2014.

ISBN 978-1421411743, 288 PAGES, PAPER, $49.95.

Potentiality is a prominent concept frequently employed to support ethical arguments in the public square where it provides a non-theological alternative to the *imago Dei* for grounding the moral status of human beings who presently lack full rational powers. Originally it was utilized in debates about abortion and stem cell research, but now has entered into debates concerning the determination of death and organ donation after cardiac death (DCD). But what is the moral significance of potentiality? Can it be legitimately employed in ethical debates? Does it have the coherence and strength required to stand up to philosophical critique?

In *Potentiality: Metaphysical and Bioethical Dimensions*, editor John Lizza has assembled essays and articles, old and new, from a diverse group of philosophers and bioethicists that explore the nature of potentiality and provide a variety of philosophical analyses. The authors are as diverse as Don Marquis and Peter Singer, and the lenses through which the concept is examined range from Aristotelian metaphysics to the "potential" of future technological advances to alter the meaning of "potential." Discussions include recent work on the concept of dispositions, the relationship of potentiality to capacity, the nature of personal identity, the distinction between passive and active potential, the importance of intrinsic and extrinsic contextual barriers to realization of an entity's potential, and the distinction between the notions of "potentiality," "logical possibility," and "actual possibility."

Despite acknowledging that the most coherent view is that which understands moral status as a substance sortal that attaches to each and every human life and that recognizes the potential for rationality as part of the inviolable nature of human beings, skepticism is raised about using "human" as a "parochial" category apart from achievement. Yet all attempts at understanding moral status as a stage sortal and establishing appropriate criteria for the achievement of full moral status beyond the event of conception are merely arbitrary and indefinable. Furthermore, such criteria violate our intuitive moral sensibilities and threaten the moral status of many vulnerable individuals who have currently been granted full status. The philosophical hoops and thought experiments concocted to argue against the scientific facts of our being are often ludicrous and insulting. It is astonishing that in our hubris, our rational and rhetorical powers are used to rationalize away what we know to be intuitively true and rationally coherent for the sake of political and ideological agendas. Accordingly, in the final chapter Lizza concludes that potentiality has no ethical significance where there are internal or external barriers to realization of an entity's potential. Potentiality, he believes, is too ambiguous to ground moral actions at the beginning or end of life.

The book is academically rigorous, containing philosophical rhetoric, counterfactual arguments, and philosophical thought experiments. As a result, it is not highly appropriate for a general audience that is not philosophically conversant. It does, however, raise provocative concerns about the concept of potentiality that play an essential role in the current debates surrounding the beginning and end of life, and with which anyone debating, discussing, or writing about these issues should be familiar.

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.

Redeeming Sex: Naked Conversations about Sexuality and Spirituality

Debra Hirsch. Downers Grove, IL: InterVarsity Press, 2015.

ISBN 978-0-8308-3639-0, 224 PAGES, PAPER, $17.00.

“My husband said to me upon first reading the manuscript of this book, ‘You really are pushing grace to just about as far as you can take it’” (208). This is an apt summary of Redeeming Sex, capturing both its strengths and weaknesses. Hirsch writes with a three-pronged audience in mind—the church in general, the more conservative/fundamentalist wing of the church, and Christian youth (with an emphasis on the last two groups)—wanting to start a conversation. “This book is about the posture one takes [about sexuality], not the position one holds. I do however want to be your conversation partner” (17). In her view, the church has floundered in its handling of sexuality, especially as it relates to the modern LGBT community.

The first section of the book, “Where Did All the Sexy Christians Go?” provides several *nuanced* definitions necessary to understand what follows. Hirsch defines spirituality and sexuality as two sides of the same coin, both constituting the desire to know and be known. Her discussion of modesty is quite provocative and pushes boundaries that will alarm the cautionary concerns of many. She differentiates the idea of “our *social sexuality* and our *genital sexuality*” (51), arguing that sexuality is more than mere coitus. Rather, she argues that sexuality involves every area of life and relationship we have. This distinction is vital in comprehending the next chapter, “Jesus . . . Sex Symbol?” which many will find pushes the limits of decorum.

The author discusses eight principles of sex in chapter four which are very important for understanding the remainder of the book. Her view is that sex is “fractured,” “deceptive,” and “needs a chaperone.” Unfortunately, two of the three (i.e., “deceptive” and “needs a chaperone”) receive minimal attention in light of the author’s overwhelming emphasis on grace and acceptance. Hirsch reminds us that gender roles—the “expressions of masculinity and femininity” (90)—are often more cultural than biological. She uses the life of Jesus to illustrate her point and concludes “Jesus not only modeled a new form of masculinity but seemed to go a step further by also actively and publicly displaying behavior and emotion that was seen as distinctly feminine” (98). Unfortunately, like other material found in the book, this is overstated. While Jesus certainly challenged various gender roles, he introduced nothing new or novel. Rather, he simply restored an original, God-designed masculinity, which is illustrated throughout Scripture.

Chapter six explores the much-confused concept of sexual orientation and its relationship to the nature/nurture question. While some will disagree with Hirsch’s use of the “Kinsey scale” (107), as a starting point by which to describe homosexual behavior and tendencies, her suggestion of “homosexualites” (106) is helpful in navigating the complex array of sexuality found in the LGBT community.

In chapter seven, Hirsch relates a story about her sister who, born with a deformed leg that was later amputated, was told when she became a Christian that God would miraculously cause her leg to grow back. This never happened. Hirsch then compares this to what is often said to LGBT converts… that God will heal their “unwanted desires” (118). This does not always happen. Are they not Christians? She reminds us that we all have besetting sins and physical weaknesses that aren’t healed this side of heaven. The chapter ends with several courses of action that LGBT converts to Christ might take, including the suggestion that they live in a monogamous same-sex relationship. However, I found this suggestion confusing. Does Hirsch find monogamous same-sex relationships a suitable solution for these Christians? And, perhaps even more importantly, is this solution Biblically acceptable or even Biblically justifiable?

Throughout the book Hirsch professes to hold a more "traditional side of Christian sexual ethics" (17, see also 136-137, 139), and even provides two very good decision-making models (chapter 8) which lead one toward a traditional conclusion. Yet, she fails to provide direction on how to confront someone concerning the *sin* of homosexuality. Her emphasis is on love and acceptance, referencing Jesus as our example. Jesus certainly was accepting and forgiving, but He also always called people to repentance ("Go. From now on sin no more." John 8:11; Mark 1:15). It appears that Hirsch separates repentance from the process of conversion. This one-sided approach begs for more explanation.

The final part of the book ("The Mission of Christian Sexuality") is marked by many insightful words of exhortation, but also by a one-sided assessment of the church's mission. There are conclusions in the book with which Evangelicals will arguably disagree. For example, is it really true that the church, as a whole, has *always* been unloving towards homosexuals? Theological principles are often overstated and unbalanced. Do we really understand more about sexual orientation today than the Spirit who *inspired* the Scriptures? And, is it unloving to confront sin?

The value of this work is found in Hirsch's unique way of forcing the reader to think through and question long-held assumptions—some which *may* well need to be abandoned, while there are others that should be *maintained* but *worked out* in a more loving way.

Reviewed by Michael G Muñoz, D.Bioethics, MA (Bioethics), MAR, MEd, who worked in fire fighting for over 30 years, is adjunct faculty at Grand Canyon University in Phoenix, AZ, and served on the Ethics Committee at Phoenix Children's Hospital before relocating to Spokane, WA, USA.

The Caduceus and the Swastika: A Novel

Steven M. Hacker. Charleston, SC: Nano Press, LLC, 2016.

ISBN 13: 9780692623221, 417 PAGES, PAPER, $15.99.

The year is 1939. The place is University of Breslau, medical school. The characters are students, faculty members, resistance fighters, Nazi officers, and Americans who became involved in rescue efforts of German Jewish intellectuals. A fictional work, this novel brings to life the personal dramas played out in the lives of these people and immerses the reader in the history and political climate of the era.

Dr. Hacker, a dermatologist by training, is also a well-known medical business consultant, and as the back cover of his book states, is "the author of *The Medical Entrepreneur*, one of the top-selling practice management books for doctors. He was the founder and course director of Medical Entrepreneur Symposium. This is his first novel."

Well-researched, and written with an insider's perspective on medicine and medical school, I found the book to be highly readable, thought provoking, and eerily suggestive of similar events occurring in our world today.

Having read earlier scholarly works on events of this time period, I was impressed at the accuracy with which Hacker captured these and wove them masterfully into his plot. I found no obvious discrepancies relative to my previous studies, but alternatively was not made aware of important factual information that hasn't been objectively outlined more completely elsewhere. Caution: some readers may find coarse language and suggestive plot lines offensive, but in general it contains no graphic sexual content or gratuitous violence.

The 417 pages are on a 5 x 8 inch paperback frame with significant white space and fairly short chapters. An easy read, this historical novel was a good vacation companion. You will likely be able to read it on a single 3-hour airplane flight, and it will be time well spent. It is not *Ben Hur* or *Brothers Karamazov*, but I will likely purchase his next novel. I enjoyed reading this.

Reviewed by Robert E. Cranston, MD, MA, FAAN, who is an associate clinical professor (Neurology) at University of Illinois College of Medicine, a hospital ethicist at Carle Foundation Hospital in Urbana-Champaign, and medical director for talent development and learning at Carle Clinic in Urbana, Illinois, USA.

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