LOSING OUR DIGNITY

How Secularized Medicine Is Undermining Fundamental Human Equality

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To my parents, Mary Ann and Raymond James, who raised me (by both instruction and example) to see the same image and likeness of God in every single human being.

Introduction

Can Fundamental Human Equality Survive Secularized Medicine?

Take a moment to think about people in your extended family and other social circles. It may not come to our conscious attention very often, but I suspect most of us have encountered a wide range of human difference, especially when it comes to neurological diversity. An uncle braving Alzheimer's disease. A cousin's prematurely-born child fighting for her life in the bed of a neonatal intensive care unit. A neighbor and war veteran suffering mental illness from post-traumatic stress disorder. A daughter's genius classmate who is off to college next year at age fifteen. A ridiculously happy younger brother with Down syndrome. The list of examples could be nearly endless.

We think even less often, I suspect, about what makes all these different kinds of human beings equal. By "equal" I'm not referring to sameness with regard to merely accidental traits, like how high they can jump or how powerful their memory is. No, here I am invoking what makes these human beings fundamentally equal to one another and to all human beings in their very essence. Being prompted to consider such a topic may seem strange, even offensive. Many of us rightly believe that a minimally decent culture must be based on fundamental human equality. Most of the Western world operates

as if it is obvious that all human beings have it, even if we sometimes disagree about what such equality means. Indeed, this may be the great moral insight of Western culture, held by an overwhelming majority across a range of political affiliations and tribes.

But many secular¹ philosophers and other thinkers have struggled to come up with a sound basis for this kind of fundamental human equality. The theistic founders of the United States assumed that their audience would overwhelmingly agree that it is "self-evident" that all humans are created equal in dignity by God.² But that is no longer the case for many who hold power over life and death in the Western world. In our post-Christian culture, especially (but not only) among some in medicine whose opinions are authoritative and influential, a focus on levels of ability relative to one's autonomous will, self-awareness, rationality, productivity (especially as understood by a consumer culture that worships buying and selling), moral capacity, communication, and the like have led some to notice that not all human beings have these abilities in equal measure.³ Indeed, some fellow members of the species Homo sapiens do not appear to have them at all. This helps explain why some of these thinkers have made a distinction between "human beings" and "persons." In this view, persons (that is, those who exhibit the kind of relevant abilities just mentioned) are indeed all equal. But not all human beings are equal. And not only that: in this view, certain human beings who are deemed non-persons may be classified as mere objects and discarded or even killed without significant moral or legal concern.4

Now, those who uphold fundamental human equality might dismiss the person vs. human being distinction as coming out of an academic fantasyland that very few who live in the real world believe in. I am sympathetic to the spirit of this critique, especially in other contexts, but in this case it doesn't apply. Particularly in the last fifty years or so, these ideas have made their way from the academic ivory tower into mainstream medical ethics and mainstream medicine. And given the authority and power medicine has had in the broader culture—especially about sacred matters of life and death—this book will focus on how such authority and power have put an increasing number of human beings outside the circle of protection based on fundamental equality.

This exclusion is happening largely without anyone realizing that rejecting Christian theology (and similar views held in Judaism and Islam) as the foundation of values undergirding our public policies has put fundamental human equality at risk. Yes, the founders of what would become the United States—especially given how they treated women and Blacks—failed to live out their belief in God-given human dignity and fundamental equality. But the ideal was never abandoned, and subsequent generations tried to live out the Christian ideal of equality more consistently.

This problem of inconsistency is not, obviously, unique to the US founders. Much of Christendom betrayed its own principles in this regard, especially via colonization of the so-called "New World." However, it was a Christian theology of universalism—focused on

fundamental human equality—that ended up becoming the basis of the critiquing forces which eventually won the day. Here I have in mind the views associated with sixteenth-century Dominican missionary friars Antón Montesino and Bartolomé de las Casas. In response to members of their Church (and even their own order) who argued in favor of exploiting the native peoples of the New World, these friars castigated their fellow Christians using appeals to fundamental human equality. Montesino, for instance, delivered this astonishing sermon to a crowded church in Santo Domingo, Dominican Republic, on the Fourth Sunday of Advent in 1511:

You are all in mortal sin. You live in it, you die in it. All because of the cruel tyranny you exercise against these innocent peoples. Tell me, by what right and with what justice do you so violently enslave these Indians? By what authority do you wage such hideous wars against these people who peacefully inhabit their lands, killing them by unspeakable means? How can you oppress them, giving neither food nor medicine and by working them to death, all for your insatiable thirst for gold? And what care are you providing them spiritually in teaching them about their God and creator, so they are baptized, hear Mass, and keep holy days? Are they not human beings? Do they not have rational souls? Are you not obligated to love them as you love yourselves?

Notre Dame moral theologian David Lantigua points out that the universalism these Spanish Dominicans defended went on to serve as the foundation for what in the West would eventually be called universal human rights.⁵ Even secular giants like the philosopher Jürgen Habermas have come to appreciate the unique role Christian thought has played in what he called "egalitarian universalism." There is no alternative to Christianity, says Habermas, upon which to ground our contemporary notion of universal human rights.⁶

But over the last half-century something has changed. Contemporary Western culture has surrendered this deeply theological legacy more generally, but the surrender is especially advanced in a secularized and even irreligious understanding of medicine and health care.7 This has put fundamental human equality at risk. Indeed, if we continue on our current path—if we cannot find a way to recover this legacy—the idea of fundamental human equality may simply die out. The damage already done has had disastrous consequences for some of the most vulnerable human beings among us, but this book will show that our rejection of human equality is on the verge of claiming a new, large, and growing set of victims: human beings with late-stage dementia. Indeed, the COVID-19 pandemic has revealed that a large-scale marginalization of this disabled population may already be underway.

This book sounds a cultural alarm about these trends, especially with regard to key stages at which whole populations have lost their fundamental equality. It will do so by focusing first on the stories of individuals put at risk

by our rejection of fundamental human equality and then connect their stories to broader historical developments and ethical arguments.

Chapter 1 begins by demonstrating how contemporary Western health care owes its existence to religious (and especially Christian) institutions and ideas. It then shows how a secularized medical culture developed and how this culture affects our foundational moral views, with a particular focus on its rejection of the equality of all fellow human beings in favor of the equality of persons with traits like autonomy, rationality, and self-awareness. It will also show how, in recent years, the culture of medicine and medical ethics has become intentionally and openly hostile to religious ideas and theological perspectives. It will finish by concluding that, though this culture imagines or pretends to be neutral, the debate over human vs. personal equality cannot take place in an imagined secularized nowhere. Religious and spiritual views must be engaged on the same playing field as secular views of what is ultimately true and good.

The next several chapters of the book focus on key medical developments over the last half-century, with attention to their impact on particularly vulnerable human beings. Chapter 2 begins with the story of Jahi McMath and the debate over living human beings with dead (or mostly-dead) brains. Chapter 3 tells the story of Terri Schiavo and the interesting new debate over human beings deemed to be in a vegetative state. Chapter 4 focuses on the story of the "Roe baby," who prompted the landmark US Supreme Court case on abortion, *Roe v. Wade.* Chapter 5 examines

the story of Alfie Evans and the contemporary debate over the moral and legal standing of babies and toddlers with neurodegenerative disease.

Chapter 6 tells multiple stories about the future victims of the cultural rejection of human equality if we stay on this terrible course—with a particular focus on human beings who have late-stage dementia. Because they frequently are no longer autonomous, self-aware, productive (again, especially from the perspective of consumer culture), or rational, they no longer have the traits of persons as defined by a secularized medical (and legal) establishment. It is therefore only a matter of time before we follow our principles where they lead and deem these people (and likely others with profound mental disabilities) to be human non-persons as well. The pressure to do this will be especially intense in the coming years because—as is the case to one degree or another in all of the stories just mentioned—adequately respecting the full and equal dignity of these human beings requires addressing the problem of scarce medical resources. Especially in a consumer culture which encourages us to live ever more "productive" lives, will we spend these resources on human beings who for all the world look like they fail contemporary tests for personhood? The pressure will be high to avoid allocating these resources to such populations, especially as (1) fiscal indebtedness puts massive pressure on national health-care budgets and (2) baby boomers and Generation X continue to age and many millions more are faced with very expensive dementia care.8

Many traditionally religious people are already quite aware of the victims produced by this rejection of fundamental human equality and worry about those who may be next. But they are also quite aware that, if this powerful secularizing influence cannot be reversed, intentional religious communities (a paradigmatic example might be the Little Sisters of the Poor) who welcome these vulnerable human beings into the intimate spaces of their lives can and will provide a bulwark against these practices. This book concludes with stories of international religious communities from ages past that provide hopeful models for our own cultural moment.

But just before that, chapter 7 calls for dialogue with those who are not as comfortable with traditional religious ideas—or at least not as comfortable placing them at the foundation of our cultural values and legal protections. The dialogue I propose appeals to the sensibilities of secular progressives with respect to social equality and social justice as a way of bridging a gap with religious traditionalists. I suggest that this dialogue highlights a common goal: resisting our consumerist tendency to rate the value of human beings based on what they can produce or on their level of ability, often in "ableist" ways which discriminate against the disabled, presuming their lives and contributions to be inferior. Such a dialogue would bring forward areas in our shared visions of the good (even if it will not be perfectly realized) which suggest that all human beings must be recognized as morally and legally equal regardless of what they can do, whether or not they happen to be autonomous, and whether or not they are considered productive members of society. If that dialogue does not bring results (or takes longer than a decade or so to produce them), however, I argue that traditional religious communities (local congregations as well as vowed religious orders) must band together to care for these vulnerable human beings in a sign of opposition to a culture that has rejected their fundamental human equality. Indeed, if the past is any guide, new religious orders will rise up (and current ones will reorient themselves) to meet the need posed by this new threat.

But it is difficult to see how religious institutions alone—at least without some kind of larger cultural religious revival—could meet the prodigious levels of need if those with late-stage dementia are abandoned by the broader culture. In order to maximize the chances of success in meeting the coming challenge, we must reclaim a vision that considers the most vulnerable human beings as the moral and legal equals of those who have power over them. It is a particular challenge when so many of those with such power have largely rejected the central theological idea behind the vision: that fellow members of the species Homo sapiens share a dignified nature in common. Our dignity comes from a common nature that bears the image and likeness of God.9 Because every living human being shares this dignified nature—regardless of age, level of ability, disease, etc.—we can speak about equality.

Can those who hold different theological and philosophical understandings still coalesce around a vision of the good that reasserts fundamental human equality? I think there are reasons for hope, but we obviously don't know yet. Here is one thing we do know: for decades now

a poison, one that is fatal to fundamental human equality, has been spreading throughout our most powerful cultural and medical institutions. That poison is a new kind of secularity, one that is hostile to the theological ideas undergirding fundamental human equality. The antidote requires dialogue that is at least open to (and perhaps even willing to embrace) traditional religious views about the God-given human nature we all share. Because medical culture is uniquely responsible for so much of the damage, it must lead the way by engaging in cultural reforms that protect fundamental human equality. Happily, not only is this possible, but in some contexts the antidote has already been administered and the healing already begun.

Chapter One

The Secularization of Medicine and Medical Ethics

Deep Connections between Medicine and Religion

For most of human history, the practice of healing and the practice of religious faith were closely connected. Often the healer and the religious figure were the same person. In fact, despite the hard separation between the two in the developed West, the historical connection is so strong that contemporary secularized medicine retains vestiges of religiosity, for instance, in the training for and practice of health care. Physicians, distinguished in their special white coats, are endowed with the bearing and cultural authority of a modern-day shaman or priest. Contemporary ceremonies at which medical students first receive their white coats—and, later on, formally recite a (properly adapted, of course) version of the Hippocratic Oath resemble religious liturgies or priestly ordinations. 10 The near complete privacy attached to the physician-patient relationship resembles the seal of the confessional, where a priest may not share what a person reveals in the sacrament. The authority of medical science—although under threat in some quarters—is still one of the closest things we have to a secular Delphic oracle. During the COVID-

19 pandemic, for instance, titles like "physician," "scientist," or "epidemiologist" were invoked as quasi-religious authorities. In public discourse, the most fatal accusation is that one's "anti-science" approach is blocking medicine's truth and progress.

In some ways this separation is obviously a good thing. Those who value real results for real people don't want a health care based on reading entrails or ritual sacrifice. But in other ways the separation is a significant problem. As we will see in more detail, a secularized (and hyper-specialized) culture can reduce caring for a patient's health merely to maintaining or fixing her organic plumbing, so to speak. This is an important part of health care, of course: several people I love are alive today because of these technical skills. But such skill, however impressive, has been largely and unnecessarily severed from something at least as important: treating the human person in the fullness of who she is, including her particular understanding of the good. And this requires considering the kinds of existential questions and ultimate concerns engaged by theology.

Christianity, in particular, shaped Western culture's understanding of medicine in this light—not least because the Gospel of Jesus Christ is chock full of healing stories. Consider, for example, the Gospel reading in the Roman Catholic liturgical calendar for the Third Sunday of Advent:

When John heard in prison of the works of the Messiah, he sent his disciples to him with this question, "Are you the one who is to come, or should we look for another?" Jesus said to them in reply, "Go and tell John what you hear and