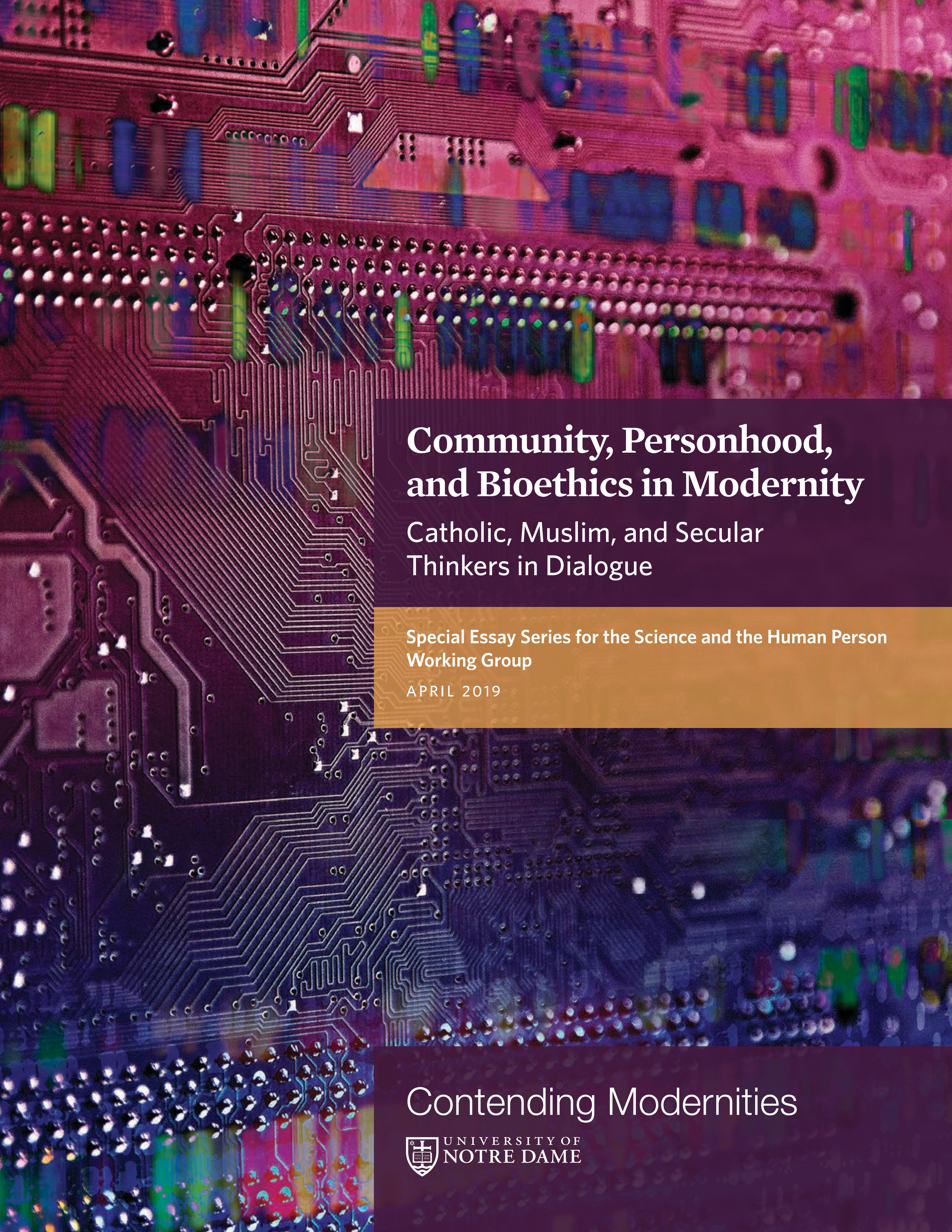

Community, Personhood, and Bioethics in Modernity

Catholic, Muslim, and Secular Thinkers in Dialogue

Special Essay Series for the Science and the Human Person Working Group

APRIL 2019

Contending Modernities

UNIVERSITY OF
NOTRE DAME

CONTENDING MODERNITIES

Exploring how religious and secular forces interact in the modern world.

This essay series was made possible by support from the Henry Luce Foundation.

CONTENDING MODERNITIES is a multi-year, cross-cultural, interdisciplinary initiative, based at the University of Notre Dame and including universities, colleges, institutes, and centers around the world. The initiative seeks to generate knowledge and understanding of the ways in which religious and secular forces interact in the modern world.

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Introduction

Maybe you have the BRCA mutation. Or you're a recessive carrier of the Tay Sachs gene. Or you live in an area affected by a deadly and pervasive parasite, like malaria.

Genetic medical technologies could soon edit your children's genes and, in the meantime, they can select embryos without chromosomal abnormalities. Thanks to gene drives, we already have the capacity to wipe out the malaria-carrying mosquito entirely.

Should we?

Will we still be the same kind of human if we do?

The question of what we consider medically necessary or worthy of bodily and environmental modification is a challenging one. It is bound up in our understandings of human personhood, life, death, the possibility of flourishing, and the limits of human identity in relation to the natural world. Our ability to modify the human and non-human is driven by the engine of research and development. Bioethical and regulatory considerations have often lagged behind, articulated more narrowly through concerns of safety and beneficence than through broader interrogations of the cultural and economic assumptions underpinning the emergence of new capabilities. In the meantime, innovations like organ transplants or pre-implantation genetic screening during in vitro fertilization (IVF) occupy a charged space, often wildly expensive, medically normalized, emotionally-laden, and socially contested. Other innovations—like our growing ability to measure "brain death"—have become publicly accepted practices around the world, sometimes after campaigns by policy actors, but have continued to trouble some in the medical and faith communities.

The Science and the Human Person working group of the Contending Modernities research initiative has brought together Catholic, Muslim, and secular scholars to engage these specific modern challenges through the diverse internal resources of each tradition. Through a working group, two podcasts, and this essay series, the project seeks to improve public awareness of the ways in which these modern capabilities enhance and challenge our ethical systems, inviting pluralistic conversations on the governance of science and technology.

In the eight individual essays that follow, we present multiple religious and secular perspectives on the normative questions raised by rapid advances in scientific and technological capabilities. This forum of bioethicists, doctors, scientists, and theologians reflects the internal diversity of the traditions represented, as well as the contestations within embodied faith and ethical systems, as adherents navigate emerging technologies and changing social sensibilities. They respond to the concerns and hopes aired in our two podcasts featuring a panel of ethicists, theologians, and journalists: "Out of the Lab," on the regulation of genetic modification, and "The Ethics Debate," on organ donation in Sunni and Shia Islam after neurological criteria for death have been met. You can find these, and more materials produced by the working group, at http://contendingmodernities.nd.edu/about/research-areas/science-and-the-human-person.

Throughout the essay series, authors consider the broader context of biomedical innovations. What does it mean to be "normal?" Should we edit out difference if it might cause pain? Where is the line between elective and essential modification? Aasim Padela (University of Chicago) shares the case of uterine transplants, and how intense social pressure and desire for motherhood can shape medical perspectives of what innovations are necessary for a woman's wellbeing. "[E]thicists need to fully consider the social forces that turn atypical anatomy or physiology into malady, and difference into disorder." His contention—that "all diseases are socio-culturally constructed," has profound implications. Certainly, it is only through normative perceptions of what it means to be human that variations in the expression of the human become medicalized. Far from rejecting any and all interventions, Padela rather invites us to take a step back and bring into focus the social construction of personhood that would lead us to consider an intervention necessary. Over the years social understandings of normative personhood shift: 20th century North American classifications of the LGBTQ community as "disordered" and in need of medical and psychological interventions are a glaring example which persisted until the American and Canadian Psychiatric Associations changed the designation in 1973 and 1982, respectively. Meanwhile, the expectation for women to become mothers to achieve full female personhood drives the demand for assisted reproductive technologies while traditions of shared parenthood, which permit infertile individuals alternative opportunities to raise children, decline. Often, rather than shifting social or cultural practices to broaden normative personhood and better include those deemed abnormal, medical technologies are instead developed to individually address deviations.

Responses to diseases such as malaria, which kills hundreds of thousands of children every year, and to fatal chromosomal disorders are a priority for parents and health practitioners. Families will move heaven and earth to ensure the flourishing of an infant, lobbying for and trying ever new technologies—Charlie Gard's tragic case a recent high profile example.[1] Yet, as Maura Ryan (University of Notre Dame) poignantly notes in the "Out of the Lab" podcast, "we can't edit out all forms of suffering." And when we can edit out some suffering, are we also editing out other ways of being? Authors Aline Kalbian (Florida State University), Dan Daly (Saint Anselm College), and Natalie Kofler (Yale University) each caution that some approaches to ending suffering can fundamentally alter our relationship with family, community, and the natural world. When we are moved to alleviate the suffering of a loved one, or pre-empt the suffering of a future child, bioethical considerations of relationship rise to the fore. Writing from a Catholic perspective, Kalbian notes, "What many find so disturbing about recent developments in genomic editing is that they threaten to undermine our bonds to future generations by altering future genomic maps." Daly too raises concerns about the impacts of genetic editing on familial relationships, contending that when medical technology enables parents to become "creators," children may no longer be viewed as gifts. Kofler, referring to our growing capacity to drive the malaria vector mosquito extinct in a matter of years, asks: In a time "when nearly 200 species are predicted to go extinct every day, is it morally acceptable to intentionally drive a species to extinction?"

These technologies raise questions of agency, identity, and privilege as well. Celia Deane-Drummond (University of Notre Dame) shares the example of a young person with albinism who adamantly rejects the thought of being any other way—her condition has irrevocably shaped who she is. But the ethical challenges posed by this example may prove little more than hypothetical to a family whose child has a preventable or curable disorder but that is unable to access the types of technologies that make such calculations possible. Certainly, the development and application of some—most—of these impressive medical technologies belies a further, financial, logic.

In her essay, Therese Lysaught (Loyola University Chicago) considers the economic and cultural backdrop of the growing numbers of medical technologies affecting human health and personhood. Neoliberalism, bent on a reduction of regulation, a view of the human as self-contained, and a pay-to-play model of access, is integral to both the development and deployment of these technologies. The economic motive defines not only which technologies are pursued but also the prevailing focus on individual responses to common problems. This recalls a previous CM blog essay in which Science and the Human Person working group researcher Sherine Hamdy (University of California, Irvine) sharply questions the silence of Islamic bioethicists on an Egyptian public health campaign that infected a shocking 10-30% of the population with Hepatitis-C in the 1970's while these same scholars focus on questions of whether the liver transplants needed as a result are religiously admissible.[2] In the United States, high rates of childhood cancer surrounding toxic industrial sites may be overlooked by political authorities, while families bear the cost of increasingly sophisticated cancer treatments—often made possible by federal and state government-supported research—alone. Lysaught continues, "Religious traditions—with their vision of thickly connected persons who develop and flourish integrally in communities—could well provide the lever to begin to shape a bioethics that privileges persons over profits."

Broad-based public discourse on innovations that affect human personhood is an important step for societies to consider whether new tools are being deployed morally. Elham Mireshghi (University of Chicago) shares the case of living kidney transplantations in Iran, revealing the deep discontent and discomfort donors and recipients experience in spite of the procedure's local religious legality. This distress, according to Mireshghi, "reflect[s] the normalization of a process in the absence of a consensus on its moral legitimacy." By contrast, organ donation after the confirmation of a patient's "brain-death" has become widely accepted after an intensive Iranian public relations campaign promoted by multiple sectors of society. In Padela's words, successful examples of ethical guidance in innovation and regulation require a "trialogue" with religious, medical, and social science actors.

Naturally, these conversations will not be easy. As Mohammed Ghaly (Hamad Bin Khalifa University) explains, medical science is value-laden, and interaction between (in this example) Muslim jurists and scientists will necessarily face challenges of translation between differing sets of assumptions, values, and norms.

From changing perceptions around "brain death" to the possibility of gene drives that permanently change entire populations, modern technoscientific innovations have already affected our personhood. Genetically modified children are no longer just a hypothetical; the challenge before ethicists, as Kalbian writes, is rather to develop moral frameworks that are able to navigate this new landscape. To do so, Deane-Drummond, Kalbian, Kofler, and Lysaught offer prescriptions to guide us in responding to these new capabilities.

Much like harnessing wind for power, Kofler urges us to remember that technologies do not fall outside of nature and ecological relationships just because they are created by humans—we are an integral part of the non-human web. It is only by fully being part of and valuing this web that we may have the wisdom to apply technologies to non-human beings. Kalbian extends this idea through the Catholic principles of human relationality and the tension between human dependence and responsibility. She notes, moreover, and Lysaught echoes in her own essay, that responsibility to persons requires us to pay particular attention to those at the margins, who may have the most need and least access. Lastly, drawing on Thomistic resources for bringing practical wisdom to bear on questions of the common good, Deane-Drummond offers a multi-level ethical framework for assessing how these technological advances stand to impact individuals, families, communities, and society as a whole.

Conclusion

These eight essays invite us to consider how modern technologies have revolutionized not only how we can further human flourishing, but more deeply, how we define flourishing in the first place. Embedded within sociocultural forces such as neoliberalism and the stigmatization of certain ways of being, medical technologies and their adoption reflect dominant forms of who we are as a human and ecological community. In the sweep of essays ranging from technical, case specific, intimate, we hope readers will find moment for pause regarding the norms that guide technological applications currently and the ethical frameworks we should strive towards.

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1 Natasha Hammond-Browning, "When Doctors and Parents Don't Agree: The Story of Charlie Gard," *Journal of Bioethical Inquiry* 14 no. 4, (2017): 461–468. doi:10.1007/s11673-017-9814-9.

2 Sherine Hamdy, "Reframing Islamic Bioethics," Contending Modernities, September 18, 2013, http://contendingmodernities.nd.edu/field-notes/reframing-islamic-bioethics/.

Producing Motherhood? Uterus Transplantation for Infertility

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One of the main findings of the Science and the Human Person working group (the larger project to which these essays contribute) is that the discursive traditions of Islam and Catholicism offer valuable insights, but not a full account, of the human person. One of the project's podcasts (in which I was honored to participate) described debates among Islamic jurists on the permissibility of organ donation.[1] Herein I will weave together these threads, albeit partially, by outlining fundamental questions raised by the science and practice of uterine transplantation. I will further suggest that to better conceptualize, and eventually furnish, ethical guidelines that attend to the bioethics of uterine transplantation a multidisciplinary model is required, one where secular and religious bioethicists partner with social and medical scientists.

Procedurally, uterine transplantation involves removing the uterus from a living individual, or from an individual who fulfills the neurological criteria for death, and grafting this organ into a willing female recipient. Uterus transplantation, like limb and face transplantation, is part of the growing area of research into vascular composite allografts where multiple tissues types are transplanted as one functional unit. Uterus transplantation is unique in that it is a temporary measure; once the transplanted uterus fulfills its function in the donor it is removed and discarded. As with all organ transplants, the viability of the organ depends on a myriad of factors including the condition of the uterus when it is removed from the donor, the medical status of the recipient, the immunological compatibility between the donor and the recipient, the surgical technique utilized, and the efficacy of the immunosuppressive drugs the recipient takes to forestall organ rejection. In order for the donor's sacrifice, the surgeon's labor, and the recipient's daily ministrations to be ethically justified, the ends of the procedure must be righteous and likely to be attained, while the risks and side effects relatively minimal. Accordingly, over the past decade, uterine transplantation has become an increasingly viable procedure with acceptable risk-to-benefit ratios, and the success of carrying to term and delivering an infant via a transplanted uterus increasingly probable.[2] This biomedical advancement births bioethics questions both old and new.

For one, uterine transplantation forces clinicians and ethicists to (re-)examine the ambiguous line between therapy and enhancement; is this purported therapy restoring bodily function, adding a new physiologic capacity, or something in-between? Uterus transplantation is an experimental procedure/emerging therapy for women with absolute uterine infertility (AUFI). AUFI refers to the inability to bear children because women either (i) lack a uterus (congenitally or because of surgical removal due to disease), or (ii) have a uterine abnormality that prevents embryo implantation and/or gestation to term. For these women, uterus transplantation holds the possibility of (re-)gaining the ability to gestate and birth a child. If uterus transplantation is judged to be a clinical therapy, then

AUFI is termed a disease. To consider the therapy vs. enhancement question ethicists must delve into both the medical and the social bases upon which AUFI becomes a disease and uterus transplantation its treatment, as well as the implications thereof.

As noted above, women with AUFI are not all the same. Some cannot bear children because they were born without a uterus or without one that permits gestation. For this group uterus transplantation is technically not restorative because their bodies innately did not have the capacities theoretically offered by a transplanted uterus. Rather, in these cases uterus transplant offers an opportunity to rectify the body's perceived deficiency by allowing for childbirth. This fix is based on patient desire, as well as on social expectations of womanhood and cultural notions of the normative body being one that contains reproductive capacity. Certainly, social scientific data will attest to the fact that some women with AUFI, as well as those unable to bear children for other reasons, experience profound loss. This sense of missing out on an essential part of life motivates their seeking procedures like uterus transplant. Yet this sense of something missing does not fully support a claim of uterus transplantation as restorative. It certainly adds meaning, value, and enhances perceived flourishing, but it does not restore an innate ability for some suffering from AUFI. In one way it is more akin to enhancement in that it provides women without a uterus the chance of having a child of their own, much like a prosthetic extremity allows congenital amputees to gain a limb. The extremity adds a capacity, enhances functioning, but does not replace something that was lost, for the extremity was either not there or not fully formed or functional in the first place. The other group with AUFI, those who have had to undergo uterus removal due to disease are, arguably, different because they lost a capacity their bodies previously contained. For them uterus transplantation may be deemed restorative.

I am certainly not suggesting that clinical therapies must be restorative in order to be ethically justified; there are many genetic therapies and surgical procedures that seek to rectify abnormalities in structure, function, and phenotype that are part and parcel of ethical medical practice. Rather, ethicists (be they secular or religious scholars) must appreciate the ways in which uterus transplant and AUFI makes visible the ways in which social expectations and ideas about the normative body interact with the ethical ends of medicine. A host of bioethical questions arise when uterus transplantation is considered as a social practice: Is the fact that some women with AUFI suffer and are desirous of a solution sufficient enough justification to categorize it as a disease that demands medical remedy? Or does the fact that gestating and birthing is perceived to enhance the flourishing of some women sufficient grounding to make it part of routine medical practice? At present uterus transplantation is a procedure undertaken by willfully consenting adults, but if we could perform it on children with less complications and better success would it be ethically justified? On a related note, would medicine deem women who are born without a uterus diseased at birth or do they become diseased only because the need for a child arises later in life? Is either group, the child or the adult, somehow physiologically deviant due to no fault of their own, therefore making it medicine's task to graft reproductive capacity upon them?

AUFI illustrates how all diseases are socio-culturally constructed; some have physiological or functional correlates (e.g. coronary artery disease), while others are thus classified because they are deviations from social norms (e.g. idiopathic short stature). Women with AUFI fit into both categories in that they are deemed to have a physiological or functional "disability" based on a "missing" function, and accordingly uterus transplant blurs the line between treatment and enhancement. There is no doubt that women with AUFI suffer considerably because they cannot have offspring. Although uterus transplantation may offer a solution to this suffering there are other potential "therapies" to not having children, such as adoption or gestational surrogacy. The appeal of uterus transplantation may be strong, and the procedure may be ethically justified, but it also carries greater risk than these alternatives. In this case, as in others, ethicists need to fully consider the social forces that turn atypical anatomy or physiology into malady, and difference into disorder. Scholars may find interesting parallels to draw upon in the deaf community where some opt to not have their deafness (or that of their children) "remedied" because they do not see deafness as a disease and reject such stigmatization.

As religious bioethicists weigh in on the ethics of uterus transplant they need to examine conceptions of the normative body from the lens of tradition. For example, both Islam and Christianity have versions of an imago Dei doctrine.[3] Does this notion offer insight into distinctions between therapy and enhancement when it comes to reconfiguring the body by adding a uterus? When building out conceptions of the normative body based on scriptural indicants, both traditions must confront the issue that in some narrations womankind was generated from the first man. What sort of normativity can be attached to the uterus, an organ only present in female bodies? Similarly, both traditions speak to the value of procreation with scriptural texts that command the faithful to "be fruitful and multiply."[4] Does this directive envisage women without a uterus as being removed from God's bounty out of wisdom, or can it ground uterus transplantation as a meritorious deed because of a desire to fulfill this teaching? In addition to these new wrinkles, uterus transplantation livens up "older" debates about organ transplantation in religious traditions. Although organ transplantation is generally permitted by Muslim scholars when it is life-saving, uterus transplantation is not technically life-saving for the individual recipient. Would the fact that it allows for a future generation to exist which would not have otherwise accord it life-saving status or does it have a different merit? Islamic scholars debate organ transplantation's ethico-legal permissibility because it can, arguably, detract from the honor, dignity, and inviolability accorded to the human being as God's creation because it reduces the human beings into a mix of interchangeable parts.[5] Does uterine transplantation change this stance appreciably?

Continuing on to other social constructions, uterus transplantation necessarily implicates notions of motherhood. The transplanted uterus, if all goes well, would allow a woman to gestate and give birth to a baby. By definition, it would then appear, that uterus transplantation generates a child-parent relationship. Yet it has always been the case that the motherhood is constructed upon social as well as biological foundations. Biomedical advancements have made the biological linkages between offspring and potential parents all the more varied, and uterus transplantation adds to this complexity. At one level, the link between a parent and a child is based on shared DNA, the propagation of these building blocks of life from one organism to another links one generation of a species to another. The DNA provides data on one's origin and ancestry, generates one's phenotypic and physiological profiles, and speaks to one's probabilities for disease and longevity. DNA science has replaced "older" methods of evaluating the linkage between offspring and parents. For example, in the Prophet Muhammad's time, the science of physiognomy was practiced to certify links between progeny and progenitors; today DNA science has supplanted this practice.[6] Yet, modern biomedicine can now offer multiple other biological claims to parenthood as the chain from progenitor to progeny can be further subdivided. Nowadays the ovum and the sperm cell (either with or without the nuclei that contain the cell's DNA) can be donated from people other than those who desire a child, and the womb within which the fused zygote is gestated can either be hired from a third party, or in the case of uterine transplant, come from a donor.

Thus the couple desiring a child can legally claim to be rightful parents of an infant they have no DNA or gestational link to. Perhaps there is no ethical issue with such a claim because adoption provides some precedent. Adoption, in ancient times as well as today, has always been a practice that privileged social over biological bonds where accepting a child into one's home and rearing them created a parent-child relationship. Contemporary biomedicine seems to have innovated beyond this older method with egg, sperm, embryo, and uterus donation. However it is likely that couples who have children via the method of egg and sperm donation plus gestational surrogacy would not consider themselves to be adoptive parents. Technically, however, they are not biological parents either. Is a new category of parenthood needed to cover this situation? Returning to the matter of uterus transplantation, the same question arises: does the act of gestation ground kinship ties and accompanying ethical claims? Gestational surrogacy arrangements, where they are legal, may provide some precedent, but these are also not without their controversies. Would the uterus donor be able to claim parental rights? Or in the case that the donated uterus was deficient in some way would the gestated child be able to make claims of the "right not to be born" against both the uterus donor and the recipient since the functional issue arose only after the uterus was transplanted into the new body?[7]

A further complication, at least for Muslim thinkers, is that the womb and gestation are particularly significant in Islamic theology. One of God's names is derived from the Arabic root for the womb; and Muslims are warned not to sever the ties of the womb lest it sever God's mercy from the individual.[8] Similarly the Qur'an emphatically declares that the "true" mother is the individual who birthed (and gestated) the child.[9] Rearing is an important function but not one that grounds parental rights in this world or the next in the Qur'anic paradigm. As such a uterus donor's ethico-legal claims of parentage would be harder to dismiss. Moreover, another analogy may be drawn from within the tradition. According to Islamic law, milk maids have parental rights, and some thinkers argued gestational mothers should be treated similarly. Does a uterus donor mother need to be added to the mix? Even if Muslims were to not seek uterus transplantation as a remedy the question is nevertheless pertinent to Muslims and Islamic law. With opt-out policies of organ transplantation gaining momentum in multiple countries, it is possible that a deceased Muslim women's uterus may be used for transplantation purposes in the future. What would be the relationship between the child born to the recipient of that uterus and the children of the donor? Would kinship ties ensue, and the prohibition of marriage amongst siblings be invoked?

Having marked out several important bioethical questions uterus transplantation gives rise to, and noting how these questions have religious dimensions, I would like to close by discussing, in broad strokes, how social science and religious tradition might work together jointly to address these questions. In my view the project of defining terms such as motherhood and distinguishing between enhancement and restoration is a task religion can take up. Religious texts and scriptural teachings provide theologies and ontologies that provide frameworks upon which to build out such conceptions. At the same time, it is important to note that religious interpretations are not neutral; the way a text is read, understood, and explicated is contextually-dependent. These contexts go back, as well as carry forth, into time and make a tradition lived and always evolving. Hence when the religious frameworks are brought to address contemporary questions, their historicity and weddedness to social contexts must be acknowledged, and the frameworks revised as needed. Moreover, the experiences of motherhood, how notions of motherhood play out in society, and how patients invoke conceptions of restoration and enhancement in seeking healthcare are all topics of social scientific research. Even if the individuals studied are religious actors, their decision-making is also shaped by a myriad of other cultural, political, and social forces. Consequently social science has much to offer religious bioethics; it helps to clarify human experiences, understandings, and contexts, both historical and contemporary.

Scholars on this forum have grappled with the many ways in which biomedical advancements spur the reexamination of religious doctrine and teaching and also have forecast how religious theologies can give fuller meaning to the discoveries of biomedicine. They have further commented on how this bilateral exchange is framed by larger social, political, and economic forces. Attending to the pressing bioethical questions of uterus transplantation requires scholars from all three disciplines—religion, medicine, and social science—to come together in trialogue.

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1 "Science and the Human Person Podcasts," *Contending Modernities*, http://contendingmodernities.nd.edu/about/research-areas/science-and-the-human-person/shp-podcasts/.

2 James Gallagher, "First Baby Born after Deceased Womb Transplant," BBC.com, December 5, 2018, sec. Health, https://www.bbc.com/news/health-46438396; Mats Brännström et al., "Livebirth after Uterus Transplantation," *Lancet* 385, no. 9968 (February 14, 2015): 607–16, https://doi.org/10.1016/S0140-6736(14)61728-1; Dani Ejzenberg, "Livebirth after Uterus Transplantation from a Deceased Donor in a Recipient with Uterine Infertility," *The Lancet* 392, no. 10165 (December 22, 2018): 2697–2704, https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(18)31766-5/fulltext.

3 Muslim Ibn al-Hajjaj, "Hadith 6325, Book 32," *The Book of Virtue, Enjoining Good Manners, and Joining of the Ties of Kinship*, https://sunnah.com/muslim/45/152; Gen 1:26-27, https://www.biblegateway.com/passage/?search=Genesis+1%3A26-27&version=NIV.

4 Gen 1:28, https://biblehub.com/genesis/1-28.htm; Ibn Majah, Sunan. "Hadith 1846, Book 9, Vol. 3," *The Chapters on Marriage,* https://sunnah.com/urn/1261630 .

5 Aasim Padela and Rosie Duivenbode, "The Ethics of Organ Donation, Donation after Circulatory Determination of Death, and Xenotransplantation from an Islamic Perspective," Xenotransplantation 25, no. 3 (June 15, 2018): 1-12. https://onlinelibrary.wiley.com/doi/10.1111/xen.12421; Sherine Hamdy, *Our Bodies Belong to God: Organ Transplants, Islam, and the Struggle for Human Dignity in Egypt*, (Berkeley, CA: University of California Press; 2012).

6 Ayman Shabana, "Islamic Law of Paternity Between Classical Legal Texts and Modern Contexts: From Physiognomy to DNA Analysis," *Journal of Islamic Studies* 25, no. 1 (January 1, 2014): 1–32. https://doi.org/10.1093/jis/ett057.

7 M. Spriggs and J. Savulescu, "The Perruche Judgment and the 'Right Not to Be Born,'" *Journal of Medical Ethics* 28, no. 2 (April 1, 2002): 63–64. https://doi.org/10.1136/jme.28.2.63.

8 Quran 4:1. https://quran.com; Muhammad al-Bukhari, "Hadith 63," *Al-Adab Al-Mufrad*. https://sunnah.com/adab/2/17.

9 Quran 58:2, https://quran.com/58/2.

Unmasking Neoliberalism's Invisible Grip: *Homo Economicus* and the Person in Bioethics

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Much has happened with gene-editing since Contending Modernities' "Out of the Lab" podcast.[1] Despite the National Academies of Sciences, Engineering, and Medicine's 2018 recommendations that gene-editing should be stringently regulated and only used for a limited number of somatic diseases at this time, a surprisingly stunned world witnessed the birth of twin CRISPR-Cas9 edited girls in China in November, with a third baby on deck.[2] Voices across the spectrum—scientific, ethical, theological, policy—excoriated the researcher, He Jiankui.[3] Repeatedly described as a "rogue scientist," it now appears that He may have had at least one US collaborator.[4]

Listening to the above commentary, a trained ear might hear a pattern, a subtle but regular pulse, that signals the heart of the matter. Where Adil Najam fears a "gap" between the ethical, policy, and "entrepreneurial realities" surrounding technologies like gene-editing, I would suggest that these are, rather, all neatly aligned.[5] To put it pointedly: the CRISPR conversation makes clear that bioethics, as it has emerged since the 1980s, is a deeply neoliberal project.

This is a big claim—one that can hardly be thoroughly argued in a blogpost. A complete argument would require detailing the intertwined histories of neoliberal economics and bioethics as they emerged post-World War II. Here I will only point to four notes that resonate throughout the literature. When taken together, they sound the dissonant chord of neoliberalism. These are: CRISPR as a technique, concerns about commercialization, dyspepsia about regulation, and the framework of bioethics itself, particularly its understanding of the person.

First, the briefest primer on neoliberalism. Bruce Rogers-Vaughn, in his important book *Caring for Souls in the Neoliberal Age*, defines neoliberalism as "the free market ideology based on individual liberty and limited government that connected human freedom to the actions of the rational, self-interested actor in the competitive marketplace."[6] Arising in the early 20th century, neoliberalism emerged in full force in the late 70's-early 80's with the Reagan-Thatcher era and the Washington Consensus. Central tenets include the liberalization of trade barriers, privatization of social services, globalization, and deregulation. In order to limit government, neoliberalism calls for sharply reducing or eliminating social services and welfare programs. The "social" is perceived as a mythic restraint on individual freedom. Neoliberalism aims to maximize the freedom of the individual, *homo economicus*—a person whose fundamental activity is choice and who chooses the good as she-or-he defines it based on a rational calculation of pure self-interest. Society is little more than an aggregate of autonomous individuals each pursuing their own good. Notably, however, freedom is redefined in market terms.

Neoliberalism is not simply an economic theory. It is a cultural project that subtly and pervasively organizes contemporary life. Rogers-Vaughn, in tracing how neoliberalism has transformed psychiatry, provides a template for making visible how it has likewise altered other areas of medicine and clinical research. CRISPR-Cas9 embodies a new approach to thinking about diseases, social problems, and human identity that he refers to as "methodological individualism." Since roughly 1980, when mental illness was reconceptualized in the DSM-III, through "gene therapy," stem cell therapies, the BRAIN initiative, neuroscience, and individualized or personalized medicine, a subtle shift has occurred that locates the source of diseases or problems within particular individuals rather than within social or political structures. Illness, here, is conceived as highly individualized, rooted deeply in the nano-loci of personal biology— genes or neural signatures. This new etiological framework drives a search for "biologically-mediated person-specific treatments."[7] CRISPR envisages the human genome as a biological text that needs "editing." *There* lies the problem. Having defined disease as biologically mediated, the medical-industrial complex then hunts for biological interventions that can efficiently fix mistakes that are located at the deepest level of our being—or, via enhancement, that shape our identities.

Though justified by the goal of reducing suffering, a second neoliberal commitment catalyzes the hunt: economic efficiency and maximizing profits. In the podcast, Maura Ryan raises concerns about "commercialization." Aline Kalbian repeatedly refers to CRISPR's "entrepreneurial aspect" and our free market, competitive context. He Jiankui's motivation for creating the CRISPR babies was "personal fame and fortune."[8] Others in the *Contending Modernities* series raise concerns about commodification.[9] But exorbitant prices, pervasive commodification, and a focus on market share and ROI is not accidental. They are the result of intentional neoliberal policies. The 1984 Drug Price Competition and Patent Term Restoration Act transformed the pharmaceutical market. In 1985, the FDA approved, for the first time, direct-to-consumer marketing for medical products. In 1989, NIH established the Office of Technology Transfer to maximize the financial profits of government-funded research. The list could go on. Moreover, via Gary Becker and the Chicago School, the market extends to an ever-wider array of social realities; the market becomes, in the catchphrase of *Freakonomics*, "the hidden side of everything."[10]

Kalbian notes in the podcast that commercial aspects of new medical technologies are not being regulated. David Baltimore, chair of the National Academies' committee on gene-editing, laments the "failure of self-regulation in the scientific community" in the CRISPR babies case. But we should not be surprised. As Michael Fitzgerald more realistically states in "Out of the Lab": "regulation gets in their way." Deregulation, as mentioned earlier, is a central neoliberal platform. Regulations, characterized as the demon of big government, constrain the market's freedom. Rogers-Vaughn notes a concerted movement, beginning in the late 70s, to make "governments reduce or withdraw laws and rules requiring corporations to consider any purposes other than pursuit of profit." In the mid-1990s, when I served on the Recombinant DNA Advisory Committee, Big Pharma was a visible presence at our quarterly meetings, exercising a watchful eye over ethicists or community members who might seek to put limits on R&D.

Almost to a point, current analyses of gene-editing reprise those 1990s debates. CRISPR-Cas9 is essentially gene therapy 2.0. New technologies are more efficient and likely more efficacious than adenovirus vectors. But the same ethical arguments were made in the 1990s as now; the same guidelines were put in place. The bioethical framework has not changed. From the National Academies' to ethicists and analysts, the debate remains mapped by beneficence, non-maleficience, justice, and respect for persons, pastiched over a bedrock of utilitarianism. Or...is it respect for persons? As I have narrated elsewhere, 1980 is not only a key moment in the history of neoliberalism.[11] It is also a key moment in bioethics. For in 1979, another subtle but important shift occurred: *Belmont's* respect for persons morphed into Beauchamp and Childress' respect for *autonomy*.

The 'person' as a regulative concept in medical ethics emerged at a particular historical moment: post-War Europe, first gestured at in the Nuremburg Code in 1948.[12] (Is it a coincidence that second phase of neoliberalism begins around 1950?) Imported to the US in the late 1960s after a series of research scandals, 'personhood' becomes integrated into the emerging bioethics discourse with Paul Ramsey's *Patient as Person* in 1970.[13] Initially, 'personhood' was protective—seeking to stem research abuses against vulnerable populations (children with mental illnesses, African-Americans), to counter medical paternalism, and to resist the "depersonalization" of modern medicine. From Nuremburg through Paul Ramsey to the *Belmont Report*,[14] the term 'person' was invoked to ensure that autonomous persons were given the right to informed consent—whether for research or medical care—and non-autonomous persons (or "all who share human genetic heritage" in the language of the National Commission's 1975 *Report and Recommendations: Research on the Fetus*) were protected, even to the point of excluding them from research that could potentially benefit others.[15]

But in 1979, almost before the ink is dry on the *Belmont Report*, respect for *persons* transmutes in Beauchamp and Childress' first edition of *Principles of Biomedical Ethics* into respect for *autonomy*.[16] Henceforth, talk of persons becomes largely "permissive"—we now have to determine who counts as a person before we can determine what, if any, responsibilities we owe them. Knowing who counts as a person helps resolve dilemmas around abortion, end of life, organ transplantation, stem cell research, etc. Most interestingly, "persons" for bioethics come to be defined as autonomous subjects who express their agency through the rational act of choosing whichever ends further "their own good," maximizing their own self-interest. Social determinants of health, social location, social structures, even family members rarely enter this calculus. The 'person' of bioethics post-Beauchamp and Childress, post-1980, is *homo economicus*.

In the gene-editing podcast, Aline Kaliban asked "what is it, exactly, that ethicists bring to the table?" While often the dignity or sanctity of persons is held up as a hedge against the endless encroachment of market forces in medicine, the attitude Pope Francis so aptly names as "the throw-away culture," it may well be that the principles of bioethics subtly serve not as a corrective but rather as a tool of the market.[17] Lisa Cahill depicts science, economics, theology, and liberal democratic political discourse as "thick worldviews" that compete in our engagement around bioethics and health policy.[18] But it's not an equal playing field. History suggests that the thick worldview of the neoliberal paradigm underlies them all. It shapes bioethics, medicine, scientific research, and medical technologies. This is why it's often hard to see what bioethics brings.

Clarifying the neoliberal structure of bioethics and emerging medical technologies not only helps us understand the contours of the CRISPR landscape. It illuminates other disquieting dynamics. For example, certain technologies, once approved, become cast as morally-normative. If one could eliminate a defective gene from one's children using CRISPR, is one not morally-obliged to do so? Belying the rhetoric of individual liberty, as neoliberalism evolves in the late 20th century, *homo economicus* becomes subservient to that sovereign master: the economic dogma of rational, utility-maximizing self-interest. In a troubling inversion, what must be free now is not persons but the market.

Or why is it so difficult to advance the notion of the common good? Perhaps the answer lies in one of the first steps in the creation of modern capitalism, that original act of privatization, the literal enclosure of the commons in England from the 16th century forward. Step-by-step, material 'commons'—even our genomes—are no longer shared. They are patented, commodified (23andMe!), and used as raw materials to create new products for profit and consumption.

If this is the case—if biotechnologies and bioethics and bioethics' concept of the person are intrinsically shaped by neoliberalism—where are we left with a technology like CRISPR? Such an angle doesn't yield a simple thumbs-up, thumbs-down, or "we must stringently regulate this new and powerful technology." Perhaps He Jiankui is not so 'rogue' after all. Rather, perhaps the CRISPR babies provide a road-to-Damascus jolt to make us analyze not only a particular technological innovation but the way the infrastructure of bioethics may have enabled it. Let me point to three avenues forward.

First, it is time to begin to make these economic dynamics of biotechnology and bioethical issues visible. The Catholic social tradition is one of the main voices that has begun to do so. Beginning with the liberation theologians in the 1970s, through John Paul II who named the structures of sin of money, power, and idolatry especially in relation to globalizing technologies, to Pope Francis' *Laudato Si'* (following Benedict XVI's *Caritas in Veritate*), Catholic social thought critiques the practices and effects of neoliberalism—particularly commodification, consumerism, and the exacerbation of economic inequality.[19]

This lens needs to be brought to bear on bioethics. Few Catholic bioethicists have yet done so. These two "doctrinal" areas have too-long been siloed.[20] A social lens asks about the historical and social contexts of concepts. Why did a particular concept arise when it did? Whose interests did it serve? It uses not only the tools of theology and philosophy, but also carefully attends to history and the social sciences. It presses for analyses that are, in the words of Paul Farmer, "historically deep and geographically broad."[21] One central tool of this "social-analytic mediation" (as liberation theologians call it) is economics, particularly political economy. My colleague Michael McCarthy and I have begun to address this gap in our recent book *Catholic Bioethics and Social Justice: The Praxis of US Healthcare in a Globalized World* (Liturgical Press, 2018). Catholic social thought here joins an emerging cadre of secular thinkers.[22] But much more work needs to be done.

Second, we need to move away from "single-issue" analyses that have long shaped bioethics ("Is CRISPR ethical or not?") to broader systemic analyses. What are the connections between the CRISPR babies in China, the new career path of the "professional guinea pig"[23] in the US, the skyrocketing numbers of human research subjects globally,[24] and the serious toll that neoliberal economics has taken on health outcomes around the world by decimating social programs and local economies, just to name a few? (Rogers-Vaughn, for example, sees neoliberalism as causally responsible for an increase in mental health issues). The list could go on.

These issues are all of a piece, pointing to ways in which human bodies become the raw material for profit-making (or cost-savings), a reality woven into the fabric of bioethics and biotech itself. Coming to see this requires, as Pope Francis notes in *Laudato Si'*, not only hard intellectual work but also moral and spiritual conversion. Can bioethics be converted? Religious traditions—with their vision of thickly connected persons who develop and flourish integrally in communities—could well provide the lever to begin to shape a bioethics that privileges persons over profits. This would move away from a bioethics dominated by the methodological individualism of autonomy and enamored of the methodological individualism of technologies. It would provide a starting point for a radical conversion of our hyper-individualistic and extractive economic philosophy that inflicts austerity on the poor while licensing the almost unbridled creation of biotech products for consumption by the wealthy few.

But it is not only bioethics that needs to be converted. Conversion calls us to a new way of living. Might we declaim against the neoliberal splinter in the eye of He Jiankui while remaining happily blinded by the log of contemporary economics in every other aspect of our own lives? The lens we turn on him, we must also turn on ourselves. As this conversation among Contending Modernities unfolds and Lent begins, it seems an opportune time to reflect on how not only religious convictions (i.e., about persons) but embodied religious practices, such as silence, simplicity, fasting, almsgiving, prayer, Eucharist, offer the potential for unshackling us from the subtle but pervasive ways that neoliberalism shapes our lives. Perhaps here is the starting point for beginning to come to see the underlying engine driving ourselves, our culture, our bioethics, and biotechnology, and to thereby begin to unhand these interventions and very selves from neoliberalism's invisible grip.

1 "Science and the Human Person Podcasts," Contending Modernities, http://contendingmodernities.nd.edu/about/research-areas/science-and-the-human-person/shp-podcasts/.

2 National Academies of Sciences, Engineering, and Medicine, "On Human Genome Editing II," November 29, 2018, http://www8.nationalacademies.org/onpinews/newsitem.aspx?RecordID=11282018b.

3 Julia Belluz, "Is the CRISPR Baby Controversy the Start of a Terrifying New Chapter in Gene Editing?," *Vox*, November 30, 2018, https://www.vox.com/science-and-health/2018/11/30/18119589/crispr-gene-editing-he-jiankui.

4 Jane Qiu, "U.S. Scientist Played Instrumental Role in 'CRISPR Babies' Project," *STAT,* January 31, 2019, https://www.statnews.com/2019/01/31/crispr-babies-michael-deem-rice-he-jiankui/.

5 Contending Modernities, "Science and the Human Person Podcasts."

6 Bruce Rogers-Vaughn, *Caring for Souls in a Neoliberal Age,* (New York: Palgrave Macmillan, 2016), 2, drawing on Daniel Stedman Jones, *Masters of the Universe*, (Princeton: Princeton University Press, 2012).

7 Bruce Rogers-Vaughn, "Blessed Are Those Who Mourn: Depression as Political Resistance," *Pastoral Psychology* 63, no. 4 (August 1, 2014): 503–22, https://doi.org/10.1007/s11089-013-0576-y.

8 Julia Belluz, "CRISPR Baby Controversy".

9 Charles Camosy, "The Case of the 'Two-Minus-One' Pregnancy," Contending Modernities, September 19, 2013 http://sites.nd.edu/contendingmodernities/2013/09/19/the-case-of-the-two-minus-one-pregnancy/.

10 "Freakonomics—The Hidden Side of Everything," Freakonomics, http://freakonomics.com/.

11 M. Therese Lysaught, "Respect: Or, How Respect for Persons Became Respect for Autonomy," *The Journal of Medicine and Philosophy: A Forum for Bioethics and Philosophy of Medicine* 29, no. 6 (January 1, 2004): 665–80, https://doi.org/10.1080/03605310490883028.

12 Joseph J. Kotva and M. Therese Lysaught, *On Moral Medicine*, (Grand Rapids, MI: Eerdmans: 2012).

13 Paul Ramsey, The Patient as Person, (New Haven: Yale University Press, 2002).

14 U. S. Department of Health, Education, and Welfare, "Belmont Report: ethical principles and guidelines for the protection of human subjects of research.," U.S. Department of Health and Human Services, (Bethesda, MD, 1979).

15 The National Commission on the Protection of Human Subjects in Biomedical and Behavioral Research, "Research on the Fetus," U.S. Department of Health, Education, and Welfare No. (OS) 76-127 (Bethesda, MD, 1975).

16 Tom L. Beauchamp and James F. Childress, *Principles of Biomedical Ethics*, (New York: Oxford University Press, 2012).

17 Charles Camosy, *Resisting Throwaway Culture*, (New City Press: Forthcoming June 2019).

18 Lisa Sowle Cahill, *Theological Bioethics,* (Georgetown University Press, 2005).

19 John Paul II, *Sollicitudo Rei Socialis*, Vatican City: Vatican City Press, 1987); Francis, *Laudato si'* (Vatican City: Vatican City Press, 2015); Benedict XVI, *Caritas in Veritate,* (Vatican City: Vatican City Press, 2009).

20 Maura Ryan, "Bridging Bioethics and Social Ethics," Contending Modernities, September 27, 2013, https://contendingmodernities.nd.edu/field-notes/bridging-bioethics-and-social-ethics-a-reply-to-charles-camosy-and-sherine-hamdy/.

21 *Reimagining Global Health,* eds. Paul Farmer et al., (Berkeley: University of California Press, 2013).

22 Global Pharmaceuticals: Ethics, Markets, Practices, eds. Adriana Petryna et al., (Durham, NC: Duke University Press, 2006).

23 Carl Elliot, White Coat, Black Hat: Adventures on the Dark Side of Medicine, (Beacon Press, 2011).

24 M. Theresa Lysaught, "Docile Bodies: Transnational Research Ethics as Biopolitics," *The Journal of Medicine and Philosophy* 34 no. 4 (2009).

Precision Earth Medicine: Decisions to Gene Edit the Environment Require a New Environmental Ethic

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The emergence of any powerful technology forces us, as individuals and as a society, to reflect upon who we are as humans and how we relate to our planet, providing an opportunity to establish new ethical norms. The recent advent of CRISPR gene editing and in particular its proposed application to genetically engineer the environment necessitates such reflection.

CRISPR gene editing allows for the precise alteration of any genetic code. In humans, CRISPR-based therapeutics could cure heritable diseases, fight off viral infections like HIV, and even be deployed in cancer treatments. Paralleling recent advances in genomics, CRISPR marks the dawn of a whole new era in personalized precision medicine; where not only is the genetic basis of disease known, but where disease-causing mutations can now be repaired.[1] The ease-of-use and low price tag of CRISPR has also allowed scientists to expand their focus beyond the human to the environment. In what I call *precision earth medicine*, CRISPR can be used to genetically design wild species in order to achieve desired health outcomes. Strategies using CRISPR gene editing are being developed to suppress vectors of infectious disease, restore valued ecosystems, and protect threatened species. This technological leap is straining our ethical frameworks.

Precision earth medicine is now possible because CRISPR enables the production of what are called self-propagating gene drives. An organism expressing a self-propagating gene drive encodes for a desired gene edit, as well as the CRISPR machinery to make that same edit in its future offspring. When an organism with a gene drive is released to mate in the wild, its offspring inherit that gene edit and the CRISPR tools needed to make that same edit in the gene it inherits from its wild parent. Over generations, gene drives can force inheritance of gene edits even if they are detrimental to a species' wellbeing, to potentially impact every individual of a species. In this way, the release of only a few gene drive organisms can alter the evolutionary arc of wild plants and animals.

The most mature gene drive project to date intends to inhibit malaria transmission in Sub-Saharan Africa by suppressing its vector, the mosquito species *Anopheles gambiae*. CRISPR-based gene drives were recently engineered in laboratories to spread sterility in female mosquitos and have since been demonstrated to collapse a laboratory mosquito population in 11 generations.[2] Since mosquitos only have a lifespan of about five weeks, if released into the wild this gene drive-bearing mosquito could cause the *Anopheles* population to be eradicated in as little as four years.

Eliminating the *Anopheles* mosquito species could save millions of human lives, but could also disrupt food webs or cause ecosystem disturbances. Unintended consequences to human health are also possible; a more difficult to control vector could evolve to transmit malaria or cause the malaria parasite to become more pathogenic.

Moreover, when nearly 200 species are predicted to go extinct every day, is it morally acceptable to intentionally drive a species to extinction, even if it does cause human suffering? These are big decisions that will be informed by how humans view their role in nature and by a pervading environmental ethic.

Yet technology and how humans relate to technology tend to fall outside dominant frameworks in environmental ethics. When it comes to the environmental application of technology, ethical decision-making tends to revert to basal, either-or stances: organic farming versus GMOs, wind versus nuclear power, trees versus engineered carbon capture. A space for nuance is shrinking and as a scientist who generally supports technology, but who also feels a deep kinship with non-human nature, I struggle to find an environmental ethic that fits. When faced with decisions about if and how a gene drive should be used, this ethical void becomes frighteningly apparent.[3]

To meet this void, I've found myself pulling from two divergent theories in environmental ethics: ecomodernism and deep ecology. Ecomodernists believe technologies (think intensified urbanization, nuclear power, and synthetic biology) can reduce dependence on natural resources.[4] Their goal is that through technology human survival will eventually decouple from its dependence on the natural world and in doing so allow non-human environs to thrive. I'm drawn to the ecomodernist ethic simply because it acknowledges a role for technology in the human relationship with nature, but its inherent anthropocentricity makes it inadequate; ecomodernism holds humans and their technologies supreme, and in doing so severs the human relationship from the non-human world. This disconnect is dangerous because responsible decisions about environmental deployment of CRISPR will require humility and respect for the ecosystems being altered and the cultivation of these virtues requires we be in relationship with non-human nature.

On the other side of the spectrum, the deep ecology school of thought subscribes to the power of relationship and the interconnectedness of both human and non-human species.[5] Humans are part of nature, not separate. Deep ecology also tends to bestow intrinsic value to nature; nature holds worth in and of itself, irrespective of *how* or *if* humans can benefit from it. However, often accompanying a deep ecologist's ethos is a deep distrust of technology. Humans are part of nature, but somehow the fruit of our creativity—technology—is separate. Despite a strong focus on relationship, technologies are often excluded from that relationship. The deep ecology ethos, in its current form, is inadequate to support decision-making concerning technological developments because it is biased towards not using technology to begin with.

I predict most deep-ecologists would be against a gene drive-based strategy to reduce malaria transmission, simply due to the fact that it's a technological intervention. Moreover, a deep ecologist would likely argue that the mosquito holds intrinsic value and thus it is morally unacceptable to intentionally drive it to extinction, no matter the benefit to human health. An ecomodernist, on the other hand, would likely feel there is a moral obligation to *use* a gene drive, given that it could promote human flourishing and reduce human impact on the environment by reducing insecticide use. And here we arrive at a moral impasse where human health is pitted against environmental heath. To relieve this tension and enable responsible use of gene drive technology we will require a new environmental ethic (or at least a more thoughtful interpretation of existing ethoses): one that respects both humans and non-human beings, and one that places us, as humans, and by extension the technologies we create, squarely within an interconnected planetary web.

To develop this new ethic, technology must first be perceived as natural. We must be reminded that technologies don't just fall from the sky—they are products of human ingenuity and are thus part of the evolutionary trajectory of our planet. Let's take CRISPR gene editing as an example. CRISPR or clustered regularly interspaced palindromic repeats is a molecular process that evolved millions of years ago to immunize certain bacteria and archaea against viral infection. By encoding CRISPR tools and viral genetic codes from previous virus infections into their genome, bacteria can pass along protection against future infection to their offspring. Prokaryotic CRISPR systems had been destroying viruses for million of years when scientists Jennifer Doudna, Emmanuelle Charpentier, George Church, Feng Zhang and colleagues adapted this ancient system to develop CRISPR gene editing technology that can instead make genetic changes to any living thing.[6] Here is just one example where humans have used what is available in nature to create new tools. This is not obviously different from harnessing fire or the development of wind-powered energy. CRISPR gene editing has been developed from within our planet not without, and thus deserves to sit within our planetary relationships.

So, what do decisions about gene-drive technology look like when decision-makers are equipped with an ethic built on respect and relationship? First and foremost, decisions would require that the flourishing of both humans and non-humans be equally upheld. Secondly, by inviting technology into our planetary relationships, decisions would reflect an appreciation that technology, when used appropriately, can be part of achieving that goal. In this way, the either-or scenario (mosquitos versus humans) disappears and a more nuanced, middle-ground approach comes into focus. A technology guided by a middle-ground ethic could result in a gene drive that merely impairs the mosquito's ability to transmit malaria, but doesn't impede its survival. This approach would save human lives, while still allowing the mosquito species to continue to live and thrive within its ecosystem. Such a strategy reflects a respect for the interconnectedness of human and environmental health and invites technology into that relationship to augment the flourishing of both.

As a global community we are standing at a crossroads. How we decide to wield new technologies in the face of climate change, resource scarcity, and biodiversity loss will shape the future of our shared planet. With CRISPR in hand, we as humans enter into an entirely new relationship with the non-human; a relationship that will require deep humility and respect for both nature and technology. It is of critical importance that our environmental ethos evolves to meet this challenge.

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1 Natalie Kofler and Katherine L Kraschel, "Treatment of heritable diseases using CRISPR: Hopes, fears, and reality," *Seminars in Perinatology* 42, no. 8, (December 2018): 515-521. https://doi.org/10.1053/j.semperi.2018.09.012.

2 Nicholas Wade, "Giving Malaria a Deadline," *The New York Times*, September 24, 2018. https://www.nytimes.com/2018/09/24/science/gene-drive-mosquitoes.html.

3 Kofler et al. 2018 *Science* 362, no. 6414 (November 2018): 527-529. http://science.sciencemag.org/content/362/6414/527.summary.

4 An Ecomodernist Manifesto, "An Ecomodernist Manifesto." http://www.ecomodernism.org/. See also Chelsea Batavia and Michael Nelson, "For goodness sake! What is intrinsic value and why should we care?," *Biological Conservation*, 209 (May 2017): 366-376. https://doi.org/10.1016/j.biocon.2017.03.003.

5 Foundation for Deep Ecology, "Foundation for Deep Ecology." http://www.deepecology.org/.

6 Jennifer A. Doudna and Emmanuelle Charpentier, "The New Frontier of Genome Engineering with CRISPR-Cas9," *Science* 346, no. 6213 (November 28, 2014): 1258096-1. https://doi.org/10.1126/science.1258096.

Policy-Oriented Fatwas and the Unsettled Morality of Kidney Sales

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Only in Iran is receiving payment to donate a kidney permissible, bureaucratically routinized, and religiously sanctioned. There are no parliamentary laws regulating the transaction, but a body of protocols has been implemented to centrally administer the matching of donors and recipients and regulate the amount exchanged between them. Though only parliamentary laws in the Islamic Republic must be formally vetted by a council of experts in Islamic law and the constitution, in practice contentious non-parliamentary policies also require the authorization of at least some Muslim jurists in order to be implemented without contestation. These policy-oriented fatwas (Islamic legal opinions on policy related topics) are usually determined through a dialogical process between jurists, policy actors, and scientific experts. When it comes to paid kidney donation, policy actors were able to secure permissive fatwas from jurists before the policy was formalized. According to most contemporary Shiʿi Muslim jurists, removing a non-vital organ such as a kidney from a consenting adult is permissible so as long as it does not cause undue harm to the donor and the organ is transplanted into the body of a patient whose life depends on it. These same jurists agree for the most part that compensating living donors is allowed, although it is best that payments be dispensed for the right to remove the organs and not for the organs themselves. Even so, the fatwas that set out these legal opinions are regularly listed in Persian-language fatwa compendia under the phraseology of "selling organs." Despite the religious sanctions afforded by Islamic jurists, selling kidneys remains socially stigmatized and morally obscure. In contrast, brain-death organ donation has not only been legalized but normalized as a heroic sacrifice, even though, from an Islamic legal perspective, the matter remains far more controversial than kidney sales.

In the summer of 2012, in the central office of the Iranian Kidney Patient Foundation (IKF) in Tehran, I sat next to a woman eager to fulfill her deceased father's will by endowing a portion of his wealth to charity. With the help of the NGO, she planned to distribute the funds among patients unable to afford organ transplants. Since transplantation surgeries are nearly free in public hospitals in Iran, the endowment was to cover the expenses of "acquiring a kidney" from a living donor. "Why not donate the funds to the sellers instead?" asked the social worker in the room who, despite years of employment at the NGO, felt uneasy about facilitating the "sale" of kidneys. Perplexed by the question, the woman explained her wish to alleviate the suffering of those in *greatest* need—patients who would be bound to dialysis machines for the remainder of their lives unless they received a kidney transplant, an existence that in the Iranian imagination is tantamount to "living death."

Since the 1980s, when the first successful kidney transplant from a living non-biologically related donor was performed in Tehran, Iranian patients with end-stage renal disease have looked to the bodies of healthy strangers as potential lifelines. When related donors have been scarce, compensating unrelated donors has been customary. As demand for kidney transplantation has grown—spurred by soaring rates of hyper-tension and diabetes on the one hand and rapid improvements in high-tech surgical interventions on the other—those organizations involved with kidney disease have sought to regulate and routinize the monetary exchanges between donors and recipients. By 1997, the IKF had secured permissive fatwas from a significant number of leading jurists and formalized a set of protocols to be administered across the country. Since then, healthy men and women between the ages of 20 and 40 have been able, under specific conditions, to undergo a nephrectomy to improve the life of a kidney patient in exchange for a small monetary payment from the state and a larger compensation from the recipient. The NGO manages the matching of donors and recipients and announces a standard "reward" amount every year. In practice, most donor-recipient pairs negotiate a different amount based on their unique needs and abilities.

While these monetary exchanges are approved by state policy, authorized by fatwas, and regulated by bureaucratic procedure, they are fraught with moral anxiety and social stigma. Bureaucratic routinization has normalized the transactions to the extent that people understand the "buying and selling" of kidneys to be a social reality and philanthropists can imagine spending their wealth on facilitating such exchanges, but the moral status of the phenomenon remains unsettled. The kidney-seller is seen as an unfortunate victim of poverty and unemployment, and the kidney-buyer the suffering patient whose only hope for continued health and vitality is a new kidney. Their exchange is mostly seen to be regrettable yet unavoidable, but no sustained public discussion has processed the phenomenon from an ethical standpoint or subjected the policy to scrutiny and debate. As a result, there are no consistent moral rubrics for how such transactions should be conducted or how they should be processed by society. In the absence of such rubrics, individuals are left to their own devices to navigate the sticky and tenuous process of reaching an agreement. Even years after transplantation, both kidney givers and patients continue to struggle as they attempt to cope (often in silence and obscurity) with fragile bonds and unresolved apprehensions.

Contrary to what one might expect, the Islamic jurists' permissive fatwas have neither filled the moral vacuum nor helped resolve the conundrums faced by ordinary people. This is largely because these fatwas were solicited as part of a policy-making and implementation process that deliberately excluded the public promotion of organ-selling. After all, there were sufficient people willing to donate for payment, so there was no need to campaign and draw attention to a program that was deemed necessary but morally tenuous and less than ideal. Since the 1980s, members of the IKF, medical doctors, patient activists, and even religious experts have been actively engaging high-ranking jurists in discussions on the science of transplantation and its life-saving potentials. These discussions have persuaded many (though not all) jurists of the expediency of organ transplantation. In turn, policy actors have been able to push forward a national transplantation program without facing overt delegitimization by critics who may otherwise think that selling body parts defies Islamic doctrine. But while these fatwas serve an instrumental purpose for policy actors wishing to lubricate the bureaucratization of transplantation, they do not necessarily serve as guidelines by which donors and patients can navigate the complicated and socially stigmatized process of their exchange. Instead, these individuals' decisions are largely determined by the fears, desires, and moral valuations that materialize in the space of their intimate encounters.

In 2012, I spoke with Seema, an extremely frail but affluent accountant and young mother who suffered from multiple ailments that had permanently damaged her kidneys. Doctors and relatives had failed to persuade her to obtain a healthy organ from a living donor. She wouldn't allow herself to pay someone "selling a kidney out of desperation," when only she knew what it was worth—"more than anything anyone could pay for." Even receiving an organ from a brain-dead person was hard to accept. "How can I wait in anticipation of someone's death so that I can live?" she said. But about a year later, Seema finally agreed to put her name on the IKF's recipient list. Despair over her declining health and fear of leaving her toddler without a mother had overpowered her previous reservations. She chose to optimize her chances of recovery by receiving a kidney from a living stranger.

Around the same time, I met a disgruntled young donor who had received payment in return for his kidney a year earlier. While he had negotiated the terms of his surgery and exchange himself, the donor complained that the recipient had been "ungrateful" because he had failed to reciprocate his kindness and sacrifice beyond paying the formally agreed-upon amount.

These stories not only demonstrate the range of anxious moral considerations that both animate and challenge paid kidney giving in Iran, but also reflect the normalization of a process in the absence of a consensus on its moral legitimacy, religiously-guided or not. What is particularly interesting is that the majority of those I encountered in Iran, even those who had opted to pay for an organ donation, were unaware of the existence of fatwas explicitly approving the monetized exchange. Some assumed that if any fatwas existed on the matter, they would be prohibitive. Others claimed that they had never asked about such fatwas, but assumed that since the policy was implemented in part by state organizations in an Islamic Republic, it must not have contradicted Islamic doctrine. This shows that the fatwas, despite being deployed for policy purposes, have done so silently and without participating in the formation of public opinion.

There are two major consequences when fatwas are directed toward policy-making in this way. One, the legal interpretations of jurists are likely to favor the premises and concerns of the policy actors who have elicited them, rather than the everyday dilemmas of ordinary people like the organ donors and recipients most affected by the policy for compensated kidney transplants. Two, while such fatwas do enable policy-making and implementation, they hardly play a role in shaping the public moral understandings necessary for their proper enactment.

Matters are different when successful policy-making requires that such *policy-oriented* fatwas become publicized through incorporation into campaigns (such as those directed toward public health) or otherwise debated in academic settings, journalistic accounts, and most important of all, radio and television programming. It is in these contexts that such fatwas often inform and shape the public's moral sensibilities and help achieve consensus.

While such public discussion never took place for compensated kidney transplants, it did occur when brain-death organ donation became a viable possibility. Though less than 30% of kidneys transplanted every year come from brain-dead donors, the number is on the rise not only because the infrastructure and logistics accommodating such time-sensitive procedures are improving, but also because more and more Iranians have been embracing the possibility of donating their body parts in the event of brain death as an opportunity for a final grand act of altruism.

The transformation of public attitudes towards brain-death as "real death" has been made possible by a concerted effort to create a "culture of brain-death organ donation." The Ministry of Health, along with the IKF and other organizations have been working closely with national radio, television, and other media to orchestrate various public campaigns to raise awareness about brain death (among other things through serialized dramas broadcast during peak family viewing times). Nephrologists and neurologists sometimes appear alongside clerics to marshal the cause of brain-death organ donation as a clinically sound, religiously sanctioned, but most of all heroic and spiritually rewarding act. This is all despite the fact that there is more disagreement among jurists on the equivalence of brain death and real death than there is on the legal permissibility of paid kidney giving.

While Western bioethicists often look to the fatwas of Muslim jurists to understand Islamic ethical positions on modern biomedical interventions, we have seen that these fatwas do not always reflect the attitudes of believers on matters of ethical import. When it comes to "kidney selling," these moral concerns are varied and unstable, dependent as they are on an individual's relationship and proximity to the context of exchange—as an ailing patient, struggling donor, generous benefactor, passive observer, social critic, and so on. Moreover, fatwas are never automatically efficacious. They must be elicited, mobilized, elaborated, and deployed by the right people, with the right instruments. To understand the ethics of any critical social practice in an Islamic milieu, then, it is paramount both to differentiate between those Islamic legal opinions that are elicited in policy contexts and those that are not, and to examine how policy-oriented fatwas circulate: as contributions to debates over matters of public interest, or as instruments of policy that languish in compendia but rarely see the light of public scrutiny.

Catholic Conceptions of Personhood and Gene Editing

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We live in an age where we have become accustomed to the constant onslaught of technological interventions in our lives. Some of it is positive, enriching, and conducive to our flourishing; much of it is frightening. In the arena of medicine, we fear the possible consequences of these interventions—consequences to our physical bodies, but also consequences to our identities. Our identities as persons cannot be separated from our bodies; nor can we imagine that they are formed in isolation from other persons. Yet, with knowledge of genetics we confront the reality that much of "who" we are is shaped by the matter that makes up our physicality. For that reason, interventions directed at our genes elicit great alarm, especially when those interventions tamper with germline cells ensuring that the effects will be passed on to future generations.

Genetic interventions are not new. Since at least the 1980s, we have been able to manipulate genes directly and indirectly. This manipulation is mostly driven by medical science with its goal of treating diseases and reducing human suffering. Yet lurking in the shadows is the worry that this goal could easily be put to nefarious uses. The most recent development in this arena is what is referred to as CRISPR-Cas9 (clustered regularly interspaced short palindromic repeats), a technique of genome editing[1] that provides an easily accessible way to directly change the makeup of individual genes. CRISPR has been described by many as a radical development in genetic engineering, mainly because unlike earlier interventions it allows us to modify individual genes in a highly targeted and cost-effective manner. As with all earlier advances in genetic technologies, the hype distorts the reality. For example, an online news account describing how CRISPR works has the following subheading: "Everything you need to know about the genome editing breakthrough that one day could cure disease, eradicate species and build designer babies."[2] One can see in such a quote that way that important distinctions, such as between treatment and enhancement, are elided.

In this brief comment, I will bracket the possibility of nefarious uses of this technology and ask instead how even positive uses of this type of intervention (to cure disease, for example) might affect human identity. My question will be framed by Roman Catholic conceptions of identity and personhood. Insight into the Catholic view is especially important in light of the perception that the Catholic church rejects bio-technological interventions. Understanding how this particular faith community navigates a path between fear of technological overreach and the pursuit of medical advances allows us to see the complexity of the relationship between human identity and genetic intervention. There are three features of identity central to the Catholic view that can also illuminate public discussions about the future of genomic editing and its impact on human identity. These are: *humans exist in a tension between dependence and responsibility, humans are relational, and humans are embodied*. As I shall argue, properly understood, all three of these features can serve as the scaffolding for a society that values justice.

Human identity in the Catholic context is derived from the understanding that humans are created in the image of God, meaning that humans possess rationality and the capacity to know and pursue the good. Humans exist in a tension between being creatures of God and "free" agents who are responsible for their actions. Hence, they are *both dependent and free*. This status grants humans the ability to pursue their moral good while also leaving them the possibility to turn away from it. Human identity and personhood are thus premised on this capacity. The choice to modify individual genes is a consequence of that fundamental freedom, but it also challenges the relationship of human dependence on God. Critics of genetic interventions often invoke the metaphor of "playing God" as a way to signal human overreaching, arrogance, and pride. This tension between dependence and freedom/responsibility ought to function as a sort of horizon against which to understand moral choices, both individually and communally. As individuals, our actions are constrained by this tension; yet when expanded to society, the tension forces us to reflect more deeply on what it means to be responsible to our fellow humans. Applied to genomic editing, this suggests a prudent course which expands the range of consequences of our actions that count as relevant. Thus, for example, responsibility to persons on the margins of society, who are least likely to benefit from these interventions, must be a driving force in our moral reflections on this issue.

Also fundamental to Catholic conceptions of personhood is the connected idea that *the person is relational and communal*. The moral injunctions to love one's neighbor and to do justice presume that human identity is shaped by and for interactions with and responsibility to others. For Catholics, there is a theological backdrop to this notion of relationality—one grounded in the idea of God as three persons in the trinity, suggesting that God, in his very essence, is relational. Yet, even without the theological backdrop relationality implies human caring. It connects caring for the other with the inclination of all humans to self-preservation. Our bonds with other humans drive us to pursue medical technologies. One common concern about recent developments in genomic editing is that they threaten to undermine our bonds to future generations by altering future genomic maps. This concern extends the idea of relationality to a different temporal horizon.

In some sense the most fundamental Catholic belief about the nature of human identity is the emphasis on the embodied nature of human existence. Beyond a mere statement of fact, this claim is normative insofar as morality is experienced in and through the body. Yet, making the body central is not to suggest that the human is merely a whole made up of its component material parts. The body is endowed with meaning and it also creates meaning. While the Catholic tradition's relationship to natural law is complicated, there is strong agreement that the body can provide information, and perhaps even guidance, for determining morally appropriate actions. Exactly how this happens is complicated by the fact that bodies are mediated culturally and the meanings we derive from them are shaped by broader webs of meaning. It is possible to see this third feature as existing in tension with the other two.

All three of these features of human identity support the centrality of respect for human dignity to Catholic ethics. Genome editing's ability to manipulate an individual's genetic identity can easily be seen as an assault on human dignity, especially if dignity is conceptualized as material integrity or wholeness. Yet, a different picture emerges when one expands integrity to mean well-being and human flourishing in a community governed by the norms of justice. Put differently, we must be vigilant to maintain the first two features of human identity alongside the third one.

These accounts of human identity and dignity tell us that tampering with the physical building blocks of the human person has far-reaching consequences that threaten to disrupt the essence of the person. Yet, do they provide us with sufficient evidence to support the view that genome editing ought to be morally prohibited? Earlier debates about the ethics of genetic technology focused on drawing lines between germ cells and somatic cells, and between therapy vs. enhancement.[3] Those lines were intended to protect any perceived threats to human identity—threats that might embolden humans leading them to forget the tension in their relationship to God, or to lose sight of their fundamental relationality, or to mistake their embodiedness as a purely material construct. The news in late 2018 that scientists had succeeded in editing the embryonic genes of twins born in China suggests that this technology will not disappear.[4] The question for moralists is whether or not the moral arguments deployed in earlier conversations about genetic technology will prove sufficient to the task of addressing this latest twist. My view is that drawing this line between shorter-term somatic cell interventions and irreversible germ cell interventions is still a prudent course of action as well as a morally sound one. The three features of Catholic thinking about human identity can function as groundwork for the line-drawing task by reminding us of human limits, communal commitments (to present as well as future communities), and the meaning of embodiment. While the ease and availability of CRISPR technology makes the line both harder to draw and to hold, it is important that we not lose sight of these fundamental views about identity.

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1 It is referred to as editing since it enables the scientist to target specific parts of the DNA sequence that have been identified using letters of the alphabet. The question of the implications of the editing metaphor is important to consider. The Nuffield Council report issued in 2015 addresses this important point and draws attention to the reductionism as well as the "overstretching" that can result from relying too heavily on a metaphor. Nuffield Council on Bioethics, "Genetic Editing: An Ethical Review," (London: Nuffield Council on Bioethics, 2016).

2 Jackson Ryan, "CRISPR Explained: The Revolutionary Tool That's Transforming Genetic Engineering," CNET, https://www.cnet.com/news/crispr-explained-the-revolutionary-tool-thats-transforming-genetic-engineering/.

3 Kelly E. Ormond et al., "Human Germline Genome Editing," *American Journal of Human Genetics* 101, no. 2 (August 3, 2017): 167–76, https://doi.org/10.1016/j.ajhg.2017.06.012.

4 "'CRISPR Babies' Scientist He Jiankui Rose from Obscurity to Stun the World," STAT, December 17, 2018, https://www.statnews.com/2018/12/17/crispr-shocker-genome-editing-scientist-he-jiankui/.

Muslim Jurists' Contribution to Islamic Biethics

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Technological progress represents one of the key characteristics, and concurrently one of the fruits, of modernity. Biomedical sciences and their technological applications in particular have witnessed revolutionary progress from the twentieth century onwards. This progress managed to achieve near-miracles by eradicating some lethal diseases, enabling humans to live longer and also to have a better quality of life in general. However, as rightly put by Thomas Misa, "Technologies interact deeply with society and culture, but the interactions involve mutual influence, substantial uncertainty, and historical ambiguity, eliciting resistance, accommodation, acceptance, and even enthusiasm."[1] In their interaction with modern biomedical technologies, Muslim individuals, societies, and countries have had to grapple with questions related to which of these technologies should be resisted, accommodated after modifications, or unconditionally welcomed. Specialists in Islamic jurisprudence (*fiqh*), or jurists (*fuqahāʾ*), were at the forefront of those who tackled these questions from an Islamic perspective. The contribution of Muslim jurists to the emerging field of Islamic Bioethics is so seminal that some critical voices find it unfortunate that there is almost no substantial contribution from other disciplines, including Islamic theology, philosophy, and Sufism.

In this essay, I give a concise analytical review of Muslim jurists' contributions to Islamic bioethics based on works written in Arabic by Sunni jurists today. I address three main questions: What are the identities of the contributing jurists? How do they address the ethical questions posed by modern biomedical technologies? What are the key challenges that need to be addressed in the future?

1. Who are the main contributing jurists?

So far, we have no Muslim jurists who specialize in addressing exclusively bioethical issues. Almost all of them are graduates of Sharia faculties who received training in addressing a wide range of topics that cut across almost all aspects of life including social, political, financial, and bioethical questions through the lens of Islamic jurisprudence. So, unlike the situation in many Western countries where theologians and philosophers will specialize in bioethics and dedicate their whole career to this field, we still have no bioethical jurists or juridical bioethicists in the Islamic tradition. One of the main consequences of this situation is that we do not see any specific interpretive techniques or modes of reasoning which are unique to Islamic bioethics. In their attempts to address bioethical questions, Muslim jurists do not feel compelled to develop any new techniques that go beyond the traditional system of Islamic jurisprudence, as will be explained further in the section below. They are usually confident that the system which helps them answer questions related to modern domains like economics and finance will also do the job with the field of bioethics.

Some of the contributing jurists have engaged with bioethical questions early on in their careers by writing their M.A. theses or Ph.D. dissertations on specific bioethical issues. Because of the relatively new character of these bioethical issues, many postgraduate students are inclined to choose such topics so that they will not run the risk of rehashing what their predecessors have already said on exhausted topics. Some of these works have found their way into wide circulation and have become important references in the field. Just as examples, I refer to the works of Muḥammad al-Shinqīṭī on medical surgery,[2] Saʿd al-Shuwayrikh on genetic engineering,[3] and Ismāʿīl Marḥaba on biobanks.[4]

Besides these junior jurists, many senior and prominent jurists also write on bioethical issues to show how their long-established expertise will help them address such complex questions in a robust and rigorous way. Just as examples, I refer to the works of Mukhtār al-Sallāmī[5] and Muḥammad Naʿīm Yāsīn[6] on miscellaneous bioethical issues and Muḥammad Raʾfat ʿUthmān[7] on genetics.

2. How do Muslim jurists address bioethical questions?

As mentioned above, the jurists who write on bioethics are generalists who address all types of questions through the lens of Islamic jurisprudence without developing any specific methodology tailored for the field of bioethics in particular. Like the approach to any other issue in Islamic jurisprudence, the jurist usually starts with consulting the main sources, namely the Qur'an and Sunna, looking for relevant scriptural references and then follows with consulting the so-called secondary sources of legislation including those related to induction, deduction, inference, and so forth. Weighing between possible benefits and expected harms, which comes close to the well-known risk-benefit assessment in mainstream bioethics, is one of the most frequently used tools to assess various biomedical technologies from a juristic perspective. In this specific regard, contemporary jurists try to benefit from the relatively new concept of *fiqh al-muwāzanāt* (lit. "jurisprudence of balancing") which has roots in classical *fiqh*.[8]

Because of the novel character of most of the bioethical issues, jurists heavily depend on the mechanism of independent reasoning (*ijtihād*) where they would independently examine available sources without necessarily adhering to any of the established schools of law in the Islamic tradition. One of the relatively unique aspects of practicing *ijtihād* in the field of bioethics is that it usually assumes an interdisciplinary character. Because of their educational background, which consists of training exclusively in the Arabic language and in disciplines related to Islam as a religious tradition (the so-called *al-ʿulūm al-sharʿiyya*), contemporary jurists have hardly had access to biomedical sources. In order to grasp the crux of the bioethical questions at hand, they get external help from biomedical scientists who simplify the biomedical information they need so that they can give informed answers. This mechanism is known in Islamic studies as collective *ijtihād*, and it was institutionalized by the beginning of the 1980s. Three main transnational institutions took the lead in this regard, namely the Organization of Islamic Sciences (IOMS) based in Kuwait, the Islamic Fiqh Academy (IFA) based in Mecca, Saudi Arabia, and the International Islamic Fiqh Academy (IIFA) based in Jeddah, Saudi Arabia. The three institutions work closely together but they do not necessarily adopt identical positions on the bioethical issues they discuss.[9]

3. What are the key challenges ahead?

The field of Islamic bioethics has witnessed considerable progress during its five-decade history, thanks to the contribution of Muslim jurists, among others. However, this nascent field still has various challenges ahead that need to be addressed.

First of all, the aforementioned mechanism of collective *ijtihād* entails serious difficulties. The collaboration between Muslim jurists and biomedical scientists was premised on the idea that the role of scientists would be restricted to providing biomedical and technical information about the issues at hand, whereas developing the Islamic perspective would remain the exclusive right of those who are experts in Islamic normative knowledge, namely the jurists. However, this division of tasks proved to be impractical and often unimplementable during the actual collective deliberations. It is true that some scientists are themselves willing to engage in the process of *ijtihād* and cross over the boundaries of their discipline by jumping to normative conclusions about how a specific issue should be judged from an Islamic perspective.[10] The real problem, however, seems to lie in the very nature of biomedical sciences. Unlike what Muslim jurists and some scientists think, biomedical information does not only convey value-neutral facts, but often also implies value-laden and normative positions. Additionally, it is true that both jurists and scientists can share common religious beliefs as Muslims, but they belong to different disciplines, each of which has its own terminologies, fact-finding methodologies, ways of reasoning, and also its own biases.

Just to give a concrete example showing how such challenges can affect the communication and collaboration between these two groups, I refer to discussions on the beginning of human life. Within Islamic jurisprudence, determining the beginning of human life is closely tied to the metaphysical concept of the soul, where life would start by the ensoulment of the embryo at a specific moment during pregnancy, a process determined in the Prophetic traditions. On the other hand, determining the beginning of human life in biomedical sciences cannot be based on a metaphysical concept but rather must be based on measurable and verifiable criteria that can be observed and tested through the scientific tools of the physician. Such discrepancies in the epistemology of each discipline created two main divergent approaches. The advocates of one approach were in favor of medicalizing the tool of determining the beginning of human life, and they argued that the recent advances in modern embryology makes dependence on metaphysics in such issues an archaic idea that cannot be part of our modern world. However, the proponents of the other approach could not envisage the possibility of betraying the long-established methodologies of *fiqh*, where scriptural references including a specified number of days after which ensoulment take place, cannot be overruled in the name of complying with scientific progress.[11]

Another challenge relates to the scope of interdisciplinarity in contemporary Islamic bioethical discussions. As mentioned above, many critics argue that the Islamic tradition cannot be reduced to the discipline of *fiqh* only and thus these discussions should be broadened by engaging other Islamic disciplines like theology, philosophy and Sufism. Additionally, the complexity of questions raised by modern biomedical technology cannot be properly and comprehensively understood by consulting experts in biomedical sciences only. Contributions from other disciplines like medical anthropology, sociobiology, and philosophy of medicine should also take part in these collective discussions. However, the abovementioned issue, resulting from involving biomedical scientists in the process of *ijtihād,* should forewarn us that broadening the scope of interdisciplinarity may also come with its own challenges.

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[1] Thomas J. Misa, "The Compelling Tangle of Modernity and Technology," in Thomas Misa, Philip Brey and Andrew Feenberg, eds., *Modernity and Technology* (The MIT Press, 2003), 3.

[2] Muḥammad al-Shinqīṭī, *Aḥkām al-jirāḥa al-ṭibiiya*. 2nd ed., (Jeddah: Maktabat al-Ṣaḥābā, 1994).

[3] Saʿd al-Shuwayrikh, *Aḥkām al-handasa al-wirāthiyya*. (Riyadh; Dār Kunūz Ishbīlya, 2007).

[4] Ismāʿīl Marḥaba, *Al-bunūk al-ṭibiyya al-bashariyya wa aḥkāmuhā al-fiqhiyya* (Jeddah/Cairo: Dār Ibn al-Jawzī, 2008).

[5] Mukhtār al-Sallāmī, *Al-ṭibb fī ḍawʾ al-īmān* (Beirut: Dār al-Gharb al-Islāmī, 2000).

[6] Muḥammad Naʿīm Yāsīn, *Abḥāth fiqhiyya fī qaḍāyā ṭibbiyya muʿāṣira* (Amman; Dār al-Nafaʾis, 2008).

[7] Muḥammad Raʾfat ʿUthmān, *Al-Mādda al-wirāthiyya: al-jīnūm* (Cairo: Maktabat Wahba, 2009).

[8] See for instance Nājī Ibrāhīm al-Suwayd, *Fiqh al-muwazanāt bayana al-naẓariyya wa al-taṭbīq* (Beirut: Dār al-Kutub al-ʿIlmiyya, 2002).

[9] See Mohammed Ghaly, "Islamic Ethics and Genomics: Mapping the Collective Deliberations of Muslim Religious Scholars and Biomedical Scientists," in Mohammed Ghaly, ed., *Islamic Ethics and the Genome Question* (Leiden: Brill, 2019), 47-51.

[10] See Mohammed Ghaly, "Biomedical Scientists as Co-Muftis: Their Contribution to Contemporary Islamic Bioethics," in *Die Welt des Islams,* vol. 55 (Leiden: Brill, 2015), 286-311.

[11] See Mohammed Ghaly, "The Beginning of Human Life: Islamic Bioethical Perspectives," *Zygon: Journal of Religion and Science, vol. 47.1* (Wiley-Blackwell, 2012), 175-213.

Reading Frankenstein in a Time of Germline Editing

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On the morning of November 26th, 2018, I met with sixteen Saint Anselm College first year students to discuss Mary Shelley's *Frankenstein*. The timing could not have been better to read a two-hundred year old text. That morning the news had broken that a Chinese scientist, He Jiankui, announced two live births from germline edited embryos.[1] Dr. Jiankui used the CRISPR-Cas9 gene editing tool that Natalie Kofler discusses in her essay in this Contending Modernities series. On that cold wintery morning, the book seemed less like early 19th century science fiction and more like a cautionary tale for our time.

During the seminar we discussed how Victor Frankenstein's unnamed creature destroyed Victor's life, whether Victor or the creature (or no one) was the sympathetic figure in the story, and whether or not Victor should have acceded to the creature's demands to create a female companion. We also took up questions related to having children and the obligations of creators to creatures. Given the news that had broken that morning, these questions took on new urgency as we debated the prospects of designing our own children.

The students noted that Victor immediately rejected the creature after bringing him to life. Some defended this response. These students argued that the creature failed to meet Victor's expectations; he was too gruesome and ugly to be lovable.

These students applied what I call the logic of creation to the case. The logic goes like this. Persons create things for a certain end. Chairs, for example, are created for sitting. All acceptance and rejection of the creation is predicated upon whether or not it fulfills its intended end. When the creation meets its goal, it is accepted. When it does not, it can be rejected and destroyed. And so, we keep functional chairs and trash the three-legged kind. Such rejection and destruction are permissible because the creation is owned by the creator. John Locke famously argued that goods become private property when a person combines his labor with what he is creating. The fruits of one's labor are privately owned by the laborer. Because the monster was Victor's creation, it was not unjust for Victor to drive him away. The monster was a "broken" creation, a three-legged chair if you will, worthy to share in such a chair's fate.

Others sympathized with the creature. They argued that only non-personal creations, such as chairs, should be created. While the word "begetting" never made its way into the conversation, their argument suggested that personal creatures should be begotten, never made.

As a theological ethicist, I heard what I call the "logic of begetting" in their arguments. Christianity's central dogmatic creed, for instance, suggests that the logic of begetting is different than that of creating. There we find that the second person of the Trinity, the Son of God incarnate in the person of Jesus Christ, "was begotten, not made." Human parents image God insofar as they beget, but do not create or design, their children. The process of begetting is mysterious, and retains a spirit of openness to whomever the child is because the child is not a manufactured product. Children emerge as gifts to parents. Gifts, Pope Benedict argued in *Caritas in veritate*, are gratuitously given, and are freely accepted.[2] Because gifts are gratuitously given by the giver, they should never be requested by the recipient. Christians throughout the world have managed to misunderstand this aspect of gifts through the creation of gift "wish lists" regarding Christmas and weddings. How many times have we requested a gift, only to be disappointed to not receive exactly what we wanted? In those moments we evaluate the gift before fully accepting it. At times, we ask the gift giver to exchange the gift for something "better." In these instances the experience of gifting has been lost. Compare those experiences with the times in which one has been surprised to receive a gift at all. In these moments, moments in which there is no expectation of or request for a gift, we are genuinely moved by the gift, and grow closer to the gift giver as a result. Here we experience the gratuitousness of a true gift and respond with appropriate gratitude for the gift, no matter how small it may be. In these instances we immediately accept the gift without first evaluating the gift's merits or flaws.

Children should be received in the latter manner, not the former. Parents should freely accept and love their children unconditionally. However, if we design our children, if we "ask" for certain kinds of children, we move away from understanding and accepting our children as gifts. Our acceptance of them becomes conditioned on whether or not they fulfilled the end we intended in creating them.

Although we may be able to edit out the genes at the germline level that code for diseases such as Tay Sachs or Huntington's, it would be immoral to do so. Germline editing (whether therapeutic or for purposes of enhancement) is morally wrong because it changes the relationship of parents and children from one of begetter-begotten to creator-creature. *Frankenstein* vividly depicts the dangers of such a relationship. Such a change harms the relationship of parents and children, rendering it more difficult for parents to unconditionally accept and love their children.

The scholars on the "Out of the Lab" podcast repeatedly queried the existence of universal moral norms to guide a cross-cultural ethical analysis of germline editing.[3] I believe that the logic of begetting/gifting is the best candidate for a universal moral norm to guide this analysis. While I have produced this argument from within the Christian tradition, one does not have to be Christian to believe that children should be begotten and should be accepted for who they are, and not who the parents would like the child to be.

Recall that the students who objected to Victor's actions did not argue that he usurped the role of God, as many Christians have argued regarding gene editing. Nor did they channel Maura Ryan's important approach in the "Out of the Lab" podcast, where she suggested that the debate ought to consider possible harms to the common good. Their argument did not emerge from religious principles. Instead, these students drew upon a normative account of the relation of parents and children. This account emerged inductively, from the experience of being a child and from the experience of other children. Personal and collective experience shows us that children rightly desire to be received and accepted by their parents as gifts, regardless of their abilities or genetic makeup.

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1 Pam Belluck, "Chinese Scientist Who Says He Edited Babies' Genes Defends His Work," *The New York Times*, November 29, 2018. https://www.nytimes.com/2018/11/28/world/asia/gene-editing-babies-he-jiankui.html.

2 Benedict XVI, *Caritas in Veritate,* encyclical letter, Vatican website, June 29, 2009. http://w2.vatican.va/content/benedict-xvi/en/encyclicals/documents/hf_ben-xvi_enc_20090629_caritas-in-veritate.html.

3 "Science and the Human Person Podcasts," *Contending Modernities*, http://contendingmodernities.nd.edu/about/research-areas/science-and-the-human-person/shp-podcasts/.

CRISPR-Cas 9, Practical Wisdom, and Human Identity

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The scientific evidence suggests that the CRISPR technique is more precise than older, cruder techniques of genetic engineering.[1] Most scientific discussions about CRISPR are likely to lean towards medical applications, especially its seeming promise with respect to currently incurable human diseases and its use as a tool in the knowledge of human genetics. The broader public debate has narrowed its focus to application questions in human genetics alongside worries about the slippage towards human enhancement, and associated issues of justice concerning access. Many of the specific ethical questions that arise in advisory bodies are the same ones that are already all too familiar to those who have worked in the ethics of human genetics, namely those questions on safety, scope of usage, and means of achieving the end sought. That is, such bodies are most comfortable dealing with the issues like safety, which amounts to a thin version of ethics that misses thicker ethical concerns.

What I want to offer here is not a claim to provide a possible consensus between such disparate groups, but rather a way of thinking which can help to rescue our ability to talk about more than safety and efficacy. This approach retrieves the virtue of practical wisdom, not least because I believe that it is relevant *even more* now that speculation about the possibility of accurate human gene editing is closer to becoming a reality.

Thomas Aquinas considered that there are small steps that ordinary people could take in order to acquire virtues, even those who did not necessarily have any particular religious faith. And crucial to those small steps is the exercise of practical wisdom. Practical wisdom is a source of insight and is a virtuous disposition that is particularly useful in the conduct of ordinary human affairs. As it is aimed at the common good, it can be applied in specific circumstances in different ways. Hence, a particular decision that follows the exercise of practical wisdom takes into account multiple factors in making that decision, even while keeping an open eye on whether that decision serves to achieve the goal of the common good.

While the moral virtues, such as justice and courage, on their own will incline their possessors towards right action, this inclination is not sufficient, which is why practical wisdom is so important. Practical wisdom helps to recognise those subtle differences that lead to a different course of action in given circumstances. Part of the challenge for CRISPR-Cas9, as with any other new and potentially influential technologies, is that ethical decision making should not consider only the implications for one individual or family, but should also consider the wider socio-political implications. Truly moral decisions are not based on autonomy alone.

Practical wisdom, for Aquinas, has eight qualities, all of which are important in making a good decision. These qualities are: memory, teachableness, acumen, insight, reasoned judgement, foresight, circumspection, and caution. Memory (*memoria*) must be ‘true to being.’ And it does not take long to realize that historical reflection forces a closer look at the long shadow of eugenics in the application of genetic science, a manipulation of human reproduction and discrimination against those with disabilities for ultimately political ends. Teachableness (*docilitas*), or open-mindedness, is a quality that many scientists will respect, since without open-mindedness discovery is much more difficult. But it is also a reminder that decisions are always embedded in complex networks of human needs and interests.

Acumen (*solertia*) includes the ability to act clearly and well in the face of the unexpected. Acumen makes it possible to act aright even when the time to make a decision is compressed. Insight and reasoned judgement, which are also in the list of intellectual virtues that practical wisdom requires, need to be brought to bear. Yes, some readers will now ask questions regarding, for example, *whose* insight and *which* reasoned judgements are assumed in such an account, but these questions do not undermine the effort to discern what should be done. What seems reasonable to one may not be to another, but in so far as prudential reasoning includes deliberation, it tries to take into account different reasonable points of view.

What additional elements need to be in place for practical wisdom to be possible? The first element here is *foresight*, which is the human corollary of divine providence, since divine providence always aims at the ultimate good, while foresight seeks to imitate that orientation. Foresight is the ability to know if certain actions will lead to a desired goal. The judgements of practical wisdom are not fixed or certain in ways that might be the case if it were simply an application of rules or principles. This component is crucial for judgments about CRISPR-Cas9, especially in view of the fact that many of the so-called predictive beneficial effects have not come to pass in genetic medicine. Is this newest and what looks like the most promising technology an exception to that trend, or is this yet another example of over-enthusiasm in the wake of a new and exciting discovery? Are the uncertainties sufficiently strong to be tolerated or not? And who will be the major beneficiaries?

Aquinas also includes circumspection and caution in the list of the components of practical wisdom. Circumspection is the ability to understand the nature of events as they are now, while foresight is the ability to understand events as they might be in the future. The difficulties with CRISPR-Cas9 are that it is very hard for a non-specialist to fully understand what is, in fact, certain knowledge and what is less so. Caution has to do with imprudent acts that are too hasty, and avoiding obstacles that might get in the way of sound judgements, though caution that leads to inaction is not really what Aquinas had in mind either. In this sense, freezing all action due to an over-inflated sense of caution may not be appropriate, but caution has to keep in mind the overall trajectory of scientific research in this field. Caution here refers not just to safety issues, but wider more substantial questions about the kind of human community that is envisaged—in other words, what human flourishing actually means. In addition, Aquinas also recognises the place of *gnome*, that is, the wit to judge when departure from principles is called for in given situations.

Practical wisdom as setting the mean of the moral virtues is concerned with individual prudential decisions. But practical wisdom reaches beyond this in order to inform political governance. While Aquinas's discussion of practical wisdom bears some relationship to that in Aristotle, in this respect it is different, for Aristotle confined his attention to individuals. The common good is that which is related to the good of all and the good of each, and in Aquinas's time it meant the state. While the rule of nation-states are more complicated now with international laws, and the power of transnational companies exceeds that of some states, the overall intention of political practical wisdom towards the common good still applies.

Part of the contestation of CRISPR is related to questions about what that good means, and for whom. In other words, what does it mean for a human community to flourish? Aquinas is also more communitarian compared with the individualism that prevails in the current climate, so when individual practical wisdom clashes with economic or state practical wisdom, the former has to give way to the latter. Distributive justice and political practical wisdom work together for the same end though they can be distinguished in their role. It may be that the rhetoric of the "common good" was once used to promote eugenic practices. But in the current context of deliberations over the use of CRISPR technologies, using such technologies to promote racial purity by a powerful elite for their own particular ends would be necessarily excluded. Hence, rather than opposing eugenic practices by avoiding any collective sense of what the good might require and resorting to individual autonomy as the way forward, a more promising approach is to insist on a greater scrutiny of what social, political, and collective goods require using the tools of distributive justice and political practical wisdom.

Just as individual practical wisdom sets the mean for the moral virtues, so political practical wisdom sets the mean for distributive justice. Distributive justice is concerned with the relationship between the community and individuals, but what this distributive justice might require is not self-evident in all cases, and needs to be supplemented by political practical wisdom in much the same way as correct decision making for the moral virtues must be supplemented by individual practical wisdom.

Political practical wisdom is one way of helping to heal the rift between public and private morality, and the false divide between a 'subjective' virtue ethic that is concerned with individuals and principled 'objective' approaches that are more often concerned with wider social contexts. This is particularly significant in adjudicating heated public contestations regarding CRISPR technologies, since much of the discussion seems, like many other controversial issues, to rest on key exemplars which provide the basis for lobbyists either in favour or against this technology. Take, for example, the case made by Erika Check-Hayden based on the example of Ruthie Weiss, who has albinism and who has appeared in media reporting on CRISPR. Check-Hayden reports that when you ask patients like Ruthie, or her parents, if they would they have used CRISPR to prevent albinism, the answer is a resounding No. Why? Because what makes Ruthie Ruthie is the challenge she has faced and the particular determination to live in spite of these disadvantages.

Poignant though this story is about the virtue of perseverance in the face of hardship, I am less convinced by arguments of this type. This is because the arguments rest on a particular subjective experience of an individual who suffers from a particular disability. Was it prudential for the parents to indicate that Ruthie should not have been engineered? Of course, simply from the parental perspective, given that Ruthie's life was viewed as positive, they would not have wanted Ruthie to be anything other than who she is. Their memory of the positive aspects of her life informed judgments about what was right to do. But what if both Ruthie and her parents had suffered inordinately from her condition and could imagine doing virtually anything to change it? In that case, the option of CRISPR could well have seemed prudential to those parents. The point is that prudence takes into account not just our subjective feelings and experiences but wider societal constraints, circumspection includes knowing *all the details* from many different perspectives, so familial anecdotes are insufficient to make public policy. Further, assuming, as the parents did, that Ruthie would have been changed for the worse, does not really understand the nature of genetic engineering. Ruthie would have been a very different child if engineering had been permitted, so it would be virtually impossible to project back into the past and ask if some of her unique characteristics could thereby be compromised. The voices of those who have been excluded from discussion certainly need to be taken into account, but as a way of informing wider discussion rather than resting on a few emotively charged media-driven examples.

Practical wisdom applies to different levels; the level of the individual, yes, but also at the level of the family, the community, and the state or system of governance. Such an approach which stresses a movement away from isolating the individual towards complex multivalent levels in envisaging the good applies whether or not a specific Christian and Thomistic understanding of that good is sought. To be clear: individual goods in the approach I am arguing for are not denied, but such goods are sought within a much broader context of what that good might mean as embedded in specific social contexts operating at different levels. Bigger questions that relate to that part of practical wisdom called *foresight* include taking account of broader consequences, such as whether the technology is desirable at all for the common good; thus, who is really going to benefit from the use of the technology, what implications are relevant for a given community, what impact such applications might have on the use of resources, and so on are just as important. Which population groups will be used in clinical trials that will inevitably be set up to test efficacy, such as gene technologies that work to 'correct' AIDS or other immune deficiency diseases such as Severe Combined Immune Deficiency (SCID)? Single gene diseases such as Tay Sachs may seem obvious as a first step in the application of CRISPR-Cas9, and may even be preferable for conservatives since the manipulation will be on sex cells rather than the embryo, but a prudential decision in a given community will also place such seeming advantages in a wider social and political context. Practical wisdom also helps to judge what the virtue of justice requires in given circumstances in so far as it is orientated towards the common good. It seems highly likely that the most vulnerable will be the target of any such campaign for trials in the lead-up to large-scale application in therapeutic treatments. Are all such treatments necessarily desirable as ends to promote overall human flourishing or not? However, in the Thomistic tradition practical wisdom provides the means, at least, to attempt to take account of a multiplicity of factors in decision-making, including what such 'balance' might look like in practice; for example, by giving moral priority to the weak, but not *just* those who are suffering various diseases.

Practical wisdom is not a panacea, but it may be an important alternative to the idea that all we need to do is apply fixed principles such as individual autonomy to ethical problems that are, at root, the same. A broad framework for decision making through a prudential lens acts as a guide that is less about absolute rules of right or wrong and instead concerns taking appropriate responsibility for human flourishing as perceived according to specific virtues of the human community, namely those virtues of practical wisdom, charity, compassion, and mercy.

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1 This blog draws on ideas that are further developed in the following: Celia Deane-Drummond, "The CRISPR Challenge and the Beatific Vision: Recovering Practical Wisdom as a Guide for Human Flourishing," in Eric Parens and Josephine Johnson, eds., *Human Flourishing in an Age of Gene Editing (*Oxford University Press, 2019), *in press*.

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