

DIGNITAS

VOL 33 • NO 1-2 • SPRING/SUMMER 2026 | A PUBLICATION OF THE CENTER FOR BIOETHICS & HUMAN DIGNITY





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ISSN 2372-1979 (Online)

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EDITORIAL

Anna B. Vollema, PhD (Cand.) | Managing Editor
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Bioethical issues lie at the center of what it means to be human and how to live faithfully in a medically, scientifically, and technologically advanced world. Because of this, bioethical reasoning must be both intellectually rigorous and deeply attentive to the human person. Isolated intellectual work is insufficient, and humility is necessary to deal faithfully with such deeply personal questions. As Augustine wrote:

To [Jesus], my dear Dioscorus, I wish you to submit with complete devotion, and to construct no other way for yourself of grasping and holding the truth than the way constructed by Him who, as God, saw how faltering were our steps. This way is first humility, second humility, third humility, and however often you should ask me I would say the same, not because there are not other precepts to be explained, but, if humility does not precede and accompany and follow every good work we do, and if it is not set before us to look upon, and beside us to lean upon, and behind us to fence us in, pride will wrest from our hand any

good deed we do while we are in the very act of taking pleasure in it.¹

Among the intellectual virtues, humility is understood as “proper attentiveness to, and owning, one’s intellectual limitations.”² From a Christian perspective, humility requires the genuine pursuit of truth out of love for God and others rather than for personal pride or self-righteousness. Because of this, as CBHD seeks to foster a *distinctly Christian* conception of bioethics, we value the pursuit of intellectual humility through dialogue and a communal pursuit of truth.

This issue of *Dignitas* represents just such a dialogical approach in several important ways. First, the article by Cayla Bland and Scott Rae characterizes interdisciplinary dialogue, using the fields of psychology and bioethics to protect the rights of whole persons in end-of-life care. David Croy continues the discussion on the use of Normothermic Regional Perfusion (NRP) in organ transplants, furthering points Adam Omelianchuk raised in his 2025 [guest editorial](#).³ Finally, Rebecca Martin and David Ramirez approach Bryce Asberg’s [article](#) (2025) on palliative sedation with an applied

lens, refining his points based on their practice as medical professionals.⁴

Also included in this issue are several book reviews. Heather Zeiger provides a review of Carl Elliot’s *The Occasional Human Sacrifice*, a book that explores why some allow unethical practices in medicine and what prompts others to work to restore justice for patients. Bryan Just reviews a proposed counter-history of bioethics in Robert Baker’s *Making Modern Medical Ethics*. In *Eggonomics*, medical anthropologist Diane Tober reports on the commodification of donated eggs and the women who contribute them, which Megan Best generously summarizes. Finally, Joy Riley evaluates Mary Roach’s journalistic and popular exploration of removable body parts in *Replaceable You*.

David Croy’s guest editorial continues the work of Adam Omelianchuk’s 2025 article. Normothermic Regional Perfusion (NRP) is the rather new practice of circulating blood through organs in a deceased donor in order to improve organ health in preparation for transplantation. As Omelianchuk’s original article suggests, in the process, some techniques involve restarting circulation of blood through the heart while keeping the flow to the brain clamped off. This brings up major ethical concerns regarding our

definition of death and whether a person who is not technically dead but experiencing a collapse of consciousness might be made a candidate for donation and reduced to their function as a means of “organ harvesting.” Omelianchuk thus argued for “ethical parsimony,” asserting that if less controversial methods exist that are effective (which they do), then they should be chosen over ethically complex options.

Croy continues the conversation on the ethical controversies tied to NRP (specifically, Thoracoabdominal Normothermic Regional Perfusion or TA-NRP), focusing specifically on ethical challenges in the determination of death. He discusses the difficulty in identifying the point of death, describing it more as a process rather than a clear arrival. For brain death to be officially determined, a person’s whole brain must be declared deceased. The development of TA-NRP complicates this ascertainment. The Universal Determination of Death Act defines death as “the *irreversible* cessation of circulatory functions or the *irreversible* cessation of whole brain function including the brain stem” (as cited in Croy). However, TA-NRP procedures merely require a determination of death by circulatory criteria. Advocates of TA-NRP defend the procedure by suggesting that the intent of restoring circulation matters—the goal is not to bring the person back to life. Croy challenges this argument, asserting that there should be no difference between a patient who is resuscitated and brought back to life on purpose—and who is therefore afforded the rights of a living person—and a patient who still experiences “stable hemodynamic parameters, oxygenation, and heartbeat,” yet who is determined “dead” and stripped of such rights. Thus, Croy argues that the dead donor rule must be upheld and protected. He writes, “certitude in the donor’s death is vitally important for compassionate reasons, for ethical and legal reasons, and for maintenance of public trust.”

Cayla Bland and Scott Rae unite to integrate family therapy and ethics to provide a model for end-of-life care that can benefit attending healthcare providers, social workers, or pastors in such situations. They offer a fictional case of an elderly gentlemen in the ICU, lacking an advance directive, without his primary decision-maker (his deceased wife), and with tense familial relations between his

four children and two siblings. With treatable but incurable cancer, the man faces an indeterminable amount of time with a likely low quality of life, and the family must decide whether it is in his best interest to pursue aggressive treatment. The reactions of each are varied, with a range of responses from the suggestion for physician-assisted suicide to the pursuit of treatment to extend his life.

In order for this family to come to a robustly Christian conclusion that honors the dignity of their father/brother, they must first deal with their family dysfunction. With an understanding of family life-cycle changes—a developmental framework that underscores the stressors that come about when changing familial dynamics require the taking on of new roles and being flexible in how one participates in the family system—the ethicist is better equipped to help the family turn toward one another in both unity and difference in the decision-making process. To do this well, it is helpful to also understand common aspects of family processing, including cohesion (familial emotional bonds), flexibility (rigid vs. flexible family interactions), and communication, which moderates the other two. Finally, Bland and Rae discuss relational ethics, or those beliefs within family systems as to whether the family unit, and each member within the family, adequately upholds the standard (whether cultural or theological) for relational interaction. These beliefs lead to a spectrum existing on an axis between trustworthiness and destructive entitlement. Throughout the article, the authors apply this developing knowledge to their opening case study.

Once the family dynamics have been addressed (which may require outside therapy), Bland and Rae suggest they turn to wrestling with the ethical issues involved. Addressing the issue of informed consent, physician-assisted suicide would not be an option, since the patient is unconscious. Here, it is also helpful to keep the family system information in mind as the ethicist or healthcare professional wrestles through a theological approach to their decision-making. After analyzing several key biblical passages, the authors suggest an approach that honors human dignity and affirms God’s control of both life and death. This communicates to the family that death need not always be medically resisted, and futile

treatments may cause more emotional or physical suffering for the loved one. Further, to choose futile treatment may be making the theological assumption that our earthly existence is the highest good to be pursued. In conclusion, the model that Bland and Rae propose takes seriously patients as whole people, contextualized in a particular family system and yet in pursuit of a higher moral good.

As the final dialogical article in this issue of *Dignitas*, Rebecca Martin and David Ramirez extend Bryce Asberg’s arguments by revising them to fit a real-world clinical care context. Asberg’s 2025 piece uses the Hippocratic Oath to evaluate the use of palliative sedation for existential suffering, finding it an inappropriate treatment and arguing instead for psychosocial restoration in such cases. Martin and Ramirez center their nuanced approach to Asberg’s points around two core questions: (1) Can one diagnostically create a clear distinction between physical and existential suffering? (2) How can a clinician therapeutically address existential suffering when there is little time and many other symptoms?

In addressing the first question, the authors cite the interconnectedness of physical and existential suffering. As an example, they note a child who was experiencing intense pain that was not responding to typical medicinal interventions. Yet, when doctors brought the child a puppy, her pain scores and use of such medication dropped exponentially. They further cite those who experience hallucinations at the end of life or combat veterans with PTSD; the question remains: Where does the physical end and the psychological begin? Expanding their second question, if indeed we could clearly diagnose existential suffering, and such a patient also had no clear cause for physical suffering, how do we provide therapeutic treatment substantive enough to meet such psychological needs with the short time patients are in palliative care? Once again, with the experience of combat veterans, such trauma is quite complex, and end-of-life hallucinations in connection to such experiences are unlikely to be alleviated by brief psychological treatment.

As an alternative to address such real-world issues, they support the use of respite sedation, “the use of sedative agents for a brief, time-limited period (usually 24–48 hours)

aimed at alleviating physical symptoms such as pain, nausea, and agitation, followed by sedative weaning and return of consciousness thereafter.” Such a therapeutic approach aims to break the cycle of anxiety and then return the patient to a state of consciousness. Ultimately, issues such as existential suffering and palliative care raise the question of what the purpose of medicine is. How can Christian physicians steward

their knowledge of the whole person and the therapeutic process to care spiritually for patients in the midst of both physical and existential suffering?

We at CBHD are grateful for our authors who engage some of the most complex questions facing healthcare professionals and ethicists alike. They do so with intellectual rigor, epistemic humility, and constructive

critique. We invite continued dialogue on these issues and in response to those questions that matter most for living faithfully in our complex MedTech world. In line with this, our next issue of *Dignitas* will engage the intersection of being human, human health, and the use of Artificial Intelligence (AI). This will also serve to introduce the theme for CBHD’s 2027 annual conference on AI and bioethics.

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GUEST EDITORIAL

The Ethics of TA-NRP: A Response to Adam Omelanchuk

David Croy, MD, MS | Guest Contributor

Editor's Note: This article extends the conversation started in Adam Omelanchuk's guest editorial, "Reviving Organs, Redefining Death? The Ethical Controversy Over Normothermic Regional Perfusion and the Way Around It," *Dignitas* 32, no. 1-2 (2025): www.cbhd.org/dignitas-articles/reviving-organs-redefining-death-the-ethical-controversy-over-normothermic-regional-perfusion-and-the-way-around-it.

I attended Dr. Adam Omelanchuk's 2024 Clemson University lecture that presented philosophical, legal, and scientific quandaries of brain death determinations and challenged whether brain-death criteria provided a sufficient proxy for biologic death or effectively reduced complex physical and metaphysical phenomenon to a clinical checklist. His more recent *Dignitas* article "Reviving Organs, Redefining Death, The Ethical Controversy of Normothermic Regional Perfusion and the Way Around It" (Spring/Summer 2025) analyzed thoraco-abdominal normothermic regional perfusion (TA-NRP) organ procurement through a similar lens.¹ Dr. Omelanchuk identified the dangers of zealously adopting this new technology when ethical questions

remain unanswered and morally acceptable alternatives exist.² This commentary extends that discussion and focuses on uncertainties unique to TA-NRP and the resulting conflict with legal and ethical standards such as the Universal Declaration of Death Act (UDDA) and the Dead Donor Rule (DDR).

For centuries, the cessation of breathing and heart function proved a reliable proxy for biologic death because the failure of remaining body systems and brain function invariably followed. The loss of spontaneous heartbeat provided a timestamp from which necessary legal and civic actions could be taken, such as funeral arrangements and the distribution of the decedent's assets.³ The development of advanced life support measures disrupted this paradigm. The variable

sensitivity of tissues to circulatory loss and their potential for recovery with mechanical restoration of lung and circulatory functions demonstrated that death was a process rather than a discrete moment. Circulatory collapse disproportionately impacts sensitive brain tissue. Neurologic functions fail rapidly and often irreversibly.⁴ In contrast, heart, lung, kidney, and liver functions can recover function with the assistance of mechanical and pharmacologic life support measures.⁵ Technology allowed more patients to survive a cardiac arrest, but some suffer such severe neurologic damage that they are left without consciousness, spontaneous respirations, sensory functions, cognition, and integration of bodily functions. The result pivoted focus from the cardiorespiratory standard of death to include a whole-brain standard.

Whole-brain death as a proxy to biologic

David Croy, "The Ethics of TA-NRP: A Response to Adam Omelanchuk," *Dignitas* 33, no. 1-2 (2026): 4-6. © 2026 The Center for Bioethics & Human Dignity

death developed in the late 1960's.⁶ The combined deficits assessed by brain death criteria imply whole brain loss and complete dependence on life-support measures.⁷ The cognitive losses of rational thought, memory, self-awareness, spirituality, language, apprehension of time, appreciation of beauty, and human agency represent *life* lost at a much higher, less mechanical, and uniquely human dimension. Materially, brain death became a second proxy for biologic death and conceptually solved immediate health-care logistical and ethical dilemmas.

Uncertainty in Brain Death Determinations

Brain death criteria require sub-specialty level medical expertise to measure and interpret.⁸ The setting is a deeply comatose patient with brain injury of known cause; the reversible causes of unresponsiveness must be resolved such as sedating medications, electrolyte derangements, or hypothermia.⁹ Consequently, the brain-death determination process begins with a warm, stabilized, well perfused, and ventilator-supported patient. If whole-brain death is confirmed, then the process terminates with purposeful removal of life support measures. Cardio-respiratory collapse rapidly follows. Only then does the patient's physical appearance resolve to the still, pulseless, and pallid state universally recognized as a death. Understandably, family members, the public, and some professionals remain dubious of brain death's validity and equivalency to a biologic death.¹⁰

A donation post brain death (DBD) presents the ideal physiologic setting for organ procurement. Support measures remain in place after confirming a brain death. The donor enters the operating theatre with ventilator-supported breaths and stable heart function.¹¹ However, there are devastatingly neurologically damaged patients that do not fulfill brain-death criteria, and the DBD pathway cannot be pursued. The patient's request for a natural death and desire to donate is relayed by advance care planning documents or family members. In response to their wishes, life support measures are compassionately withdrawn and a cardiac death observed. A donation following a circulatory death (DCD) maintains compliance with the legal definitions of death and the DDR but at the cost of becoming a race against time and tissue decay.¹²

TA-NRP techniques were developed to rescue this situation and replicate the stable hemodynamic profile of a DBD after a circulatory death. Extra-corporeal membrane oxygenation (ECMO) techniques artificially reestablish circulation of warmed and oxygenated blood. The goal is recovery of donor heart function before procurement (which violates the irreversibility standard) and the preservation of other vital organs.¹³ To add complexity, reestablishment of systemic circulation by ECMO theoretically supports residual brain function even with targeted intervention.

Standards for the Determination of Death and the Dead Donor Rule

The current ethical and legal controversies surrounding TA-NRP center on the Universal Determination of Death Act (UDDA) and compliance with the Dead Donor Rule (DDR). The UDDA defines death as either the *irreversible* cessation of circulatory functions or the *irreversible* cessation of whole-brain function, including the brain stem.¹⁴ TA-NRP objectives include the procurement of transplant-worthy hearts post a death by circulatory criteria (DCD), defined by irreversible cessation of heart function. The DDR requires certainty of the donor's death prior to organ retrieval.¹⁵ Said more directly, organ procurement should never be the mechanism of a donor's death. The linguistic gymnastics begin here. The donor's do-not-resuscitate status is honored, but heart function is resuscitated in place. Death is declared by an irreversible loss of circulation standard, but circulation and heart function are restored. The risk of residual neurologic activity revived through restoration of circulation is recognized and addressed by carotid artery occlusion.

The counter argument claims that "permanent" loss of heart and brain function invariably follow spontaneous loss of circulatory functions. The intent to restore donor heart function prior to procurement is immaterial because autoresuscitation of heart function did not occur during the prescribed observation period. Consequently, the donor's trajectory to a biologic death would remain unchanged without intervention. Others opine that carotid occlusion exchanges one mechanism of death for another in compliance with the DDR.¹⁶

On their face, both assumptions prove

inadequate precisely because of intervention. The *irreversible* loss of circulatory function becomes a fallacy if the donor's heart function is revived in place prior to procurement, and the procurement setting does not allow for brain-death testing. Furthermore, limited brain perfusion remains possible through alternate pathways.¹⁷ Given that, TA-NRP introduces uncertainty of compliance with both legal definitions of death and introduces potential harms to the donor. TA-NRP advocates "solve" the conundrum by leveraging intent as the differentiating factor.

What do I mean by intent? The Universal Law Commission has been challenged to revise UDDA definitions and exchange *irreversible* cessation for *permanent* cessation of the heart or whole brain function. The words *irreversible* and *permanent* are synonyms. Semantically, there is little difference. Pragmatically, a quantitative assessment is exchanged for a qualitative assessment that interpositions intent. Classically understood, death's defining characteristic is irreversibility or absolute finality. There is no return. The intent argument introduces relativity. Death becomes what the speaker desires or needs it to be.

Consider two identical clinical scenarios. Each begins with a ventilated patient in the ICU. Each patient suffers a prolonged cardiac arrest followed by the introduction of extra-corporeal membrane oxygenation (ECMO) support with recovery of stable hemodynamic parameters, oxygenation, and heartbeat. The physiological statuses are equal. Yet intent directs two very different outcomes. Resuscitation efforts were *intended* for patient 1 despite impossible odds. Resuscitation was not the intent for patient 2; however, ECMO successfully resuscitated heart function in-situ and restored systemic circulation for both patients. After successful resuscitations, both remain in the ICU to monitor and balance their physiology. Despite physiological equivalency, patient 1 has been resuscitated but remains critically ill. Treatment focus remains fixed upon the patient's best interests. Patient 2 becomes a corpse without the rights and respect afforded to patient 1 and their organs represent a commodity that others seek.

Uncertainty of Life's Boundaries

Humanity's response to uncertainty at life's boundaries has been to act first and dismiss

the consequences through the morality of good intentions. Examples include the viability construct found in *Roe v. Wade* and *Planned Parenthood v. Casey*.¹⁸ In essence, the Casey decision deconstructs embryology to claim *that life cannot be forfeited if a life is not present*. Yet the exact moment when life begins remains a mystery, and viability evolved as an arbitrary legal construct to answer an unanswerable question. Similar to *Roe* and *Casey*, the proposed UDDA changes provide a legal safe harbor that shields participants from prosecution and professional sanctions in the pursuit of perceived public good.

Death determinations use proxies (loss of circulation or brain functions) to infer death from non-ideal physical metrics designed to demonstrate the absence of life. At the conceptual level, scientifically proving an absence is a complex logic problem reflected in Carl Sagan's observation that absence of evidence does not equate to evidence of absence.¹⁹ The exclusion of irreversibility removes a differentiating quality of death from the equation. As evidenced by ventilators and ECMO, future technological advances may further confound death determinations. The key question may not be whether definitions are adequate but

whether proxies are sufficiently precise to bear the moral risk of potentially taking a life.

The DDR has long provided an ethical safeguard. Some claim that the DDR should be eliminated, yet certitude in the donor's death is vitally important for compassionate reasons, for ethical and legal reasons, and for maintenance of public trust. The DDR provides a legal and moral safe harbor that benefits the transplant community. Without certitude in a donor's death, the logistics of organ procurement would risk professional sanctions or prosecution. The demise of the DDR seems unlikely.

Despite technological advances, the precise moments of death and life's dawning remain unsolvable mysteries. In more reflective moments, I apprehend the deep metaphysical nature of such questions and realize that scientific training and clinical reasoning fail. Properly considered, life and death are complex metaphysical and physiological processes that map poorly onto discrete moments. However, organ procurement procedures require precise time stamps and certitude in the donor's death to comply with the DDR. The TA-NRP technique amplifies uncertainty, yet the physician's

role demands an uncompromising respect for life's boundaries. Physicians are stewards of life and cannot assume the role of life-giver or life-taker. Medicine retraces a morally regrettable path when truth falls victim to the pursuit of a desired commodity. The intent argument invites ambiguity and diverts attention away from the donor as a person to the donor's organs as a commodity. This highlights the importance of honest debate with broad input from medical, legal, philosophical, and theological sources.

Challenges to the UDDA have failed. Irreversibility remains the definitional legal standard at present. Germane to this discussion, identical phraseology debuted in the revised 2023 American Academy of Neurology (AAN) Brain Death Guidelines.²⁰ The AAN response deserves further analysis and moral interpretation.

As demonstrated above, a single-minded approach falls desperately short and returns the discussion to Dr. Omelianchuk's point. Medicine *should* be reticent to champion this new technology when the ethical questions appear unsortable and morally acceptable options exist.

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Family Dynamics and Ethics at the End of Life

Cayla Bland, PhD, MFT and Scott Rae, PhD | Guest Contributor and Academy of Fellows Member

Imagine you are a physician, nurse, social worker, or chaplain/pastor who is dealing with the end-of-life care of an elderly, seriously ill 83-year-old man. As you observe the family dynamics that are playing out in the ICU waiting room and even at the patient's bedside, you realize that you need help from someone trained in both family therapy and ethics. To insist that the family is a bit troubled would be a major understatement. In fact, the end-of-life scenario that their loved one is facing has resulted in old wounds resurfacing and long-festering conflicts reemerging.

The family attending to the care of this gentleman consists of his four adult children, some of whom live close and others who live out of state. In addition, the patient has two siblings with whom he is still very close and who are attending to his care. The patient's wife would be, by law, the primary decision-maker while she was living, but she passed away several years ago. In addition to his other medical conditions, he also suffers from dementia, which has rendered

him incompetent to make his own decisions about treatment. The patient does not have an advance directive, nor has he spoken with any family member about what his wishes might be should he no longer be able to make decisions for himself. The family are all Christians, devoted both to their faith and to the welfare of the patient.

The patient suffered complications from recent treatment for pneumonia and is in the ICU. He has serious lung damage but was not considered terminal until, upon further examination, physicians discovered a series of tumors in his lung. His physicians believe that the condition is not curable but treatable, meaning that the cancer can be delayed but not cured. But they are cautious with the family about the likely poor quality of life he will experience due to his age and overall weakened condition. At some point, he would likely require ventilator support to ensure adequate oxygen getting to his lungs. In their view, it would be understandable for the patient to forego aggressive treatments for a regimen of palliative care, leading

eventually to hospice.

As discussions among the family members took place regarding the treatment decisions they had to make, conflicts among them became evident. Some family members insisted that they must do everything to keep their loved one alive since that is consistent with their commitment to the sanctity of life. In addition, they see that any decision to stop, or not start, treatments would constitute them being complicit in killing their loved one. Other family members strongly disagreed, insisting that his quality of life is what counts. One of his siblings even mentioned the possibility of physician-assisted suicide as the most compassionate alternative for him. Once that was mentioned, the discussion became quite heated, and they accused him of wanting to kill their loved one—in effect, he was shouted into silence and out of the room.

In addition, the two adult children who live close to their father attempted to exert their decision-making authority due to their taking care of their dad and shaming their two siblings who live out of state for not caring enough about their dad and his care. This brought up a host of old wounds between

the siblings, including the local sibling's view that their out-of-state siblings had selfishly moved away and prioritized their own lives. They have also accused them of wanting to hasten their father's death so that their inheritance could come to them sooner rather than later. You also discovered that the patient's two siblings believe that they have decisional authority since they have the longest-standing relationships with him and care for him in ways that his adult children do not. They believe that everyone involved in these discussions has ulterior motives that underlie their opinions about what to do. As these discussions go on, they deteriorate further into allegations, guilt, anger, and shaming. They are no closer to consensus about what to do than when they started.

These types of discussions are not uncommon at the end of life. This family needs a theological basis for how they should view the end of life. But their most immediate need is for someone to help them understand the dynamics that have emerged as the discussions became more contentious. This is where knowledge from the field of family therapy as well as Christian ethics can be extremely helpful.

As is often the case at the end of life, ethical decisions are complicated by family patterns of interaction. This family needs help with the ethical dimensions of stopping or continuing treatment, entering hospice/palliative care, and how to view these decisions through the lenses of their Christian faith. But if they do not make progress dealing with the dysfunctional family dynamics, they may not get to a place where they can achieve consensus on the important decisions they need to make for their loved one. This is not to say that physicians, nurses or even social workers need to have the expertise of a family therapist or be a theologian. But a greater understanding of why family members are interacting in destructive ways—along with relevant theological considerations—can help healthcare professionals guide this patient and family toward the decisions that need to be made for the patient's benefit. Ultimately, end-of-life decisions must take into consideration the complexity of what it means to be human by considering one's place in their family, the family dynamics at play, and the family's faith in such an ethical decision-making process. Because practical implications of

our ethical stances are embodied in real-life circumstances and relational contexts, our goal in this essay is to provide a resource for healthcare professionals to better help and support families facing end-of-life decisions. We believe integrating knowledge from the disciplines of family therapy and Christian ethics can significantly expand our understanding of the relational and emotional complexities involved when faced with end-of-life decisions.

A life-threatening illness of an only remaining parent is a major life event for families and can be very stressful, if not a moment of crisis, for all involved. Understanding the factors influencing family dynamics allows the healthcare professional to address conflict proactively rather than being caught off guard and to respond with appropriate support rather than treating conflict as a purely disruptive behavior. While this does not yet solve the ethical dilemma, the reduction in conflict will help the family come to a greater consensus on the decisions ahead. It also honors the humanity of the situation by offering dignity and care to the important relational connections of the patient.

We will first address the family dynamics and conflict by considering family life cycle transitions, family process factors that impact interactions, and destructive entitlement stemming from violations of love and trustworthiness. We will then turn to a theological and biblical framework that can guide ethical decision-making at the end of life.

Families and Transitions

To understand this family, it is helpful to view them first from a developmental frame in order to appreciate family conflict and challenges in light of normal changes, gains, and losses across the lifespan.¹ Family life cycle changes are times of transition requiring new emotional adjustments and changes to the structure and roles of the family system. Some common life cycle transitions can be moving into young adulthood, becoming a couple, having children, launching children, entering midlife, and elderhood. Other examples include life cycle disruptions such as separation, divorce, coping with chronic illness, loss, and death.² Family life transitions, even positive ones, are when stress is at its highest. It requires the family to be more flexible, adaptable, and

take on new demands while maintaining as much continuity and stability as possible. This family has been thrust into the midst of a sudden, unexpected life cycle transition. The adult children are stepping into shifting generational roles, with the need to make decisions and step into greater care of their father. All involved are being faced with the potential and imminent loss of the loved one, requiring coming to terms with this loss and what it will mean to no longer have him in their life. It is not uncommon for families to need extra support through the emotional roller coaster of these transitions, as they are caught between the old way and new way of being.

Ideally, family members turn towards each other during times of crisis and life transitions, but this is not always the case. Furthermore, each family member's own stage of life will influence their capacity to meet transitional moments. For this family, adjustments are required to meet the need for ongoing care and support of the father/brother to attend his doctor appointments, potential treatment, and daily care. While the patient's siblings may have more time to care for their brother, the children also feel a responsibility to care for their father and to be there for him. Despite this desire, complications can arise such as work and their own family responsibilities, which add the stress of juggling all areas of life well. When family members live far away and can't share the load, more responsibility falls on those living locally. This can lead to guilt on one side and resentment on the other.

Each family member may also experience the inevitability of losing their loved one differently. Each family member's ability to adapt to loss can be influenced by prior losses (such as the loss of the mother) and the quality of the relationship with their loved one: the closer the relationship, the greater the emotional loss. However, if the relationship has been conflicted or contentious, guilt and blame can make facing the loss more complicated. The benefit of a developmental framework is that it helps one to appreciate the layered complexity of what the family is facing. Rather than isolated stressors, the family must contend with competing life cycle pressures and the need to reorganize and add roles of responsibility. The emotional work of this transition and the reality of impending loss is often daunting.

By acknowledging and naming these compounding stressors when faced with end-of-life events, healthcare professionals can normalize the enormity of what the family is facing and thereby affirm and acknowledge the level of distress contributing to intense emotions and conflict.

Family Process of Interactions

Now that we appreciate the emotional and physical demands and adjustments this family faces, we now turn to their process of interaction. Family process refers to the ongoing dynamics, patterns, and communication styles that shape relationships. Family dynamics and ways of relating are heightened during moments of crisis. When crises occur, the added stress leads to an increase in anxiety and reactivity within family systems.³ To understand how a family responds under this kind of stress, it helps to look at Olsen and colleagues' framework, which identifies common dimensions of family interactions: cohesion, flexibility, and communication.⁴ Cohesion is the emotional bonds that family members have towards one another and the balance between separateness and togetherness.⁵ Cohesion exists on a dynamic continuum versus a fixed state and is adjusted depending on family circumstances and developmental level. Several factors impact cohesion, including cultural norms, family relational styles, and the age and developmental stage of those involved. Extreme levels of togetherness (unable to tolerate any differences) and separateness (significantly disengaged systems) tend to be problematic and lead to poor family functioning, while families that find a balance between the two tend to be more functional.

The second dimension, flexibility, refers to the family's ability to adapt interactional style, including family leadership, roles, and relationship rules in the face of life changes and challenging circumstances.⁶ Flexibility is also on a dynamic continuum, shifting over time and life circumstances. Extremely low levels of flexibility (rigidity) and extremely high levels of flexibility (chaos) lead to increased conflict and inability to manage change or crises. Families with more balanced styles can balance change with stability in a more effective way.

The third dimension, communication, functions as a facilitative element within the family system.⁷ Positive communication

skills, such as active listening, empathy, clarity, staying on topic, and respect, are what allows families to shift their levels of cohesion and flexibility to more effectively deal with developmental and situational demands. Negative forms of communication, such as criticism, blame, defensiveness, and withdrawal, impede family functioning. Research has found that families with balanced cohesion and flexibility tend to have good communication skills, whereas families that tend to operate in the extremes have poor communication.⁸

How might we now apply these concepts to the family interactions discussed above, and what might you do in your role as a professional to help? Concerning family cohesion bonds, on the surface it does not seem that these family members are close to one another at all. Yet, they all have gathered together at this crucial moment, even those from out of town. They also have strong opinions on what should be done about their loved one. Although not yet at consensus, the fact that they do have strong opinions and have all shown up underscores the fact that there is a family bond. To be helpful to this family, it would be important to acknowledge the one thing they all have in common, and that is, they really care about their loved one and are concerned for his welfare. Even though they are suggesting different actions, acknowledging the good intentions around their suggestions such as wanting him to live as long as he can, wanting to prevent pain and suffering, or wanting to have integrity with their faith all can be framed as love and care. Acknowledgment of shared goals often takes the heat out of interactions.

Regarding family flexibility, this family is currently struggling to shift roles and make decisions about medical treatment or palliative care. Not having an advance care plan or any prior family discussion about end-of-life decisions contributes to greater family conflict when end-of-life decisions need to be made.⁹ Furthermore, family disagreements over whether to pursue curative treatment versus palliative care are one of the most common reasons for family conflict.¹⁰ Therefore, this family is sitting in a perfect storm of events for conflict to ensue. Furthermore, moments of crisis are when individuals become more rigid in their thinking and heightened emotionally. It can be helpful to empathize with the

family about the enormity of the decision to be made and to help them refocus on what their loved one would want. In fact, if the patient regains consciousness and can articulate his wishes, then encouraging the family to heed his wishes may help them feel more confident and unified in the decision to be made. If this is the case, the physician can intervene and inform them that the law requires them to respect their loved one's wishes. Time will tell whether this family will remain in this activated state or if, given time, the family can rally together for the good of their loved one.

Destructive Entitlement: Violations of Love and Trustworthiness

One final reason for this family's conflict may be preexisting issues between family members that run deep and have a long history. Family theorist Boszormenyi-Nagy conceptualized such conflicts as best understood through a term he coined: *relational ethics*.¹¹ *Relational ethics* is the subjective sense of fairness or moral behavior between family members concerning expressions of love, trustworthiness, and loyalty. In other words, relational ethics refers to the unique way each family interprets or embodies culturally and theological accepted ways and rules about how families should interact. This makes relational ethics particular to each family and an important factor in understanding how patient's families are responding in moments of stress and crisis.

When family members express love, act fairly, and are loyal towards individual family members and the family as a whole, then a sense of trustworthiness develops within the family. However, when family members experience what they perceive as violations of love and trustworthiness this can lead to *destructive entitlement*.¹² *Destructive entitlement* is when family members act out of a sense of injustice due to these violations and turn to destructive ways of relating that they feel justified in, such as threats, manipulation, blame, and withdrawal.

To complicate this further, because this is a subjective experience, there is potential for family members to perceive fairness differently. For example, one family member's view of compassion and love was seen as possibly assisting his father's passing. This clearly was experienced by other family members as the complete opposite of love

and compassion. It also appears that tension between the family members who moved away versus those who stayed near the father is being seen as a violation of family loyalty. The “out of town” siblings feel it is unfair to have their love or loyalty to the family questioned simply because they moved away. Meanwhile the “in town” siblings may feel they personally sacrificed to remain close to their parents and now unfairly bear the greater burden of caring for their father. This family is clearly showing signs of a lack of trust in one another. It has led to accusations of selfishness, only wanting an inheritance, and distrust of having the father’s best interest in mind.

One sign that violations of love, trustworthiness, and destructive entitlement are at work in a family is the level of intense emotional responses and rigidity. So, what can you as a professional do? Resolution of these issues will take time and is beyond your role at this moment. However, it might be beneficial to provide a referral for family therapy. Nonetheless, there are still things you can do in your capacity. First, seek to listen, understand, and empathize with each of the family members. This can build a sense of trust with you as a professional. This may best be accomplished by talking with some of the family members individually and keeping in mind that each family member has the right to be heard and understood from their perspective. Next would be to refocus the family on their loved one, his needs, and what he would want from them. It can help to share that research shows that family conflict is often hardest on the patient, creating more stress, distress, and feeling unsupported.¹³ As a third party, you can encourage the family that the most loving thing they can do is consider how to work together and share the load as a team to best support and care for their loved one. Certainly, this take on relational ethics does not supersede a more critical perspective or one that is informed by a more dispassionate relational stance. However, when dealing with fractious family dynamics under stress, one must consider how more broad ethical assumptions and prescriptions are animated by other implicit and explicit entrenched family dynamics.

Although medical decisions at the end of life are about the individual patient, families are often highly involved in the decision-making process and are the ones

providing emotional support and help with the physical care of the patient. The psychological dynamics above and the suggested tips hopefully provide a mental framework for understanding what is transpiring when family conflict arises. The goal is to get the family to a place where your expertise can be heard, processed, and taken in by the family to make necessary decisions and changes. For religious families like this one, chaplains and clergy also can provide additional support to the family by addressing the theological and ethical questions that end-of-life decisions evoke. It is these concerns that we turn to next.

Ethical Decisions at the End of Life

Once the family dynamics have been addressed and the family is proceeding in a healthier manner, the family still has some significant ethical decisions to make for this patient. Since this is a believing family, appeal to the Bible carries substantial weight for their decisions. They are at odds with the decision to remove or maintain life-sustaining treatments for their father.

Though one of the family members suggested assisted suicide, it quickly became clear what the majority of the family thought of that option. The fact that someone could bring it up at all suggests that it is legal in their state, which is the case in 11 US states and the District of Columbia, and several countries in Europe. If this conversation were taking place in Canada or Europe, then euthanasia could also be considered. However, regardless of the family’s views on the ethics of assisted suicide, the patient must be able to give consent. Given the patient being incompetent to make medical decisions, this would render the debate about the morality of assisted suicide unnecessary. If the patient was competent to make such a decision, the moral and theological dimensions would then become relevant.

When it comes to the decisions about life-sustaining treatments, those are more complicated, and a family’s lack of consensus about this is not uncommon, both for emotional and moral reasons. What this believing family needs at this point is some theological guidance as well as emotional support for making the necessary decisions when the day comes that the patient loses competence. These important theological aspects may be difficult for the family to

accept, thus making emotional support and empathy important for the family as they wrestle with the implications of the theological framework that the ethicist is giving them. This will likely require listening to the family’s concerns and questions and walking with them through a proper understanding of the sanctity of life and how it applies here. It will also involve consoling a clearly grieving family and helping them accept the eventual loss of their loved one.

The theological aspect of death and dying begins with the sanctity of life. This is fundamentally grounded in the notion of human beings made in the image of God. It is important to recognize that the image of God is a status bestowed on human beings that gives them their intrinsic dignity, regardless of their ability to perform the functions often deemed necessary for full human personhood. For if both the image of God and human personhood are dependent on those functions (such as self-awareness, consciousness, capability for relationships, etc.), then both become degraded properties, which in Scripture they are most certainly not. The intrinsic dignity conferred by the image of God is the reason why taking innocent human life is prohibited in the Bible. In addition, Ecclesiastes 3:1–2 indicates that there is a time “to be born and a time to die,” suggesting that it is God who appoints those times. Hebrews 9:27 echoes this when it says that “it is appointed for man to die once, and then comes judgment” (ESV)—again, appointed by God himself. That is, God is the One who determines the timing of our deaths.

However, the theological account does not end there. To go deeper involves how the Bible views death and the dying process itself. As a result of the general entrance of sin, death and the dying process entered the world, making it an enemy of the good that God had created and not a part of God’s original design. Though it is true that death and dying are a normal and natural part of everyone’s life, that does not make it morally neutral, as the broader culture often assumes. Theologically, the reason that these things constitute a natural and normal part of life is due to the pervasiveness and universality of sin (Rom 5:12). But the good news theologically is that death, although an enemy, is a *conquered enemy* by virtue of the death and resurrection of Jesus (1 Cor

15:50–57). What follows from this for the end of life is the critical point for this family—that is, if death has been conquered, not only does it not have to be feared, but *it also need not always be resisted* by medical means. That is, under the right conditions, it is morally and theologically acceptable to say “enough” to medicine and allow disease to take its natural course. The decision to say “stop” to medicine can actually be seen as the family entrusting the patient back to God and accepting from his hand the patient’s remaining days before his home-going.

The conditions under which decisions to stop life-prolonging treatments are morally and theologically consistent are critical for the family to understand. First, under the law, if the patient himself, while competent, indicates a desire, either in writing or orally, to stop treatments, the physician and the family must accept the patient’s wish and stop aggressive treatments, transitioning the patient to a regimen of palliative care. If the patient has a valid advance directive, the family and physicians are obligated to follow it, even if they disagree with what it indicates. If a family member has been designated as the surrogate decision-maker, in the event the patient loses the ability to speak for himself or herself, their role is to enforce the terms of the advance directive, not override them.

In most cases, the patient or family will make such a request when one or more of the remaining conditions are met. A second condition is that continuing such treatments would be futile. Though there is a long discussion of what constitutes medical futility, the consensus that has emerged is that a futile treatment is one that will not reverse an imminent downward spiral toward death for the patient. A third condition is the most common one—a treatment is more burdensome than beneficial for the patient. Families are sometimes not aware of the physical and emotional burden of life-sustaining treatments for their loved ones, and sometimes patients are not well informed about the burdens of continuing treatments that may have a serious adverse effect on their ongoing quality of life. No one is obligated to increase the net level of suffering for loved ones, and no patient is obligated to endure a degree of suffering that is disproportionate to the potential benefit of a treatment.

We would suggest that it is almost always immoral to subject a loved one to treatments that increase their net level of pain and suffering. One reason this sometimes happens is that families are unwilling to let go of their loved ones for the variety of reasons we discussed above. Although their loved one will be in a better place once they have died and are no longer suffering, that is not true of the family and other close friends, who will have to deal with the pain of the loss of a person dear to them. It also may be that the family has not been prepared for the decisions they will have to face, leading them in some cases, to “dig in their heels,” resisting making the decision to stop treatments and transition to palliative care.

For these reasons, the family is likely to have some difficulty with the idea that one can say “stop” to medicine for the patient. They may think that terminating treatment will cause the death of their loved one—that is, they have killed their father. It is not hard to understand why they might feel this way. They could easily envision a scenario in which they request ventilator support to be removed and within a relatively short time following that removal the patient will likely die. It may be hard to escape the notion that their decision and subsequent removal were the actual cause of death, when in reality it is the underlying disease progression that has been allowed to take its natural course. The emotional toll this might take should not be underestimated and may involve pastoral care or even therapy to help them process what they have decided and deal with the grief of their loss. They may even have the sense that they are “playing God” with their father’s life, and if they were actually causing his death, that might be true. But the term “playing God” refers to human beings usurping a prerogative that belongs to God alone, including the taking of innocent life, which would be the case if assisted suicide was a consideration. At a minimum, they should be encouraged to see their decision as entrusting their father back to God to live out his days as from the hand of God but without burdensome medical interventions.

They may also wrestle with the thought that their decision to remove treatments violates the biblical notion of the sanctity of life. They may be approaching this with a view of the sacredness of human life that mandates keeping their loved one alive at

all costs, no matter what. But that is a misreading of the sanctity of earthly human life. For if it is true that they are obligated always to keep the patient alive, then they are making a theological statement that I do not think they actually believe—that earthly life is the highest good for human beings. Theologically, that is simply not true. Our highest good is our eternal fellowship with God, which renders earthly life a *penultimate* good, not the ultimate good. A family’s desire to keep their loved one alive indefinitely often reflects a view of earthly life that is not theologically consistent with the Bible. In my role as a hospital ethics consultant, I have often been tempted to ask believing families (but more often than not refrained), “Do you really believe what you say you believe about resurrection and eternal life?” It’s very important for families in these situations to realize that the sanctity of life does not obligate them to continuing aggressive treatments indefinitely, and to realize that their decision to “keep going” may only be delaying an inevitable and imminent home-coming for the patient.

The family’s desire to “keep going” may also be expressing hope for a miracle, and such a hope may be a statement of their faith in a miracle-working God. Though it is true that medical miracles do occasionally occur, the family should be encouraged to view this through the framework of resurrection and eternity as opposed to a miracle on this side of eternity. The much greater miracle will be accomplished when their father meets the Lord in heaven, when this disease and all others will be healed and, in addition, his character will be like Christ’s. In some cases, this hope for a miracle is masking an understandable reluctance to let go of their loved one. It would be tempting to say to the family, “If we’re hoping for a miracle, then let’s really go for it, and remove everything, because God doesn’t need medicine to work miracles.” Perhaps if you know the family quite well, this might be appropriate, but perhaps not if you don’t have that kind of relationship with them.

Conclusion

Many end-of-life scenarios present these kinds of complex family dynamics for which most people in healthcare teams are not trained, save for some chaplains and social workers skilled in family interactions. In fact, it seems that a good deal of

family dysfunction that is not normally evident comes out in these stressful life cycle moments. This is the case even without the ethical issues that come to the fore when decisions about treatments and even about assisted suicide are on the table for discussion. The ethical part further complicates the decisions that have to be made and can exacerbate existing family tensions. It is not enough to deal with the family dynamics or the ethical issues alone, as they are often intertwined. As a result, the expertise of

both the ethicist and family therapist can help families come to these decisions and do so peacefully, without leaving family wreckage in its wake. It is common for healthcare personnel to enlist the services of the hospital's ethics committee, and social workers and chaplains are sometimes capable of helping families sort through their issues. But we are suggesting that the resources of people trained in both family dynamics and ethics are crucial contributors to effective decision-making at the end of life. Since we

are whole persons who are integral parts of families and who care deeply about our loved ones, end-of-life care and decision-making should not be reduced to treatments and technologies. Rather, appreciating the complexity of who we are as human beings and the families that we are a part of should take into account a person's place in the family and the family dynamics involved in end-of-life decisions.

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Palliative Sedation and Existential Suffering: Real-World Diagnostic and Therapeutic Considerations in Applying Hippocratic Wisdom

Rebecca Martin, MD and David Ramirez, BA | *Dignitas* Editorial Board Member and Guest Contributor

Editor's Note: Martin and Ramirez refine and apply Bryce Asberg's work in "Palliative Sedation for Existential Suffering: The Enduring Wisdom of the Hippocratic Oath," *Dignitas* 32, no. 1-2 (2025): 6-9, www.cbhd.org/dignitas-articles/palliative-sedation-for-existential-suffering-the-enduring-wisdom-of-the-hippocratic-oath.

We deeply appreciated Bryce Asberg's essay, "Palliative Sedation for Existential Suffering: The Enduring Wisdom of the Hippocratic Oath," and enjoyed reading it with profound engagement and resonance. It is a beautifully written piece, composed with clarity and elegance. He concisely addresses the relevant moral and ethical concerns that arise with the use of palliative sedation as a therapeutic approach for suffering that stems from non-physical causes. The authors of this response piece are in general agreement with both of Asberg's main theses—namely, that "because existential suffering is not . . . a physical phenomenon, it should not be treated with a physical intervention," and furthermore that "the practice of palliative sedation for existential suffering

undermines [its] validity."¹

To highlight our agreement with these core premises, we affirm that a fitting treatment is necessarily proper only when it is appropriate for a given diagnosis. While we agreed broadly with Asberg's theses and arguments, and certainly also with the Christian Hippocratic tradition underpinning his premises, this piece also provoked some questions for us as medical professionals—namely, as a palliative medicine attending physician (Rebecca Martin, RM), and as a third-year medical student (David Ramirez, DR)—that we felt worthy to raise, in the dialogical spirit of *Dignitas*. These questions arise primarily out of my (RM's) specific context of practice, which will be

elucidated shortly.

In our response, we will frame our considerations in the form of two questions: (1) Diagnostically, can a clear distinction reliably and practically be made between physical and existential suffering at the end of life, particularly in the face of significant symptom burden? And (2) therapeutically, how can clinicians best address existential suffering at the end of life, whether presenting in pure form or as a contributor to suffering more broadly, when time is short and symptom burden may preclude necessary therapeutic engagement?

In our first part, then, we will consider diagnostic challenges posed in the real-world application of Asberg's analysis, where distinguishing between physically and existentially mediated suffering is not always clear-cut. In the second part, we will explore some of the practical challenges

Rebecca Martin and David Ramirez, "Palliative Sedation and Existential Suffering: Real-World Diagnostic and Therapeutic Considerations in Applying Hippocratic Wisdom," *Dignitas* 33, no. 1-2 (2026): 13-17. © 2026 The Center for Bioethics & Human Dignity

that arise when seeking to offer appropriate therapeutic approaches to existential suffering at the end of life. We will also offer one potential path forward in the form of a middle-ground approach to addressing existential distress—namely, respite sedation. We will then conclude with a reflection on how Catholic Christian theology uniquely informs an approach to existential distress.

Diagnostic Considerations:

Distinguishing Physical and Existential Distress at the End of Life

In my (RM's) experience as a palliative medicine attending practicing in a large, acute-care, tertiary hospital context, refractory end-of-life suffering is fortunately more the exception than the rule. The overwhelming majority of patients cared for by palliative medicine teams have generally well-controlled symptoms, including appropriate management of pain, dyspnea, and anxiety, in their final hours and days before natural death.² I have, however, attended rare but memorable cases in which terminal agitation and/or severe, intractable pain persisted despite escalating doses of myriad medications intended to offer relief. These medications are typically some combination of opioids, such as morphine or hydromorphone; benzodiazepines, such as lorazepam or diazepam; and first-generation antipsychotics, such as haloperidol. Furthermore, physical symptom burden has long been known to interact meaningfully and be modulated by psychological/existential distress, and vice versa.³

A number of years ago, as a family medicine resident, I (RM) attended a Christian Medical & Dental Associations retreat presentation given by Dr. James Avery, a Christian palliative medicine physician. As I recall that lecture, Dr. Avery shared the story of a young girl in his pediatric intensive care unit who was suffering terribly with intractable pain that was refractory to all approaches he and his team had thought to try. Despite their best efforts, she was suffering immensely, requiring massive doses of intravenous hydromorphone—until, he said, someone on his team found her a “puppy.” With this “intervention,” the child's pain scores (and hydromorphone usage) plummeted exponentially.

The response was so dramatic, in fact, that when it was related during their team interdisciplinary rounds, Dr. Avery initially took

“PUPPI” to be an acronym for some kind of new medical device and asked for clarification. Yet it was, indeed, simply the introduction of a young dog—and a new relational dynamic. In this case, the patient received a small animal that could offer safe physical touch and unconditional companionship in the isolating, fearful, painful environment of a hospital ICU—that made a dramatic difference in her organically rooted, physical symptomatology. Dr. Avery's point in sharing this anecdote was to always bear in mind that suffering is multifactorial; when physical pain seems intractable, consider what other factors might be contributing to, and modulating, the total experience of a patient's suffering.

This story echoes other experiences observed clinically, where the etiologies of suffering may not be readily sorted into clean, binary categories of “physical” and “existential.” Consider “terminal hyperactive delirium,” for instance—that state of marked confusion/altered sensorium, restlessness/agitation, and hallucinations that can occur in a patient's final hours or days. Is that condition purely physical, or can existential aspects contribute to this presentation? Current evidence suggests that hyperactive delirium afflicts 14% of patients in palliative care settings⁴ and up to 88% of patients in palliative care inpatient units in their final hours to weeks of life.⁵

A retrospective matched-cohort analysis of hospice patients exploring rates of terminal delirium showed that nearly 47% of the sample had documented symptoms of hyperactive terminal delirium.⁶ Approximately 48% of that same sample self-identified as being spiritually active, and there were no statistically significant differences between patients who had delirium and those who did not with regard to physical, psychological, or spiritual factors. Interestingly, a slight majority of patients who displayed hyperactive terminal delirium (52%) endorsed having significant fears upon their admission to hospice, raising the question whether existential and/or spiritual distress may play a role in such presentations, but it was by no means an overwhelming proportion. In that same study, logistic regression analysis showed that place of death was the most significant driver, with a 2.3 times greater risk of hyperactive terminal delirium for patients who died in the hospice inpatient unit setting compared to those who died at home ($p < 0.05$); subsequent studies, however, have

demonstrated mixed results with regard to this finding.⁷

For some patients suffering with severe/intractable end-of-life pain and/or terminal agitation, particularly those with identified risk factors—young age, military veterans with a history of combat, prior history of trauma with associated PTSD⁸—there can be meaningful overlap, and interplay, between these two causal realms. There is not always a clear separation.⁹ In fact, as we have seen, the presence of refractory end-of-life suffering is itself often a clue to the astute palliative clinician that underlying existential (emotional, mental, relational, spiritual) distress may be contributing, at least in part, to challenges in adequately controlling a patient's physical symptoms.

This overlap and complex interplay is also alluded to in emerging evidence on the treatment of complex chronic pain presentations, where multimodal approaches employ a combination of pharmacologic, psychotropic, and psychological modalities.¹⁰ Studies have demonstrated benefit from protocolized use of low-dose psychedelics such as MDMA, psilocybin, and ketamine for treatment-resistant mood disorders,¹¹ as well as chronic pain presentations;¹² similar to certain SNRIs,¹³ these new applications of psychotropic medications offer relief in both physical and psychological/existential domains. At the very least, it is understood that psychiatric distress plays a role in modulating the refractoriness of physical symptoms.

Therapeutic Considerations: Addressing Existential Suffering at the End of Life

We now arrive at the second front—namely, questions pertaining to real-world challenges in therapeutically addressing end-of-life refractory suffering. Let us posit for the moment that there exists a clean, readily diagnostic approach to distinguishing between physical and existential distress, and furthermore that a patient presenting with terminal agitation at the end of life lacks any clear physical cause for their distress. While this is unlikely in the actively dying patient, it is, perhaps, theoretically possible. If that were the case, and we could confidently assess a patient as suffering from distress that is purely existential in nature, we would want to provide that sufferer with appropriate treatment. If clinicians with experience in this area have had success

with such treatment approaches, this would be an area for further education and clinical professional development offered through peer-based trainings, potentially coordinated through national professional organizations such as the American Academy of Hospice and Palliative Medicine (AAHPM), the Center to Advance Palliative Care (CAPC), or the Hospice and Palliative Nurses Association (HPNA).

The core premise of this distinction, of course, is entirely reasonable and appropriate—namely, that any proposed treatment should fit the diagnosis. Psychiatric disorders warrant psychiatric approaches from evidence-based mental health best practices, just as physical treatments should be employed to address somatic complaints. Thus, existential (spiritual, relational, meaning-making) treatments that seek to make meaning and achieve reconciled relationships with God, self, and others are appropriate for those suffering existentially. And current evidence suggests that such approaches exist; when patients disclose statements indicative of existential suffering, demoralization, and loss of meaning, psychotherapeutic modalities such as Meaning-Centered Psychotherapy (MCT) and Dignity Therapy (DT) offer fitting approaches. High-quality evidence supports the use of MCT for improving quality of life and reducing psychological stress, particularly for those expressing existential disarray, described in the literature as “meaning-centered concerns,” when facing serious or life-threatening illness.¹⁴ Similarly, DT has also been found beneficial in the palliative population,¹⁵ particularly in improving quality of life and alleviating dignity-related distress,¹⁶ through the process of a long-form interview and creation of a legacy document that “effects a sense of generativity, meaning, and acceptance near the end of life.”¹⁷

Unfortunately, however, these modalities are not well-suited for the particular population at hand—namely, those experiencing refractory end-of-life distress, even if that distress *were* known to be purely existential in origin. As we have seen, both in anecdotal experience as well as in the current evidence, those with PTSD—patients suffering from effects of trauma that has perhaps gone unaddressed for years or even decades, whether owing to insufficient resources, inadequate inner distress tolerance, or a lack of appropriate culturally mediated

frameworks to support healing—are more likely to have severe, refractory, terminal delirium in their final hours to days of life. For such patients, the time-limited nature of this end-of-life distress would obviously preclude any ability to adequately address such longstanding and complex trauma. This is both because time is short (perhaps only hours to days, in the acute-care context), and also because a patient’s end-of-life symptom burden (including somnolence, which is part of the normal dying process) is likely to be significant enough to preclude any ability of the patient to attend well to such end-of-life tasks as unearthing and resolving whatever complex trauma history is contributing to their terminal delirium.

The assertion that existential distress should be addressed through existential interventions of meaning-making and spiritual care, while valid, also assumes that such interventions are likely to be successful. When we are dealing with challenging physical symptoms, even the best clinicians in the best hospitals face limits in their ability to resolve physical pain and restore function. How much more so for existential distress, when we are seeking to bring restoration to patients at the level of one’s spirit, their relationship with the transcendent, their sense of being and meaning? We should absolutely try, no doubt; this is as much within the purview of whole-person medical care as is the use of anti-platelets in the treatment of cardiovascular disease. Yet we should also be circumspect and avoid the temptation to triumphalism, as if our efforts will inevitably be successful. That is not true for the alleviation of existential despair any more than it is for physical symptoms.

Respite Sedation: An Approach Warranting Further Exploration

One area that may warrant more exploration, however, is the use of respite sedation, which refers to the use of sedative agents for a brief, time-limited period (usually 24–48 hours) aimed at alleviating physical symptoms such as pain, nausea, and agitation, followed by sedative weaning and return of consciousness thereafter.¹⁸ The aim of respite sedation is to “break a cycle of anxiety and distress that precipitated the request for [palliative sedation] and nullify the need for further sedation.”¹⁹ In fact, in their published 2009 guideline for the use of sedation in palliative medicine, the European Association for Palliative Care states that

“continuous deep sedation until death should only be considered after repeated trials of respite sedation,”²⁰ a position statement that was upheld in their 2024 revised EAPC guideline with increased emphasis on the principle of *proportionality* in palliative sedation use.²¹

Newer pharmacologic agents may also offer a promising middle-ground approach in addressing existential distress at end of life, including terminal delirium. Conscious sedation using IV dexmedetomidine, a relatively new alpha-2 agonist with analgesic and sedative properties, has been used successfully in the management of refractory end-of-life symptoms, including that of severe anxiety and psychological distress.²² This application of dexmedetomidine permits patients to be lightly sedated while remaining communicative, in a state that has been termed *cooperative sedation*, where the patient is awake or lightly sleeping but also able to remain calmly interactive.²³ Several published case reports describe marked benefit for management of not only pain but also anxiety, insomnia, and agitation at end of life, using an approach that minimizes opioid usage and permits sufficient wakefulness for patients to interact with loved ones.²⁴

While dexmedetomidine holds appeal for this clinical application because of its potential to preserve some degree of wakefulness, its requirement for continuous intravenous (IV) infusion can restrict widespread use. For clinical settings in which maintaining IV access is either overly burdensome or infeasible, current guidelines for palliative sedation also offer protocols for the use of subcutaneous benzodiazepines including lorazepam and midazolam, or non-IV phenothiazines such as subcutaneous levomepromazine and intramuscular or rectally administered chlorpromazine, for enhanced ease of access.²⁵

At the risk of oversimplification, might one think of respite sedation as analogous to the restorative role played out in each night’s sleep cycle. Consider how often the end of a day can leave one feeling discouraged, stressed, or fearful in the face of personal challenges or shortcomings. In these moments, sleep makes an attractive offer: Close your eyes and things may seem better when you wake up. Sometimes, the same obstacles are viewed the next day in a more hopeful and healthy perspective, allowing

one to face the day with newfound confidence. In fact, palliative medicine physician Paul Rousseau makes a case that “because many dying patients are afflicted with existential turmoil that engenders fear, fatigue, and insomnia, respite sedation may break a cycle of sleep deprivation and existential distress and allow such patients the opportunity to regain psychological strength and assuage the existential issues that precipitated the need for palliative sedation.”²⁶

If a patient suffering from purely existential distress is placed in a state of permanent sedation until death, there can be no opportunity to attend to existential concerns. If sedation is maintained through natural death—even if death that is neither hastened by, nor aimed at through, palliative sedation (scenarios that would clearly lie far outside the bounds of the Christian Hippocratic ethic)—a patient is still deprived of any potential opportunity to attend to end-of-life priorities and tasks, as they might following a time-limited period of respite sedation. In this way, respite sedation may offer a categorically different approach from that of typical palliative sedation, insofar as it has the potential to alleviate symptoms of fatigue, agitation, and anxiety contributing to existential distress at end of life.

How Catholic Christian Theology Informs an Approach to Existential Distress

Questions about the appropriateness of palliative sedation to address existential suffering touch upon the very heart of medicine’s purpose. Granted, there is surprisingly little consensus in our modern medical context around what, even, is the purpose of medicine.²⁷ A Christianly understanding of medicine’s purpose might propose that the role of medicine is to restore a person to right relationships—most fundamentally, relationships within the physical body, when those have been disrupted by illness or injury, but also relationships between the sufferer self and body, as well as self and other selves, and ultimately, self and God. The final line of one unattributed prayer for medical clinicians reads: “And when I cannot heal them, Lord, let me lead them on at least to a deeper faith and resignation in Your love.” Through medical care, then, clinicians are granted an opportunity to treat patients in order to put them in a better position to improve their relationships with their own selves, with others, and with God.

How, therefore, do we help facilitate healing and relational connection with God and others, as we seek to address existential distress, whether in its pure form or insofar as it is contributing to physical suffering? Is permanent sedation until natural death really the best route to this, even in cases where time is short? The concept of cultivating one’s capacity for “growth at the end of life,” posited by palliative medicine physician Ira Byock, is a powerful way of thinking about the potential for transformation, growth, restoration, and reconciliation at every stage of life, right through to the very end.²⁸

I (RM) have personally witnessed such transformation and reconciliation in the most unlikely of places, where siblings reconnect after decades of estrangement—not in spite of death’s looming shadow, but precisely *because* of it, and the humanly fragile limits on time that it portends. When existential distress is contributing to suffering, we do not serve our patients well by robbing them of the opportunity for such growth, eliminating any chance for them to weave new fabric in places of relational fray or to write new narratives in their final chapter of life.²⁹

One additional word of caution in the context of any discussion on palliative sedation: Regardless of the reason for administering sedation—even for physical suffering, and even for brief, circumscribed periods—we must be extremely circumspect in how we use this intervention. The Roman Catholic Church teaches that taking away one’s consciousness takes away the person’s right to prepare for his or her death, including the opportunity to participate in and sanctify personal suffering.³⁰ This teaching is rooted in an understanding that even in the midst of great personal suffering, human activity can be reoriented from that corporal, outward-looking glance to an inward, spiritually-directed transcendence. This inward movement of our being in our final days and hours can involve a kind of transformation or conversion, sometimes quite dramatic, as in the case of the good thief. . . . [involving] a contemplative internalization of the mysteries of human existence, a stripping away of everything, and a period of “rending naked” the soul.³¹

For this reason, the USCCB Ethical and Religious Directives for Catholic Health Care Services assert that “since a person has the right to prepare for his or her death

while fully conscious, he or she should not be deprived of consciousness without a compelling reason.”³² There is no way to predict the grace that can come from cooperating with God’s will, even if it means enduring some degree of pain. One cooperates best by engaging the human faculties of consciousness and reason. Just as numbing consciousness avoids the spiritual root of existential suffering, so does it avoid the spiritual aspect of physical suffering. The same spiritual awareness that enriches the Christian approach to existential suffering may inform the approach to physical suffering with regards to palliative sedation.

At the same time, the authors of this essay agree that God, in his sovereignty, is able to minister through his Spirit to patients even when rendered unconscious by human medications or by the natural dying process (where somnolence is an expected part of that). We can commit even these patients into his good hands for spiritual communion and communication that is possible even when human communion and communication is not. Furthermore, we believe the Lord is extremely generous with his graces towards individuals who are close to death. The extraordinary administration of sacraments for the dying, as well as the promise made to the good thief, reveal this generosity.

Conclusion

Returning to the original essay by Bryce Asberg, we recall three central assertions underpinning his thesis, namely that (1) palliative sedation undermines the validity of existential suffering, (2) the act of sedating existential suffering diminishes its significance, and (3) the Christian approach uniquely takes existential suffering seriously. In order to encompass the complexity of real-world clinical care of patients experiencing existential distress at the end of life, maintaining an awareness of the aforementioned diagnostic and therapeutic challenges inherent therein, we might revise his first two assertions as follows: (1) *reflexively implementing* palliative sedation undermines the validity of existential suffering, and (2) the act of sedating existential suffering *in the absence of exhaustive attempts at otherwise ameliorating it* diminishes its significance.

Regarding Asberg’s third assertion, we would prefer his language to acknowledge

the legitimate and well-intentioned care of atheist colleagues towards the dying, while also expressing the Christian's appropriate humility towards our God-given faith, by grace. As Asberg points out, proponents of palliative sedation claim to take existential suffering seriously. They are sensitive to the severity of existential suffering and employ all available and acceptable tools to combat it. While the atheist's approach does not

acknowledge the full scope of spiritual realities operative in a Christian understanding, it is no less serious in its effort, concern, and good will. To say only a Christian view takes it seriously may be dismissive of their own good-faith care for the dying.

Christian faith and its magnificent theology is a gift that disciples of Christ are blessed, by his costly grace, to possess and share.

While we admire the holy boldness that likely motivates the author, a gentler approach would highlight our shared humility in possessing the greatest gift of our lives and invite non-believers into graceful dialogue.

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BOOK REVIEW

Eggonomics

Diane M. Tober, *Eggonomics: The Global Market in Human Eggs and the Donors Who Supply Them*.

Routledge, 2024. ISBN 978-1-0325-4991-0, Paperback, 326 Pages, \$21.99

Megan Best, MD, PhD | Academy of Fellows Member

This monograph is a detailed report of a study exploring the experiences of human egg (oocyte) donors in the United States and Spain, tracing their journeys as suppliers of valuable commodities. It is a sobering read. Diane Tober is a medical anthropologist who has spent a decade investigating the world of egg donation. Regulatory differences between the two countries allowed Tober to compare the impact of greater regulation (in the Spanish system) with the relatively unregulated and more commercial context of the US. In Spain, doctors choose donors on behalf of the patients based solely on phenotypic resemblance, rather than intended parents choosing their own donors as occurs in the US. In Spain, a national donor registry is being developed to track donor cycles and live births so that limits to each can be enforced. Such measures increase the safety of egg donation and reduce the risk of consanguinity. Tober uses her investigations to explore whether the Spanish system might

offer insights that could improve egg donation in the United States.

In the world of assisted reproductive medicine, donor eggs are recommended for women whose own ovaries no longer function, for women with hereditary genetic disorders, and for couples with unexplained infertility. Use of donor eggs in the treatment of infertility has dramatically increased since the first live birth from donated eggs in 1983. This is due to factors such as delayed childbearing, increased restrictions on international adoptions, and the rising numbers of single people and same-sex male couples accessing fertility treatments.

A significant change in the donor egg landscape occurred in 2013 when the ASRM (American Society for Reproductive Medicine) removed the “experimental” label from oocyte cryopreservation (egg freezing) after reviewing scientific evidence that showed it to be a safe and effective method

for fertility preservation.

At the same time, the technology improved. Egg freezing in the early years had a low success rate, resulting in a preference for “fresh” eggs. Then in 1999, Japanese veterinarian Dr. Masahige Kuwayama pioneered his Cryotop® vitrification method for human eggs and set up the first egg bank. The first live birth from a vitrified egg came in 2002, and his laboratory reported their improved success rates in the medical literature.

Egg vitrification removed the need for the donor and recipient to synchronize their cycles, and the need for the egg donors, the prospective mother, and the clinic personnel to be in the same place at the same time for egg retrieval, embryo creation, and embryo transfer. This single technological improvement revolutionized the fertility industry. With improved frozen egg survival rates, clinics could expand their own donor egg banks and, for the first time, standalone donor egg banks began to appear.

In the US, there was a rapid increase in the use of frozen eggs for in vitro fertilization (IVF) cycles, increasing by 44% within two

years of the ASRM decision. It also had a profound impact on “oocyte bioeconomies” due to new global opportunities for egg procurement and distribution. Now eggs, like sperm, could travel through space and time, enhancing the profitability of the human egg market and the global fertility industry.

Tober quotes the price of frozen donor eggs in a range between US\$14,000 and \$22,000 for a batch of five. Therefore, if a single egg donor produces 30 mature eggs on a single donation cycle, the clinic could potentially receive up to \$132,000, less their payment to the donor, which on average is around \$7,500. According to this metric, the average price of an egg is around \$4,150, so if the donor produces more eggs, profits will increase accordingly. For the clinic, that is: donors are paid per cycle, not per egg.

The heightened profit potential in this market has attracted private equity investors seeking new opportunities for increased revenue. But if the number of eggs produced by donors is directly linked to the extent of profit for the clinic, there emerges a potential ethical conflict. There is evidence that medical decisions can become less donor-focused, and medical professionals can be pressured to maximize profits.

Medical risks, about which donors are often poorly informed, can be substantial and increase according to the medication protocol used and the number of eggs the donor produces. Donation involves interventions that in no way benefit the physical health of the donor. The process is time-consuming, uncomfortable, can be emotionally draining, and recovery can take days to weeks. The future fertility of donors may be compromised. Suffering may be ongoing. To be fair, not all clinics are run by large conglomerates. But according to Tober, while motivation can be complex and include an altruistic desire to help others, in the end, few women would donate if financial compensation was not involved. The question of coercion cannot be avoided.

The author suggests that the highly lucrative commercial market for human eggs in the US is driven by several intersecting factors:

(1) inconsistent and insufficient regulations surrounding gamete (egg and sperm) donation and surrogacy throughout the US, which makes it a primary international fertility treatment destination for those from countries with restrictive policies; (2) the high costs of higher education and accompanying student loan debt, compounded with consumer debt, creating a cohort of young women seeking financial relief; and (3) unrestricted egg donor compensation rates enhancing commercial competition for both donors and recipients. These factors combine to create an environment in which there is an enormous demand for local IVF with outsourced labor and an ample supply of young women to meet that demand.

Tober gives case history after case history of women who have suffered within this network. Stories of problems with informed consent, misleading enticements to donate, pressure to keep donating after complications have occurred and safety margins have been exceeded. Stories of health problems that lead to the donor ending up with increased, not decreased, financial burdens. Tober also documents problems for donor offspring, who often find their desire for knowledge of their biological origins ignored. A darker side to egg donation is revealed, with links to abuse and exploitation of poor women in developing countries, baby trafficking and illegal adoptions, and human eggs sold on the black market. Stark evidence that suggests that the industry is unable to regulate itself.

Human eggs are the primary raw materials that enable the fertility industry to thrive. Yet donors themselves are precariously placed on the spectrum of financial benefit and personal empowerment. While some women do not regret their donations, and some even report a positive experience, the take-home message for me was that, in this industry, the donors are viewed as a source of spare parts for others and treated as a means to an end.

In the world of egg donation, clinicians downplay the importance of the genetic link to dismantle the perception of the egg donor as parent. Instead, stress is given to

the importance of the gestational and social role of (commissioning) mothers. Donors are often persuaded at the time of donation by the idea of altruistic donation of eggs that are “going to waste.” But feelings change over time, and Tober found that when donors had their own children or faced infertility, their genetic offspring often became more important to them, with most donors open to contact at some point. In fact, 56.7% of Tober’s sample had attempted to find their offspring. It is complex because the clinical reframing of motherhood gives potential donors permission to proceed and also to make sense of what they have done, and anyway they needed the money.

While Tober believes that egg donation can be a wonderful thing, she feels the lack of enforceable standards and contracts makes the industry ripe for abuse. The book ends with recommendations for how the practice of egg donation might be improved if rooted in the values of reproductive justice and human rights, aiming for equality of rights of donors, intended parents, and donor offspring.

Global fertility services are projected to grow to \$68.32 billion by 2032. Egg donors tend to be poor, young, and often non-white. Long-term impacts of donation are unclear, but the donors are not followed up to investigate health outcomes. Instead, the focus is on the production of materials; the focus is on the eggs. Yet after all that, the majority of donors Tober interviewed found the process rewarding even in the face of regrets. She seeks a system where it is not achieved at so great a cost.

This is not a Christian book. The author self-identifies as pro-choice and promotes the idea of unrestrained individual liberty to pursue parenthood. She uses language that endorses fluid gender ideology. Ethical questions for Christians, such as the morality of assisted reproduction in general and gamete donation in particular, are not addressed. Nonetheless, I think this book is a valuable insight into what happens when we commodify human bodies.

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BOOK REVIEW

Making Modern Medical Ethics

Robert Baker, *Making Modern Medical Ethics: How African Americans, Anti-Nazis, Bureaucrats, Feminists, Veterans, and Whistleblowing Moralists Created Bioethics*. The MIT Press, 2024. ISBN 978-0-262-54737-6, Paperback, 317 Pages, \$55.00.

Bryan Just, MA | Operations & Events Manager

In *Making Modern Medical Ethics: How African Americans, Anti-Nazis, Bureaucrats, Feminists, Veterans, and Whistleblowing Moralists Created Bioethics*, Robert Baker introduces a counternarrative to traditional histories of bioethics. In the standard histories, such as David Rothman's *Strangers at the Bedside* (1991) or Albert Jonsen's *The Birth of Bioethics* (1998), bioethics is seen as a mostly American phenomenon arising in the twentieth century as a result of "morally disruptive medical technologies," such as ventilators, dialysis machines, and organ transplantation (p. ix). These technologies necessitated a reevaluation of medical ethics and the physician-patient relationship and instigated a series of conferences, court cases, legislation, government commissions, and think tanks to address the emerging issues.

Baker seeks to amend this standard history, instead framing the bioethical turn in medical ethics as a moral revolution. And, as he

writes, "moral revolutions, like their political and scientific counterparts, are not initiated by establishments but by the dissidents, critics of the established order" (p. x). Thus, in Baker's account of the birth of bioethics, credit must be given to those people and groups who ushered in the moral revolution that made bioethics possible: the African Americans, anti-Nazis, bureaucrats, feminists, veterans, and whistleblowing moralists referenced by his subtitle.

Baker traces the origin of contemporary bioethics to the European and American response to the Nazi medical atrocities committed during World War II. He dedicates a full chapter to outlining Nazi medical ethics, demonstrating that their belief that the physician's role was not just to help the patient but to promote the health of all of society led to a twisted perception of morality in which atrocities such as the Holocaust or illicit experiments on prisoners were seen as morally righteous acts. At the Nuremberg Trials

held after the war, two American moralists, Leo Alexander and Andrew C. Ivy, were committed to ensuring that such atrocities would never reoccur and were instrumental in developing the Nuremberg Code, a set of ten principles for the ethical use of human subjects in research. This code became a launching point for several later documents by the World Medical Association, including the Declaration of Helsinki, which would be used as the basis for America's own regulations on human subjects research. In tracing this history, Baker brings attention to several often-overlooked figures in the development of medical ethics and also creates a counternarrative to claims that bioethics arose as a result of American moralism and exceptionalism; according to Baker's history, bioethics' origins are international in character, and American bioethics built off of this foundation.

Baker next turns his attention to numerous moralists who questioned the dominant paradigm of research ethics. These include Frances Kathleen Oldham Kelsey, an FDA bureaucrat who was responsible for preventing Thalidomide's approval in the US

and was instrumental in incorporating language from the 1962 draft of the Declaration of Helsinki regarding informed consent into official FDA policy; Maurice Pappworth, a Jewish physician and veteran in the UK who wrote about unethical research practices among both American and British doctors; and Henry K. Beecher, an American physician and veteran who wrote about research ethics and published a famous article in the *New England Journal of Medicine* calling out some of the most egregious ethics abuses of his day. Baker also dedicates a chapter to the many people who drew attention to the Tuskegee syphilis experiment and the public outcry that arose from its exposure.

Though some might call these moralists whistleblowers, Baker contends that this term is insufficient, for they were not alerting an unwitting public to hidden abuses but rather drawing attention to research that was happening in plain sight. The problem was not that doctors were covertly doing unethical experiments; the issue was that doctors did not see their experiments as unethical in the first place. This forms the basis for the primary claim and through-line of *Making Modern Medical Ethics*—that the story of bioethics is the story of a moral revolution. Borrowing from Thomas Kuhn's theory of scientific revolutions, Baker describes the dominant paradigm of early- and mid-twentieth-century medicine as scientific medical paternalism: the belief that "by virtue of their training and experience and emotional equipoise, physicians alone are the sole rational decision makers, and they alone should determine what is best for a patient's care" (p. 130–31). Doctors could engage in ethically problematic research without troubling their conscience because, under the paradigm of scientific medical paternalism, it was up to the doctor to decide what was best. Drawing from the language of Francis Kelsey, Baker portrays physicians under this paradigm as thinking of themselves as "Lords Almighty" and behaving as such (p. 126).

Even as these moralists challenged the paradigm of scientific medical paternalism in research ethics, other groups challenged the paradigm as it related to patient care. These included many of those whose voices were not valued in the medical system of the time, including women and feminist organizations; minority groups, especially black

civil rights activists; the poor who were reliant on Medicare and Medicaid; as well as the elderly. These groups fought for physicians and hospital systems to acknowledge their right to have a say in their own care and won major concessions in the form of a Patient's Bill of Rights. At the same time, questions arising from the morally disruptive medical technologies more commonly associated with the birth of bioethics were starting to be addressed by people and institutions already familiar in the bioethics literature: the Hastings Center, the Kennedy Center, the government commissions, Beauchamp and Childress' *Principles of Biomedical Ethics*, etc. They developed bioethics at the academic and institutional level and created a shared language for "a common secular ethics based on an egalitarian paradigm of transparency and shared decision-making" (p. 189).

As is the case with all revolutions, scientific or moral, a new paradigm had to take the old one's place. Baker summarizes the new paradigm as one of autonomy, which "emphasized transparency, informed consent, non-discrimination, and patient's and subjects' rights, often justified by invoking concepts valorized by Beauchamp and Childress's mnemonic synecdoche quartet, 'autonomy, beneficence, nonmaleficence, and justice'" (p. 189). In Baker's account of the history of bioethics, it was much more than just disruptive medical technologies that led to challenging the paradigm of scientific medical paternalism. Those technologies, and the people who thought deeply and critically about their use and adoption, are but one of a much larger group who ushered in the bioethics revolution.

Baker's *Making Modern Medical Ethics* is a valuable contribution to the history of bioethics and calls attention to numerous individuals and groups that have been overlooked or downplayed in previous histories. Due to the minority status of many of these marginalized figures, Baker is especially concerned that their contributions be acknowledged in order to challenge the conception that bioethics arose as a predominantly white, male-dominated field. In this, he succeeds. And yet, it is also a source of several tensions within the book.

In the preface, Baker claims to be introducing an "alternative origin narrative" for bioethics (p. xi), and in several places seems to

imply that he will be replacing the typically acknowledged founders of bioethics with a new set of heroes and heroines: African Americans, Anti-Nazis, Bureaucrats, Feminists, Veterans, and Whistleblowing Moralists. However, while Baker's recontextualization of the history of bioethics as a moral revolution is novel, he does not actually negate any of the previous history; he merely works it into his larger narrative of moral revolution and the paradigm shift away from scientific medical paternalism. In fact, in his own summary statement at the end of the book, he adds back in those groups conspicuously absent from his subtitle: commissions and think tanks. Thus, while "counter-history" or "alternative history" sound flashy, it might be more accurate to say that his work is an expansion of traditional bioethics histories.

Because Baker is so concerned with identifying previously unrecognized contributors to the history of bioethics, there are places where his narrative puts undue emphasis on particular persons or groups without fully substantiating his claims. As one example, Baker is keen to argue that American bioethics was heavily influenced by international precedent, especially the Declaration of Helsinki. He does show how language from a draft of the declaration was incorporated into US law in the 1960s, but he later states that for all of the whistleblowing moralists he considers, it was the Nuremberg Code, not Helsinki, that formed their touchstone for the morality of research ethics (pp. 121–22). These types of questions are raised with numerous figures Baker covers. This is not to deny that they have been overlooked, but it is not always clear whether the scope of their influence matches the importance Baker assigns to them.

Most problematic is Baker's treatment of past historians of bioethics, Albert Jonsen and David Rothman in particular. In his final chapter, Baker provides a metahistorical analysis of the standard histories of bioethics. Many of his comments are insightful as he unpacks the narratives that Rothman and Jonsen have constructed. However, Baker also engages in much speculation as to *why* they emphasized or left out certain figures or groups, and he frequently makes unsubstantiated accusations of overt sexism or racism. For example, in discussing the limited coverage Jonsen gives to Frances

Kelsey in *The Birth of Bioethics*, Baker admits that it is possible that Jonsen “never found source material documenting Kelsey’s role”; however, he then goes on to speculate that Jonsen may have assigned her only a limited role because “crediting a female with the initiative to challenge paternalistic male doctors’ scientific prerogatives as ‘Lord’s Almighty’ is ‘uppity,’ unfeminine, and so,

perhaps, not to be mentioned” (197). Baker provides no evidence that Jonsen or other historians held prejudiced views; not including certain people or organizations in their accounts is taken as de facto proof that they must have been deliberately discriminatory.

Baker’s work may not create a full alternate history, but it certainly shows the limitations and oversights of the standard histories. His

insights into the nature of moral revolutions and his application of these to the history of bioethics are also valuable and provide many avenues for future study. *Making Modern Medical Ethics* does not replace the standard histories, but it does succeed in expanding the narratives around the development of bioethics to include many voices that have previously been ignored or marginalized.



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BOOK REVIEW

Replaceable You

Mary Roach, *Replaceable You: Adventures in Human Anatomy*. W.W. Norton, 2025.

ISBN: 978-1-3240-5062-9, 304 pages, Paperback, \$18.99.

By Joy D. Riley, MD, MA | Advisory Board Member

Reading best-selling author Mary Roach is an adventure in itself. Several years ago, I read her book *Stiff: The Curious Lives of Human Cadavers* (W.W. Norton, 2021) and realized that options as a donated cadaver held no real attraction for me. With that humbling recollection, I approached her *Replaceable You: Adventures in Human Anatomy* with some trepidation. What would I learn, and how would I be impacted by that knowledge through this, her latest opus?

In this newest work, Mary Roach pulls back the curtain on attempts to replace absent, diseased, malformed, removed, or unwanted human body parts. Each of her 17 chapters deals with a separate organ or system. The author delves into the historical, current, and cutting-edge approaches to replacement of human hair, noses, and limbs, and many of the parts between these physical landmarks. How successful are these attempts? This book functions as a red

“you are here” button on our collective map of human progress.

The author’s wit is on display from the book’s beginning. She leaps into a discussion of false teeth, quoting from the late author, John Woodforde. His book was entitled *The Strange Story of False Teeth*, which Roach characterized as “a book I chewed through to here expectorate a few morsels” (p. 1). By page 186, she compares Wikipedia to a rectum and finds the former wanting.

Roach is a reporter—not a physician or scientist—as she points out several times. That said, she does an admirable job of translating science into understandable language and concepts. She does it with her own distinctive style and provocation, including crudity. Consider a few of the chapter titles: “Giving the Finger,” “Intubation for Dummies,” “Shaft,” and “The Ass Men.” Proceeding from one chapter to the next in this diverse array could cause mental whiplash, but the author is too astute for that. The

segues are interesting, subtle, and well written.

Her journalistic name as well as her personality open doors that would be closed to many. The book is a first-person account of meeting scientists, physicians, nurses, technologists, business executives, and others in her quest for knowledge. But Roach is more than a peripatetic interviewer: Her notes are replete with articles and books that range from obscurity to current day. She sifts data like a goldrush miner pans for gold. The difference is not only that she shares the nuggets. She also appreciates and shares other, often tangentially related things she sees or thinks along the way.

To research cataract surgery, she accompanies American and Mongolian ophthalmologists working with Orbis International, an eye health nonprofit. Chapter 11 opens with a description of the Mongolian countryside, owned by the government. One could say it “has few roads” or is “one big road,” because you can go wherever it is possible to aim and drive your car (p. 155). Such seemingly even-handed evaluation is attractive in a

book about science, but it is not a feature of this book on science.

Rather, *Replaceable You* is filled with accessible prose that clearly communicates complex ideas and procedures. The differences between burn degrees are explained as “like Richter earthquake numbers—one step up doesn’t sound like much, but in terms of the damage wrought, it’s substantial” (p. 28).

The chapter on limb amputation—“The Cutoff Point”—includes a description of a surgical attempt to “prevent phantom limb pain”:

I watched a lower leg amputation in which the surgeon would take the end of any major severed nerve and embed it in some muscle, to “give it a task.” So that it’s not, to use another surgeon’s metaphor, a loose power line sparking in the roadway. The technical term for what I observed is “regenerative peripheral nerve interface” (p. 99).

In Chapter 13, “Out of Ink,” Roach describes the problems encountered in 3D printing:

Organs are malleable—flimsy, even. An extrusion 3D printer builds what it’s building from the bottom up, the first layers serving as the base for the layers to come. To facilitate this, plastic inks are made to solidify within seconds. I own a 3D printed facsimile of a human rectum, made of hard plastic. You could not print an actual rectum this way, any more than you could build a cathedral out of tofu. The farther up you build, the floppier the structure becomes (p. 191).

Colorful descriptions abound, and there is more. Scattered throughout the book are little-known facts that do not necessarily hit the radar of the media or the general public but are useful and important to know. For instance, people are familiar with the usually extensive testing of potential new drugs required by the US Food and Drug Administration (FDA). Medical devices are a bit different: For these, the safety and efficacy trials require fewer subjects and shorter time frames than with drug trials. Moreover, once a device is approved, any other “substantially equivalent” device invented in that category “need not conduct trials at all” (p. 185). Stem cell treatments are in still a different category. Roach labels

stem cell treatments as “a cellular wild west, and it’s big money.” If one is “simply taking someone’s own cells out and putting them back somewhere else, FDA approval isn’t required” (p. 225).

Her investigation of human tissue donation takes her to an organ procurement organization (OPO). She visits CORE, the Center for Organ Recovery & Education, in Pittsburgh. CORE is a Tier 1 OPO, whereas “almost half” of OPOs are rated Tier 3, the lowest ranking. (p. 243). Roach reports:

Digital donor tracker boards are mounted on the wall at intervals, like airport arrival and departure boards. These display the names of people who’ve recently died, or are expected to soon, in area hospitals—people under consideration as organ and tissue donors. . . . Once a hospital notifies CORE of a patient’s death, the team has twenty-four hours to secure the medical examiner’s release, have the risk-assessment conversation, get consent from the family, and begin the tissue recovery. (p. 245).

The author’s philosophy, “I support everyone’s right to do to their body whatever makes them feel good about themselves” (p. 237), could underscore the wide range of possibilities for replacing various human body parts presented in *Replaceable You*, but she occasionally injects moments of realism. In considering 3D printing, she opines that “everything is more complicated than you think it’s going to be” (p. 194). Indeed, Roach makes this point repeatedly throughout the book. She also, and somewhat paradoxically, exhibits realism in her treatment of plastic surgery’s search for the golden ratio ideal in breast aesthetics. In one study of 37 subjects, plastic surgeons gave the “highest aesthetic ranking” not to a human, but to “a ‘virtual subject’—a computer-generated torso.” Roach opines that “plastic surgeons and their patients are chasing an ideal that rarely exists in undoctored human anatomy” (p. 232)—a statement that stands in contrast to her espoused philosophy.

In other arenas, Roach exhibits little if any evaluative prowess. She would like to “marvel at the strangeness of a few strands of long, flowing head hair growing on, say, my leg.” Plastic surgeon Richard Chafsoo “agrees to do it, if only because it’s easier to move a

follicle than to argue with a nitwit” (p. 207). In this recounting, there is no sense of an understanding that the *telos* of medicine might include something besides the fulfillment of one’s desires.

Medicine in the service of desire fulfillment—even if it is not described by the author as such—is the subject of Chapter 5, “The Vagina Dialogue.” This chapter details a dinner the author had with a urologist in a two-person banquet of an Italian restaurant in Los Angeles. There, while the waiter attended and served them, they discussed a surgical procedure that uses ascending colon to fashion a neovagina in a male desiring to be a woman. They talked about the advantages of using that particular section of bowel and how the bowel needed to be oriented in the body for the new function. It was noted that surgical procedures do not have FDA or other federal regulatory oversight. No institutional review board (IRB) oversight is needed either, if the procedure is a modification of an existing one. Therefore, the urologist and a colorectal surgeon had “consulted with the patient, explained the possible complications and side effects, and obtained consent.” (p. 71). No comment from the author about this.

There is more to digest. The urologist, Dr. Garcia, “holds a patent on a dilator designed specifically for women who have undergone intestinal vaginoplasty” (p. 74). The word “women” is not defined here, but seems to be restricted to men, who, through surgery and other therapies, are attempting to live as women. This patient population provides a new market for innovation not only in surgery but also in devices. Dr. Garcia “owns a medical device company” (p. 74). Again, no comment regarding any possible conflict of interest, ethics, etc.

To be fair, Mary Roach is a popular science writer; she does not pretend to be otherwise. She is very well skilled at translating complex ideas into accessible language. Her tenacity in conducting research is remarkable and wide-ranging. The notes she provides her readers are replete with details as well as digressions. She writes in a conversational tone and is witty, engaging, and self-effacing. Her humor often involves sexual content or innuendo, and, perhaps mirroring medical humor, can be rather macabre at times.

Replaceable You is chock-full of information

about attempts at replacing various human body parts, through the ages, currently, and even what is on the horizon. It is wonderfully collected in one place: no small feat. Information is important and very helpful as we contemplate various technologies, especially those that interface with our human

bodies. Beyond information, though, wisdom is required. We need to know who and what we are, what technology is, and how we are to navigate new technologies. Understanding the difference between *can* and *should* requires moral knowledge—something mere information cannot yield.



In April 2026, we launched a series of online book discussions that span a full calendar year. The aim of these discussions is to reflect deeply on current and emerging medical and bioethics trends that are currently relevant to daily life or likely to become more relevant within a generation. Participants are encouraged to engage in online written discussions and teleconferences to consider what is going on, why (or whether) it should be going on, and how Christians should live in light of these developments.

The four books we will read and discuss together are:

- David VanDrunen, *Bioethics and the Christian Life: A Guide to Making Difficult Decisions*
- Ewan Goligher, *How Should We Then Die? A Christian Response to Physician-Assisted Death*
- Paul Ramsey, *Fabricated Man: The Ethics of Genetic Control*
- TBA

Join us for the discussion! More details coming soon. Join the CBHD email list to be the first to know: <https://bit.ly/cbhd-email>

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BOOK REVIEW

The Occasional Human Sacrifice

Carl Elliott, *The Occasional Human Sacrifice: Medical Experimentation and the Price of Saying No*. W.W. Norton, 2024.

ISBN 978-1-324-11683-7, Paperback, 368 Pages, \$19.99.

Heather Zeiger, MS, MA | Research Analyst

For seven years, Carl Elliott waged a battle against his own institution, the University of Minnesota, over the death of Dan Markingson, an unwilling participant in a drug trial for the anti-psychotic drug Seroquel. Markingson's mother had objected to the study and to the conditions of the study, and Markingson, who was confined to in-patient care at the University of Minnesota's psychiatric hospital, was likely not able to provide proper consent for the trial. Markingson eventually killed himself with a razor blade in a bathtub at the psychiatric center. When his mother tried to sue the university, she was told that public institutions had immunity, and the university instead tried to hold her responsible for their legal fees.

Elliott learned about the Markingson case after a journalist friend at the *St. Paul Pioneer Press* sent him the multiple-part story. Elliott, who had been a professor of philosophy at the university for seven years,

took it personally that he had known nothing of this case even though he was a bioethics instructor and on the institutional review board when the trials were going on. He then made it his mission to right this wrong by calling for an external investigation, only to be stonewalled and alienated by his colleagues.

Eventually a state investigation vindicated Elliott, but the victory, as is the case for most of the whistleblowers described in his book *The Occasional Human Sacrifice: Medical Experimentation and the Price of Saying No* (W. W. Norton & Company, 2024), was a costly one.

Elliott recounts his experience in the opening chapter of the book, but he does not paint himself as a helpless victim. Rather, he describes his efforts as “an all-consuming self-destructive, seven-year public crusade,” which he points out was over a mistreated research subject who was already dead (p. 4). His experience as a whistleblower

sent Elliott down what he calls “the hole,” a phrase taken from Kurt Vonnegut’s “[man-in-the-hole](#)” idea for constructing a story arc.¹ “The hole,” as Elliott describes it, is a metaphorical place where whistleblowers end up when they blow the whistle, a place of isolation and solitude because no one believes you and you are left alone with your thoughts. Those thoughts often, although not always, turn into paranoias, obsessions, and resentments, while the thing the person is fighting against, the right they are trying to wrong, becomes all-consuming to the whistleblower.

Elliott is not proud of the person he became while he was “in the hole.” His actions were at times obnoxious and counterproductive, and Elliott describes his motives as mixed—as much about his sense of shame and personal vindication as the injustice done to Markingson and his mother. He wrote *The Occasional Human Sacrifice* “in an effort to climb out of the hole” (p. 31) by looking at other whistleblowers, their motivations, the stories they told themselves, and the repercussions of their actions. Elliott says that it is his hope that “by looking at these stories

Heather Zeiger, “Review of *The Occasional Human Sacrifice*,” *Dignitas* 33, no. 1-2 (2026): 27-29. © 2025 The Center for Bioethics & Human Dignity

alongside each other, I could see patterns emerge that might help others undergoing similar struggles” (p. 31).

The Occasional Human Sacrifice catalogs some of the most egregious medical research abuses in recent American history, beginning in the 1950s with the Tuskegee Syphilis studies and concluding with Paolo Macchiarini at the Karolinska Institute, who was convicted in 2022 for fraud. While many of these cases are covered in bioethics classes, Elliott’s book differs from the typical textbook treatment because he interviews those who exposed the cases, the whistleblowers, and the journalists who reported on them. These people are often left out of the narrative about the cases.

The book starts with the Tuskegee Syphilis trials, one of the most infamous examples of a government-sponsored experimental trial, that lasted forty years and exploited poor black men who were not treated for syphilis even when treatment was available. Elliott talked to Peter Buxtun, now eighty years old, who worked at the health services department when the trials were going on. Buxtun was the one who gave Edith Lederer at the Associated Press information about the trials. Lederer gave the story to Jean Heller, whose article exposed the government-funded trials. As a result of the article, the Common Rule and the Office for Protection from Research Risks were established, as well as institutional review boards in universities.

The story of the Tuskegee syphilis studies is now a textbook case in bioethics courses. But Elliott’s thesis is not just to tell the story of how these cases were exposed but to analyze why someone went public about it while others did not. Buxtun, for example, had a Jewish Czech father and a Catholic Austrian mother. Buxtun, unlike Elliott and some of the other whistleblowers in the book, was not angry at those who opposed him. He just felt that the research was “Nazi medicine.” Notably, Buxtun did not experience the PTSD and mental torment that many whistleblowers experienced, but he also was not punished for being a whistleblower.

Buxtun’s experience contrasts with Mike Wilkins and Bill Bronston who worked at the Willowbrook State School. The Willowbrook studies involved using institutionalized

children with diminished mental capacity to test the efficacy (and dosage) of gamma globulin for inoculating against hepatitis. The case involves problems with informed consent, intentional exposure of hepatitis by feeding the test group food with some amount of hepatitis-positive fecal matter, and experimentation on vulnerable populations. However, the bigger problem with the Willowbrook school was the conditions in which the children were living.

Wilkins, Bronston, and a few other doctors applied to work at the school because they were suspicious that there were abuses going on. The children at Willowbrook were living in squalid conditions that enabled hepatitis to spread. The justification for intentionally infecting the test group was that everyone at Willowbrook would get hepatitis at some point. It was Wilkins who called Geraldo Rivera, and this led to a documentary exposing the inhumane conditions of the residents. Several years after the experiments and the conditions at the school were exposed, Wilkins and Bronston still lived with the trauma of having worked at the Willowbrook State School. Wilkins developed a crack addiction and needed treatment for PTSD. Bronston fared better but says that he has perpetual melancholy.

While each of the whistleblowers that Elliott interviewed in the book have different stories, motivations, and personalities, all of them had a strong desire to do the right thing, if for no other reason than so they can live with themselves. Many of the whistleblowers Elliott interviewed specifically used the language of honor and shame. Elliott says that part of the injury of being a whistleblower is the loss of moral meaning in the world, so whistleblowers need a narrative to make sense of the injustice that they encountered, and they need to make sense of their actions as a “traitor” to their organizations.

Elliott does not write from a Christian perspective, yet he respects those with religious convictions. This book, I believe, is his way of contending with the problem of evil by analyzing what Hannah Arendt has called the “banality of evil.” Why do some people remain silent and others speak up? The modern-day version of “I was just doing my job” in the bureaucratic organization. Elliott specifically, referencing *Moral Mazes*, a 1988

book on how bureaucracy shields individuals from moral responsibility. In his conclusion he states, “The mystery of human evil is the mystery of human weakness” (p. 287), a sentiment he articulates as he toured the Richard Nixon Presidential Library and Museum.

Overall, *The Occasional Human Sacrifice* is a good book for surveying instances of egregious human research abuses and the personal toll people have paid to bring those cases to light. The book delves into power structures and the cost of holding powerful people accountable, and it addresses the psychology of the whistleblower, which Elliott describes in the introduction:

Whistleblowers in search of a hopeful ending must often find a way of putting a morally positive spin on an act of betrayal whose consequences have been outwardly disastrous. They need to tell a story of heroic sacrifice in service of a just cause, or of a righteous struggle against an unforgiving world, or the higher rewards of remaining true to your principles. Otherwise, their story risks looking like that of Judas as told in the Gospel of Matthew (pp. 27–28).

This seems to be what this book is about, making sense of what he and others have gone through, and continue to go through, as they wrestle with the aftermath of doing something heroic or traitorous, depending on who is writing the story.

I struggled to understand Elliott’s faith in institutions and why he sees Judas in a sympathetic light, namely as a whistleblower. Judas took money for turning Jesus in to the authorities. The whistleblowers in this book did not stand to gain anything for themselves other than possibly a clear conscience, but even that proved elusive. I do not think their stories risk looking like Judas as told in the Gospel of Matthew because Judas betrayed a righteous person and the whistleblowers betrayed an institution comprised of sinful people. Judas instigated sending an innocent man to death, while the whistleblowers in this book were trying to prevent innocent people from harm. If the whistleblower reminds me of any biblical character, it would probably be Joseph more than Judas.

References

1. “Kurt Vonnegut on the Shapes of Stories,” posted October 30, 2010, by David Comberg, YouTube, 4:36, <https://youtu.be/oP3c1h8v2ZQ?si=sUVEK5-XYa7m-r5U>.

Master of Arts *in* Bioethics



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BIOETHICS NEWS STORIES

January–June 2026

Heather Zeiger, MS, MA | Research Analyst

AI IN HEALTHCARE

[“Exclusive: 40 Million People Turn to ChatGPT for Health Care”](#)

by Megan Morrone, *Axios*, January 5, 2026

Americans are turning to AI tools to navigate the notoriously complex and opaque U.S. health care system. . . . Users turn to ChatGPT to decode medical bills, spot overcharges, appeal insurance denials, and when access to doctors is limited, some even use it to self-diagnose or manage their care.

[“Patients Are Using Chatbots to Fight Medical Bills, with Mixed Results”](#)

by Sarah Kwon, *New York Times*, April 8, 2026

Chatbots might seem to offer patients a way to fight back. But critics warn that the tools can dispense flawed advice, especially to users who are less experienced in using A.I., or who do not have much knowledge about the health care system.

One way people are using ChatGPT is to find billing errors, including duplicated charges or violations of Medicare rules. This has helped some patients, although others report that ChatGPT and other chatbots often miss the context and provide inaccurate information. This is a bigger problem for people who also use ChatGPT for diagnoses. One article reported that chatbots often miss when something requires immediate medical attention [[“1 in 3 Americans Use Chatbots for Health Advice. These 6 Patients Explain Why”](#)]. Additionally, uploading personal medical information to chatbots can be a privacy issue.

Nature reported that [“Dozens of AI Disease-Prediction Models Were Trained on Dubious Data,”](#) and *CBS* reported that over 4,000 fabricated citations were found in biomedical journal articles that used AI [[“AI Is Fabricating Citations in Biomedical Studies, Researchers Find”](#)]. Still, AI has helped people when doctors were unavailable or going to a doctor would be prohibitively expensive.

AI CRITICISM

[“The American Rebellian Against AI Is Gaining Steam”](#)

by Amrith Ramkumar, Katherine Blunt, and Lindsay Ellis, *Wall Street Journal*, May 19, 2026

The only thing growing faster than the artificial-intelligence industry may be Americans’ negative feelings about it—as former Google Chief Executive Eric Schmidt saw on Friday. . . . Like some other graduation speakers mentioning AI, Schmidt was met with a chorus of boos.

Americans, especially Gen Z, have soured on AI. In May, several tech industry graduation speakers were met with boos and protests when they mentioned AI. Sam Altman’s home was attacked by a 20-year-old who wrote a manifesto against AI. A congressman’s house was shot at because he voted in favor of data centers. While political violence should be condemned, many people were sympathetic to the grievances. This is, in part, due to the disconnect between Silicon Valley’s positive picture of AI and people’s actual experience with it, as reported in *The New Republic* [[“The AI Industry Is Discovering That the Public Hates It”](#)].

404 Media reported on a study by researchers at the Center for Democracy & Technology in which they outlined 37 “dark patterns” in chatbot conversations [[“New Study Reveals the Manipulative ‘Dark Patterns’ of AI Chatbots”](#)]. These patterns play on users’ psychological vulnerabilities to keep them engaged and to provide more personal information than they intended to. These dark patterns are by design, according to the report.

The Atlantic writer Tyler Austin Harper, who is not necessarily religious, struggled with the fact that best word he can find for the “deep moral failures of AI” is “sin” [[“There Is Already a Word for the Deep Moral Failures of AI”](#)].

And Pope Leo XIV released his first encyclical, *Magnifica humanitas: On Safeguarding the Human Person in the Time of Artificial Intelligence*, in which he critiques several aspects of AI, including the concentration of power by those who control it [[“Pope Leo’s](#)

['Magnifica humanitas': AI Must Serve Humanity Not Concentrate Power'\]](#).

“These Rural Americans Are Trying to Hold Back the Tide of AI”

by Anvee Bhutani and Amrith Ramkumar *Wall Street Journal*, February 2, 2026

Fearing rising utility costs, job losses and privacy violations, locals blocked or delayed about 20 projects around the country representing nearly \$100 billion in combined investment in the second quarter of last year, according to Data Center Watch, a research firm tracking the fights.

In December 2025, Lauren Goode in *Wired* wrote that [“Billion-Dollar Data Centers Are Taking Over the World,”](#) drawing from a quote from OpenAI CEO Sam Altman who said OpenAI’s Roman Empire is the *actual* Roman Empire. Tech companies want massive amounts of land, electricity, and water to house and operate massive data centers for AI computing. However, there has been strong opposition to building data centers by the people in these rural communities. *The Wall Street Journal* has published several articles analyzing the business of building data centers, including how politicians have responded.

REPRODUCTIVE ETHICS

“The Supreme Court Keeps Abortion Pill Mifepristone Available by Telehealth”

by Selena Simmons-Duffin, *NPR*, May 14, 2026

The Supreme Court decided to keep the status quo in place for medication abortion access Thursday [May 14th].

In May, the US Supreme Court extended a stay in a case by the Fifth Circuit Court of Appeals that would have banned mail-order mifepristone via telehealth. Mifepristone is part of a two-drug regimen prescribed to terminate a pregnancy. The Fifth Circuit is in Louisiana, which has strict abortion laws. The Fifth Circuit reinstated an FDA requirement that people seeking mifepristone must visit a healthcare provider in person, rather than receiving drugs over telehealth. The Supreme Court’s dissenting opinion by Justice Alito points out that this should be a matter decided by each state.

“Scientists Edit Human Embryo Genes with Startling Precision”

by Carl Zimmer, *New York Times*, June 4, 2026

Scientists at Columbia University have edited the DNA of early human embryos with unprecedented accuracy, an achievement that could open the way to babies engineered with particular characteristics.

Geneticist Dieter Egli at Columbia University has called for a public discussion after posting a paper of work done by his research team showing that base editing can precisely edit targeted genes in embryos. CRISPR tends to either cause off-target cuts or it fails to find all the targets. By combining CRISPR with other compounds, Egli’s group used a technique called “base editing” that can remove a single DNA base letter and prompt the cell’s machinery to fix it. Egli’s work is funded by Nucleus Genomics, a private company

that screens IVF embryos and has been criticized for promoting screening for features like high IQ.

PHARMACEUTICALS

“Health Officials Slash the Number of Vaccines Recommended for All Kids”

by Pien Huang and Rob Stein, *NPR*, January 5, 2026

In an unprecedented change, the Centers for Disease Control and Prevention is reducing the number of vaccines routinely recommended for all children from 17 to 11.

The Centers for Disease Control and Prevention decreased the number of recommended vaccines for babies. Among the vaccines that are no longer recommended are hepatitis A, hepatitis B, rotavirus, RSV, meningococcal disease, flu, and covid. Vaccines that are still recommended for babies and children are measles, mumps, and rubella, whooping cough, tetanus, diphtheria, Hib, pneumonia, polio, chickenpox, and HPV.

Some parents choose not to follow even the recommended vaccinations, which has resulted in an increase in measles cases throughout the US among those who are not vaccinated [[“Charted: The Big Measles Surge”](#)].

“Pancreatic Cancer mRNA Vaccine Shows Lasting Results in an Early Trial”

by Kaitlin Sullivan, Marina Kopf, and Anne Thompson, *NBC News*, April 18, 2026

Scientists caution that more research is needed, but nearly all of the patients who responded to the personalized vaccine are still alive six years later.

Pancreatic cancer is an insidious cancer that is difficult to detect and to treat. Most people diagnosed with pancreatic cancer will not live for more than five years after diagnosis. A new mRNA therapeutic has changed this for several people involved in a phase 1 clinical trial. The therapeutic was given to patients post cancer de-bulking surgery with the hope that it would prevent recurrence. Like the mRNA covid vaccines, this cancer therapeutic works by recruiting the body’s own immune system to fight off any cells that have the same genetic signature as the pancreatic cancer cells.

As a note on wording, *MIT Technology Review* reported that Moderna and BioNTech, makers of the mRNA covid vaccine, have started calling their mRNA products “cancer immunotherapies” rather than “vaccines” [[“What’s in a Name? Moderna’s ‘Vaccine’ vs. ‘Therapy’ Dilemma”](#)]. The companies’ reasoning is that these products are given to people after they have been diagnosed with cancer and serve as a therapy rather than a vaccine to prevent cancer. Some speculate that the companies have changed their wording to distance their products from the controversies around the covid vaccines.

“Wegovy Obesity Pill Now Available at Pharmacies”

by Sydney Lupkin, *NPR*, January 5, 2026

The Food and Drug Administration approved the pill for obesity on Dec. 22. It's also approved to reduce the risk of heart attack and stroke in patients who are obese or overweight.

Novo Nordisk, maker of Wegovy, the semaglutide GLP-1 weight loss injection, now has a pill version of their weight loss drug. Studies show that participants on the Wegovy pill lost as much weight over a 64-week period as those on the Wegovy injection. Participants reported similar side effects as the injection, too. Several articles reported on interesting side effects of GLP-1 injections, including anhedonia, or losing the ability to enjoy things that were once enjoyable [[“The Mysterious Symptom Popping up in Some GLP-1 Users”](#)]. This may be tied to the way GLP-1 drugs turn down “food noise” for many people. A *New York Times* Article reported on people’s experience with GLP-1s quieting what they describe as incessant thoughts about food [[“The Day the Food Noise Died”](#)]. However, once a person stops taking the drug, the food noise returns, and in almost every case, the person gains back the weight that they lost. An article in *The Guardian* reports on a study from the University of Oxford showing that people who stop taking GLP-1 drugs regain all the weight they lost in under two years, which is

much faster than other types of weight loss programs [[“People Who Stop Taking Weight-Loss Jabs Regain Weight in Under Two Years, Study Reveals”](#)].

OTHER NEWS

“Novartis Settles with Henrietta Lacks’ Estate over Use of Her ‘Stolen’ Cells to Advance Medicine”

by Brian Witte, *Associated Press*, February 26, 2026

Novartis has settled a lawsuit by the estate of Henrietta Lacks that alleged the pharmaceutical giant unjustly profited off her cells, which were taken from her tumor without her knowledge in 1951 and reproduced in labs to enable major medical advancements, including the polio vaccine.

HeLa cells are a mainstay in pharmaceutical testing and biomedical research. These cells, named for Henrietta Lacks, were obtained without Lacks’ consent from a cervical cancer tumor by doctors at Johns Hopkins Hospital, where she was being treated. Those cells were the first human cells that were grown and replicated in a lab indefinitely, a so-called immortal cell line. This recent lawsuit with Novartis is the second lawsuit brought by Henrietta Lacks’ family accusing a pharmaceutical company of profiting from her stolen cells without compensating the family.

GLOBAL HEALTH TIMELINE

January–June 2026

Heather Zeiger, MS, MA | Research Analyst

JANUARY 2026

January 6: “Israel Tells Doctors Without Borders to End Its Work in Gaza” ([New York Times](#))

January 19: “Families of Israeli Soldiers Killed in Gaza Are Retrieving Sperm from Their Bodies” ([NPR](#))

January 26: “Amid Botched Procedures, China Is Cracking Down on Cosmetic Surgery” ([Washington Post via MSN](#))

January 29: “Why These Women Break the Law to Sell Their Eggs for IVF” [India] ([NPR](#))

FEBRUARY 2026

February 3: “Biblical Diseases’ Could Resurge in Africa, Health Officials Fear” ([New York Times](#))

February 10: “Guinea Worm Nears Eradication, May Be Second Human Disease Wiped Out After Smallpox” ([Optimist Daily](#))

February 13: “WHO Slams US-Funded Newborn Vaccine Trial as ‘Unethical’” [Guinea-Bissau, Africa] ([Ars Technica](#))

February 13: “4 Months Trapped in a Hospital for an Obsolete Way of Treating Their Disease [Tuberculosis]” ([New York Times](#))

February 24: “Community Health Project in Kenya and Uganda Dramatically Cuts New HIV Infections” ([Science](#))

MARCH 2026

March 3: “Iran War Heralds Era of AI-Powered Bombing Quicker than ‘Speed of Thought’” ([The Guardian](#))

March 10: “The Most Accurately Predicted Genocide in History” [Sudan] ([The Walrus](#))

March 13: “Somali Conjoined Twins Rahma and Ramla ‘Successfully Separated’ in Riyadh” ([Arab News](#))

March 20: “What the World Happiness Report Reveals About Social Media and the World’s Happiest Country” ([Associated Press](#))

March 23: “How These Secretive Traditional Circumcision Rites Are Responsible for Dozens of Deaths” ([Associated Press](#))

March 26: “Maternal Mortality Rises in US Aid-Dependent Countries Under Republican Presidents, Study Shows” ([The Guardian](#))

APRIL 2026

April 2: “The Gig Workers Who Are Training Humanoid Robots at Home” ([MIT Technology Review](#))

April 13: “Mutually Automated Destruction: The Escalating Global A.I. Arms Race” ([New York Times](#))

April 16: “Ukraine Says Russians Are Surrendering to Robots” ([404 Media](#))

April 20: “The Killer Robots Are Coming. The Battlefield Will Never Look the Same.” ([New York Times](#))

MAY 2026

May 1: “Long a Dream, It’s Now Real: A Fast and Accurate TB Test That Doesn’t Need Phlegm” ([NPR](#))

May 7: “‘Spreading Like Wildfire’: Fiji Grapples with Soaring HIV Cases” ([The Straits Times](#))

May 11: “Hantavirus Is on the Rise in Argentina, Where a Stricken Cruise Ship Began Its Journey” ([AP](#))

May 15: “The World Is on Track to Miss Its Health Targets” ([MIT Tech Review](#))

May 18: “India’s DNA Map Uncovers Millions of Missing Genetic Variants” ([Nature](#))

May 19: “Ebola Raged for Weeks in Congo Before Anyone Raised the Alarm” ([New York Times](#))

May 21: “Efforts to Contain Ebola May Have Been Hindered by Lack of U.S. Involvement” [Democratic Republic of Congo] ([New York Times](#))

May 21: “How Wet Weather in Argentina Helped Fuel the Cruise Ship Hantavirus Outbreak” ([Wired](#))

May 26: “Residents Burn an Ebola Treatment Center in Congo as Anger Grows Over the Outbreak” ([AP](#))

May 28: “U.S. Races to Set Up Quarantine Facility in Kenya for Americans Exposed to Ebola” ([Wall Street Journal](#))

May 29: “Contagion of Conspiracy Theories Makes Ebola Epidemic Harder to Contain” [Democratic Republic of Congo] ([Washington Post via MSN](#))

JUNE 2026

June 5: “Moderna Gets \$50 Million to Develop mRNA Ebola Vaccine Against Bundibugyo” ([Ars Technica](#))

June 11: “This Could Be the Worst Ebola Outbreak in History” ([New York Times](#))

June 15: “Ukraine’s Defense AI Chief Predicts ‘New Paradigm’ of Warfare” ([Reuters](#))

June 18: “Scientists Confronting the Rising Global Threat of Mosquitoes” ([Phys.org](#))

June 25: “France Identifies Its First Case of Ebola” ([New York Times](#))

BIOENGAGEMENT

Readers are cautioned that these resources are highlighted because they raise bioethical issues. Given the complexities of the issues, the resources represent a wide spectrum of perspectives, genres, and content, and they may contain material that is not appropriate for all audiences, including material that may bring up difficult experiences for some. Thus, both the content and the perspectives represented therein are not necessarily endorsed by CBHD. Readers are encouraged to further research each resource before engaging.

If you have a suggestion for us to include, send us a note at research@cbhd.org.

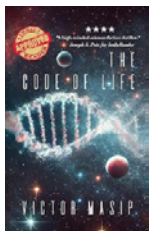
BIOFICTION



Baby X

(Kira Peikoff, 2024)

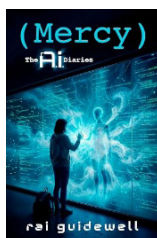
Genetic Engineering, *In Vitro* Fertilization, Commodification of Human DNA



The Code of Life

(Victor Masip, 2025)

Genetic Engineering, Biotechnology, What It Means to Be Human



Mercy: The A.I. Diaries

(Rai Guidewell, 2026)

Artificial Intelligence, What It Means to Be Human, Virtue Ethics

PRIMETIME BIOETHICS



Silo, Season 3

(Apple TV, 2026)

Artificial Intelligence, Utilitarian Ethics, Informed Consent



The Burroughs

(Netflix, 2026)

What It Means to Be Human, Mortality, Grief



Waiting for the Out

(BBC One, 2026)

Human Dignity, Moral Responsibility, Men's Health

BIOETHICS AT THE BOX OFFICE



Joy

(Netflix, 2024)

In Vitro Fertilization, Research Ethics, Infertility



Mercy

(Amazon, 2026)

Artificial Intelligence, Ethics of Automation, Algorithmic Justice



The AI Doc: Or How I Became an Apocaloptimist

(Focus Features, 2026)

Artificial Intelligence, What It Means to Be Human, Human Transformation

UPDATES & ACTIVITIES

CBHD Events:

Annual Conference

- Operations and Events Manager Bryan Just successfully planned and executed another educationally rich conference in alignment with LeTourneau's identity as "*The Christian Polytechnic University*." *Polytechnic Bioethics* highlighted plenary speakers who focused on the *practical* side of bioethics. Included in this was the annual virtue ethics lecture given by Dr. Gilbert Meilander, along with addresses from Jesse Michael Kay, Dr. Tara Sander Lee, Dr. Jonathan Lett, Dr. John Seago, and Dr. Patrick Briscoe.

Other Events

- In February, CBHD's Academy of Fellows met for its final time in Deerfield, IL. As an open-themed year, Fellows presented current research projects and engaged

in invigorating interdisciplinary dialogue. LeTourneau University's Dr. Kelly Liebengood and Dr. Jonathan Lett joined the meeting this year, with Dr. Lett also presenting current research. It was a representation of the fruitful partnership blooming between LeTourneau University and CBHD.

- Our Bioethics Reading Group has been terrific! We've completed reading and discussing David VanDrunen's *Bioethics and the Christian Life*, and we are now in the midst of Ewan Goligher's *How Should We Then Die?* Meetings take place every other week over the course of two months, and they are recorded for reading group members who can't join us live. The discussions have truly been rich. In October and November, we will be reading Paul Ramsey's *Fabricated Man*—registration for that opens in September, so keep an eye out for the announcement. We'd love to have you join us.

Staff Bioethical Engagement:

Matthew Eppinette

- Moved personally to Longview, Texas.
- Moved and established CBHD offices from Trinity Evangelical Divinity School to LeTourneau University.
- Spoke at LeTourneau University's monthly Athletic Department staff meeting.
- Planned, prepared, and launched, with Jon Holmlund, CBHD's Bioethics Reading Group.
- Hosted CBHD's annual Academy of Fellows meeting.
- Attended the 2026 *Bioethics Conference*, Dallas Theological Seminary's Hendrick's Center, Southwestern Christian Fellowship (University of Texas Southwestern Medical Center).
- Spoke at LeTourneau University's School of Business faculty meeting.
- Attended the Society for Christian Bioethicists annual conference, *The End of Life, the Gift of Life: Reflections on Death and Organ Donation*.
- Attended Discovery Institute's *Dallas Conference on Science & Faith*.
- Attended the 2026 Conference on Medicine and Religion, *The Prophetic Voice: Creativity, Compassion, and the Pursuit of Healing*.
- Gave two introductions to bioethics talks at LeTourneau University's Spring Homecoming.
- Attended the Christian Medical and Dental Associations annual Convention.
- Attended the Colson Center National Conference, *You Are Here*.
- Taught "The Ethics of Life and Death" for The Passage Institute, a week-long theology camp for high school students at LeTourneau University.
- Hosted CBHD's Annual Conference, *Polytechnic Bioethics*.

UPDATES & ACTIVITIES

Bryan Just

- Organized CBHD's annual Academy of Fellows consultation in Deerfield, IL.
- Moved to Longview, Texas along with the rest of the Center staff.
- Published "Artificial Medicine? The AI "Doctor" Is (Not) In," *Salvo* 75 (Winter 2025): <https://salvomag.com/article/salvo75/dr-who>.
- Published "Closer to Perfect? Advanced IVF & Embryo Screening," *Salvo* 76 (Spring 2026): <https://salvomag.com/article/salvo76/closer-to-perfect>.
- Attended meetings of the Paul Ramsey Fellowship with the Center for Bioethics & Culture.
- Organized CBHD's 2026 summer conference, *Polytechnic Bioethics*.

Anna Vollema

- Moved to Texas to continue working with LeTourneau University.
- Planned and launched "Shared Convictions: CBHD and LeTourneau on Mission" for our *Intersections* forum to highlight the new school partnership.
- Coordinated speakers and themes for the annual Academy of Fellows meeting.

- Completed a research project on digital technologies and spiritual flourishing.
- Began a grant project with Biola University through the National Institutes of Health on theological engagement with genomic medicine.

Heather Zeiger

- Led a workshop in February on end of life at the *Bioethics Conference* at Dallas Theological Seminary's Hendrick's Center, hosted by Southwestern Christian Fellowship (UT Southwestern) and the Christian Medical and Dental Association.
- Spoke on human dignity at the Discovery Institute's 8th annual *Dallas Conference on Science & Faith*.
- Helped at CBHD's annual conference, *Polytechnic Bioethics*.
- Finished out her first year teaching full time as a high school physics teacher at a classical Christian school in Dallas.
- Finalized the editorial work for a forthcoming book entitled *Medical Excess and the Frail Elderly: Ethics and Overtreatment in Aging Populations* (Cambridge University Press, March 2027)

Social Connection with CBHD



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The Center for Bioethics and Human Dignity (CBHD) is a Christian academic research center at LeTourneau University that conducts, disseminates, and advances biblically informed, theologically rich research, analysis, and reflection on the complex and pressing ethical issues in medicine, science, and technology.

Dignitas is the quarterly publication of the Center and is a vehicle for the scholarly discussion of bioethical issues from a Judeo-Christian Hippocratic worldview, updates in the fields of bioethics, medicine, and technology, and information regarding the Center's ongoing activities. 

