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A Commentary of The National Catholic Bioethics Center on Health Care and the Life Sciences

Also in this issue: "Ordinary and Extraordinary, Part 2," by Rev. W. Jerome Bracken, CP

## Pumping the Brakes on the Latest Biomedical Research

Charles C. Camosy



nyone who followed professional football in the 1980s—or professional wrestling in the 1990s—likely knows the name Steve "Mongo" McMichael. A true giant of those eras, both physically and socially, McMichael has recently been made much smaller, physically smaller, by a terrible foe: ALS, or Lou Gehrig's disease. He is also declining quickly from a neurological standpoint. In a recent interview, he said, "This ain't ever how I envisioned it was going to end."

Mongo is by no means alone. Here are sobering numbers on current neurological diseases from the Harvard NeuroDiscovery Center:

- Approximately five million Americans have Alzheimer's disease,
- More than one million have Parkinson's disease,
- More than four hundred thousand have multiple sclerosis (MS), and
- Approximately thirty thousand have amyotrophic lateral sclerosis (ALS).<sup>2</sup>

The numbers are even more frightening when we consider the future, especially as those who make it to older ages tend to live longer and longer. Worldwide, the number of people living with dementia is set to double every twenty years. This disease affects a broad range of people but disproportionately affects vulnerable populations, especially blacks.<sup>3</sup>

Attempts to find cures for these diseases have faced setbacks in recent years; thus, one can certainly understand the desperation to address this situation. My forthcoming book, *Losing Our Dignity: How Secularized Medicine Is Undermining Fundamental Human Equality*, is sounding the alarm on what it will take to address these trends. Simply put, we already do not have the caregivers necessary to take care of the populations as they exist now. It is not clear, therefore, what we will do twenty years from now.

Personally, I fear that we will slouch toward robot "care" and physician-assisted dying. If that sounds like a frightening concept, that's because it is. And in some ways, the process is already underway as we overmedicate millions of people with dementia in nursing homes to keep them "docile." <sup>4</sup>

This is present in the new trajectory of research proposals meant to create better models of human neurological disease—especially ones involving neural organoids and neural chimeras. Last year, happily, the National Institutes of Health (NIH) asked a special committee of the National Academies to study the ethical implications of such research. And even more happily, they asked for the input of religious thinkers as background for their report.<sup>5</sup>

Though the report does not call for limiting such research in ways one might hope, it does raise important concerns, and it calls for more conversation and study of these trends. Religious thinkers and leaders must make their voices heard on this important issue.

This research trajectory too aggressively moves in the direction of what are admittedly very important goals and leaves essential ethical considerations largely to the side. In some ways, medical ethics as we have come to know it today (after Nuremberg, Tuskegee, and so on) was born by attempting to foreground questions of value and justice which resist straight-up consequentialist reasoning. This approach to medicine calls us to pause and hold the line once more.

The ethical issues involved here are not so much about neural organoids. Even if we were to create full brains, this does not present a risk of their becoming conscious. Human consciousness (much to the chagrin of those who would like to reduce all of human reality to the neurological) cannot be found or located in the brain. Indeed, the best theories of human consciousness today think of it as the product of the human organism itself, holistically considered, interacting with its environment.

No. The primary ethical issues here are related to the chimeric research. Embryonic chimeras are created with human neural information such that a nonhuman animal would grow human neural components—maybe even a human frontal cortex.

The older ideas and frameworks surrounding animal ethics in medical research can generally be described, as the report indicates, as "The Three R's" (replace, reduce, refine) and a general consequentialist impulse to make sure the good of the research outweighs the harm done to nonhuman animals. But these ideas and frameworks are ethically impoverished and do not reflect the best research and arguments in animal ethics today. Virtually none of the leading voices in animal ethics today thinks of nonhuman animals as mere tools or things to use. They have their own inherent value quite apart from whatever good might come from our use of them, and therefore they ought to be treated as the kinds of creatures they are.

Significantly, this has deep resonances with a Christian theology of creation (with strongly related views in Judaism and Islam). Animals, especially—which share with us the breath of life and were

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made on the same day of God's creation—were not made as mere things for use by human beings. On the contrary, God pronounces them good in themselves before human beings are even created and brings them to Adam because it is not good that he should be alone. The dominion God gives to human beings is that of a caretaker or steward. We are akin to viceroys ruling on behalf of the king and must be obedient to his wishes and designs until he returns.

The National Academies' report itself notes that nonhuman animals may have the kind of value which explicitly forces us to respect their dignity apart from a consequentialist calculation about what benefit they may be able to bring us. This is especially true when we consider nonhuman animals who have a clear sense of themselves, develop plans, and have sophisticated emotional lives and relationships. The report, though it does not appear to take this seriously in its findings, admirably notes that contemporary thinkers in animal ethics now want to expand The Three R's model into a more comprehensive ethical framework, one that implicitly accepts and provides for what is necessary for an animal to be the kind of thing that it is: from housing to companionship to stimulation to exercise.

Again, religious thinkers should be aggressively participating in the discussions to follow—especially on whether we need to move beyond a consequentialist analysis weighing goods against harms and first ask whether it is morally acceptable to create these kinds of beings *at all*.

Significantly, this takes us back to the ethical question of the creation of a chimeric embryo in the first place. The Church, via the Pontifical Council for Pastoral Assistance to Health Care Workers, has given us the following guidance on xenotransplantation, which offers us important insights: "Not all organs can be donated. From the ethical perspective, the brain and the gonads are ruled out as potential transplants, inasmuch as they are connected respectively with the *personal and procreative identity of the person*. These are organs specifically connected with the uniqueness of the person, which medicine must safeguard." Significantly, the NIH currently prohibits funding of chimeric research as well. While legal, the most important supporter of research in the United States comes to a similar conclusion about whether we should be doing research on neurological diseases via neural chimeras.

The older ideas and frameworks currently used when evaluating medical research on animals are mostly dealing with different kinds of questions. Their default conclusion is that the research should be done, and they are primarily concerned with how to nibble around the ethical edges. But the newer ideas and frameworks in animal ethics are in a much better position to respond to this new research trajectory.

What is behind the ethical claim that nonhuman animals have a right to species-appropriate housing, companionship, stimulation, and exercise? It is that we have a strong ethical duty to respect the kinds of creatures nonhuman animals are and to help them flourish as those kinds of creatures. We must pay close ethical attention to their nature or their kind and, in a related story, to their end or *telos* which flows from their being of a particular nature or kind.

This must not be merely a question about welfare and balancing helps and harms, pleasure and pain. Crucially, this is about our duties to certain animals based on the kinds of creatures they are. Roman Catholics obviously have a story to tell about why this is the case—but again, the cutting-edge of secular research on animal ethics is right here with us as well.

Even if one tries to justify such research on animals like mice and rats—a problematic notion given what I have just argued—human neurological diseases almost certainly are related to a largely unknown and incredibly complex confluence of factors present in the body of a human organism. It is therefore highly likely that study of organoids and so-called lower-level chimeras will not give researchers adequate models, and this will produce a push to use more sophisticated animals. If an ethical barrier is not clearly put in place, then the urgency of the moment will likely crush any half-hearted and lukewarm Three-R's resistance as it hurtles toward the use of dogs, pigs, and primates.

Again, we must be clear-eyed about just how high the stakes are when it comes to the goals of human health and flourishing addressed by this research. Our success in finding a cure for these diseases will dramatically affect the lives of dozens of millions of human beings—and their families and friends. But it is precisely when the stakes are highest that we need to be most careful about not discarding important ethical boundaries. Thinking historically, again, we can see that this is when the greatest atrocities have taken place—especially for those with no voice or power in the conversations about their fate. The latest research in both religious and secular animal ethics is telling us to pump the brakes on this new trajectory.

Far too often, especially in recent decades, biotechnology gets so far out ahead of any cultural discussion of the ethical implications of what is being done that it is already too late. Not so with this research. Happily, the NIH and National Academies seem to understand the need to slow down and be clear that we will benefit from additional discussion of ethical and social issues. Religious thinkers and leaders—and especially Roman Catholics—should take full advantage of this invitation and make our voices heard.

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#### Notes

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# Ordinary and Extraordinary: Theology and History, Part 2

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year before Daniel Cronin's dissertation was published,<sup>1</sup>
Pope Pius XII gave the key magisterial teaching regarding ordinary means and extraordinary means in a speech delivered on November 24, 1957:

Man (and whoever is entrusted with taking care of his fellow man) has the right and the duty in cases of serious illness to take the necessary treatment for the preservation of life and health. This duty ... usually only requires the use of ordinary means (according to the circumstances of persons, places, times, culture), that is to say means which impose no extraordinary burden for oneself or for another. A more severe obligation would be too burdensome for most men, and would make it too difficult to acquire greater superior goods. Life, health, all temporal activity are in fact subordinated to spiritual ends. Moreover, it is not forbidden to do more than what is necessary to preserve life and health, on the condition one does not fall short of a more serious duty.<sup>2</sup>

This statement came seven months after Pius XII answered three questions about the use of analgesics, which laid the groundwork for the above teaching on ordinary means.<sup>3</sup>

In that preceding document, Pius XII carefully worked out what was required morally in terms of both reason and faith. Morally speaking, the use of anesthesia and narcotics which make one more or less unconscious is not evil in itself and can fulfil good purposes. They can calm the patient psychologically and facilitate a needed surgery. To deprive one of consciousness is morally wrong only when it transgresses a moral obligation. Suffering can play a positive role. In terms of one's nature, voluntary suffering can help one resist sin and grow in virtue. In terms of faith and the light of revelation in Genesis, while human sin brings on the punishment of suffering, human dominion enables one to avoid suffering. In the light of the Gospel, in which Christ refused a drug to dull his consciousness so that he might fully give his life over to the Father, one can imitate Christ and take on a likeness to his death and Resurrection by accepting such suffering. Nonetheless, a good reason for avoiding pain is that it can prevent one from using "means of progress in the interior life, of more perfect purification, of more faithful accomplishment of the duty, of greater promptness to follow the divine impulses."4

In his subsequent address on resuscitation and artificial respiration, Pius XII takes a similar approach of "natural reason and Christian morals." Concerning the removal of "the respiratory apparatus" when the person is in a "state of deep unconsciousness" and the reception of "the last sacraments" is at stake, Pius XII writes, "If one has not yet administered Extreme Unction, one must attempt to prolong the respiration so that this can be done." <sup>5</sup>

Then, in setting forth the principle about the use of ordinary and extraordinary means, Pius XII refers to two kinds of ends: those that concern life and health and those that are spiritual. So, while "life, health and all temporal activity" are one's immediate concerns, they are in fact to be "subordinated to spiritual ends." For this reason, Pius XII gives priority to the last sacraments. They enable one to accomplish not only spiritual ends but also supernatural ones. For instance, the Anointing of the Sick strengthens one spiritually in the face of illness or old age for one's supernatural destiny.

Having stated the two sources of his moral teaching, natural reason and Christian faith, Pius XII uses the terms *right* and *duty*. These are co-relative terms regarding justice. *Right* refers to what is due a person as a human being and what is needed to maintain that life. *Duty* refers to what one must do for that life and what is needed for it, a duty of justice to one's self as well as to another.

Then Pius XII states the essential content of this right and duty in regard to a grave illness. One must take the necessary care in order to conserve life and health. This applies to both the patient and caregivers. He emphasizes what is essential and not accidental to the act, namely, the means (taking the necessary care) and the end (the conservation of life and health). What makes an act substantially good is that the means and the end are both good for human nature. That is, before one examines any of the circumstances of the act that could increase the act's goodness or deny it, one must determine whether the act is essentially good. This would mean at the very least that the treatment must accomplish some good for the ill person.

For example, in the tenth edition of the Declaration of Helsinki, the World Medical Association stated that "in the treatment of an individual patient ... the physician, after seeking expert advice, with informed consent from the patient or a legally authorized representative, may use an unproven intervention if in the physician's judgement it offers hope of saving life, re-reestablishing health or alleviating suffering." Whatever the particular circumstances, the treatment and its purpose must be considered first.

The duty of providing necessary treatment for the preservation of life and health relates to the ends for which one acts—one's self, God, the human community, and particular persons. Moreover, Pius XII derives this duty from within ourselves, not only from our nature, but from God's gift of charity, our natural inclination to submit to our Creator, the virtues of strict justice and social justice, as "well as from devotion towards one's own family." In strict justice, the doctor must serve the patient, and the patient must cooperate with the doctor. In social justice, one acts not just for one's own good but for the good of the community. In what St. Thomas Aquinas names "distributive justice," one is inclined to see that the health care needs of the members in community are met fairly.

The more we use these aids, the better will be our judgments and our choices of the treatments for our life and health in times of serious illness.

The one kind of aid not mentioned in Pius XII's statement of principle follows later:

As for administering the sacraments to a man immersed in unconsciousness, the answer stems from the doctrine and practice of the Church, which, for its part, follows as a rule of action the will of the Lord. The sacraments are destined, by virtue of the divine institution, to the men of this world for the duration of their earthly life. . . . The sacraments are instituted by Christ for men, in order to save their souls; also, in case of

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extreme necessity, the Church tries the extreme solutions to communicate to a man the grace and the sacramental help.<sup>10</sup>

Having set forth the context in which to judge what are ordinary and what are extraordinary means, Pius XII considers the treatment itself. First, he says that the necessary treatment for one's life and health "usually only requires the use of ordinary means." On the positive side, the treatments that are ordinary are those that accord with the persons, time, place, and culture that are involved. On the negative side, those treatments that are not ordinary are those that impose an extraordinary burden. For instance, surgeries for the life and health of the person in the early nineteenth century were usually done only as a last resort. Without effective analgesics, the surgery would have involved extraordinary pain, and without antiseptics the result would have often led to infection, even death.

In so far as the treatment involves persons, they are the ones by and for whom the decision about ordinary treatment is made. The treatment would be judged ordinary on the condition that it does not impose an extraordinary burden.

Pius XII's reference to culture is another circumstance that can make a treatment an extraordinary burden and thus not ordinary and obligatory. In the United States, many times siblings, upon growing up, take jobs or make marriages far from where a parent is living. Should one sibling still be living near, home care of a seriously ill parent could become an extraordinary burden for that sibling. In this case, the moral duty of caring for one's parents does not end, but naturally extends to the other members of the family. For this sibling's own sake as well as for the sake of the ill parent, the sibling must elicit the aid of the other members of the family so that no one is excessively burdened. If this is not possible, aid should be sought from the community.

In all these instances, nonetheless, Pius XII writes that "it is not forbidden to do more than what is necessary to preserve life and health, on the condition that this does not fall short of a more serious duty." Thus, caring for the seriously ill should be for one's life on earth and with God now and in eternity. The means of treatment

must be able to achieve these good purposes and be suitable to the conditions of the ill person and caregivers.

To determine what is an ordinary and required means, one needs to answer, as best one can, three questions. If one answers yes to all three, it is ordinary and required, otherwise it is not. The three questions are: Is this the ordinary, usual, or valid way of treating this condition? Is it working—that is, is it achieving this purpose? Is the ill person able to undergo this treatment, and are the caregivers able to give it?

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#### Notes

- 1. See Daniel A. Cronin, *Ordinary and Extraordinary Means of Conserving Life* (Philadelphia: National Catholic Bioethics Center, 2011).
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- 4. Pius XII, Discours concernant l'analgésie.
- 5. Pius XII, Discours sur réanimation.
- 6. Thomas Aquinas, *Summa theologiae (ST)* I-II.13.4 corpus, trans. Fathers of the English Dominian Province (1920; 2017, New Advent). "Just as intention regards the end, so does choice regard the means."
- 7. Aquinas, ST I-II.18.2 corpus.; see also I-II.18.6 corpus.
- 8. World Medical Association General Assembly, Declaration of Helsinki (October 2013), n. 37, https://www.wma.net/policies-post/wma-declaration-of-helsinki-ethical-principles-for-medical-research-involving -human-subjects/.
- 9. Pius XII, Discours sur réanimation.
- 10. Pius XII, Discours sur réanimation.
- 11. For salvation a person needs only to be alive to receive the sacrament; consciousness is not required.

