

Bioethics and the Character of Human Life

Gilbert Meilaender

When the Hastings Center was founded in 1969 as the first bioethics "think tank" in the United States, it planned research in four areas of concern: death and dying (and efforts to overcome the limits of our finitude); behavior control (and the relation between human activities and the happiness attendant upon them); genetic screening, counseling, and engineering (including questions of kinship, procreation, and attitudes toward future generations); and population policy and family planning (which, at least implicitly, asked about the relation of our own time to future generations). If we add explicit attention to moral problems raised by human experimentation, the list could still today serve well as a brief itemization of the central concerns of bioethics. The reason these issues have been and continue to be central, and no doubt the reason bioethics has been an object of such lively public interest and concern, is obvious: These topics are not driven simply by concern for public policy regulations; rather, they involve some of the most important aspects of our humanity and raise some of the deepest questions about what it means to be human.

There is no neutral ground from which to discuss such questions. They are inevitably normative, value-laden, metaphysical in character. Our starting point, therefore, should not deny this. Our approach cannot be that taken by the Human Embryo Research Panel (established by NIH in the mid-1990s), which characterized its stance as follows:

Throughout its deliberations, the Panel considered the wide range of views held by American citizens on the moral status of preimplantation embryos. In recommending public policy, the Panel was not called upon to decide which of these views is correct. Rather, its task was to propose guidelines for preimplantation human embryo research that would be acceptable public policy based on reasoning that takes account of generally held public views regarding the beginning and development of human life. The Panel weighed arguments for and against Federal funding of this research in light of the best available information and scientific knowledge and conducted its deliberations in terms that were independent of a particular religious or philosophical perspective.

There are no such terms, and the public is not likely to believe such protestations of neutrality. We are not philosopher-kings who can adjudicate disputes between

Gilbert Meilaender holds the Richard and Phyllis Duesenberg Chair in Theological Ethics at Valparaiso University and is a member of the President's Council on Bioethics. This essay was originally prepared as a discussion paper for the President's Council on Bioethics.

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conflicting views without ourselves being parties to the argument. We are human beings, invited to reflect upon what that humanity means and requires in the field of bioethics.

This essay aims to invite such reflection and conversation. It explores, without attempting to resolve, some of the background issues that will inevitably shape thought in bioethics. Acknowledging from the outset that much more might be said about any of them, I will unpack briefly four aspects of a truly human bioethics.

The Unity and Integrity of the Human Being

The beginning of wisdom in bioethics may lie in the effort to think about what human beings are and why it matters morally. From several different angles, medical advance has tempted us to lose sight of any sense in which the embodied human being is an integral, organic whole. We can illustrate this first by noting how advancing genetic knowledge encourages us to think of human beings as no more than collections of parts.

I begin with some sentences from Ernest Hemingway's *The Old Man* and the Sea:

He looked down into the water and watched the lines that went straight down into the dark of the water. He kept them straighter than anyone did, so that at each level in the darkness of the stream there would be a bait waiting exactly where he wished it to be for any fish that swam there ... I have no understanding of it and I am not sure that I believe in it. Perhaps it was a sin to kill the fish ... He urinated outside the shack and then went up the road to wake the boy. He was shivering with the morning cold ... Then he was sorry for the great fish that had nothing to eat and his determination to kill him never relaxed in his sorrow for him. How many people will he feed, he thought. But are they worthy to eat him? ... That was the saddest thing I ever saw with them, the old man thought. The boy was sad too and we begged her pardon and butchered her promptly ... The boy did not go down. He had been there before and one of the fishermen was looking after the skiff for him.

Hemingway's prose is, of course, generally regarded as clear and straightforward, and I suspect that any single sentence in this passage was probably simple and transparent to the reader. I also suspect that the whole of it probably made almost no sense at all. There's a reason for that. The sentences in the passage are drawn at random from pages 29, 104–5, 22, 74, 48, and 123—in that order.

One of the great blessings of the computer age, we are sometimes told, is that one can move sentences or whole paragraphs with ease. One needn't work out a thesis or an argument. Just write—and then move the pieces around later. It's as if the argument were somehow built up from below—from words, phrases, and sentences moved around, combined and recombined. As if a thesis would

just emerge without an organizing intelligence, an authorial perspective, at work from the outset.

In our age of rapid advances in genetic knowledge, an analogous image has been used to characterize our humanity. Consider, for example, the following frequently quoted passage from biologist Thomas Eisner:

As a consequence of recent advances in genetic engineering, [a biological species] must be viewed as ... a depository of genes that are potentially transferable. A species is not merely a hard-bound volume of the library of nature. It is also a loose-leaf book, whose individual pages, the genes, might be available for selective transfer and modification of other species.

I have tried to provide a humble illustration of this by splicing together sentences from different pages of just one book—producing thereby something unintelligible. And, letting our imaginations roam just a bit, I might also have spliced in sentences from *Anna Karenina* and *A Christmas Carol*—producing thereby something we may not even know how to name. To think of a book this way would be to ignore the presence of an authorial hand. It would treat a book as if it were just the sum of a number of words, sentences, or paragraphs. We might try to think of human beings (or the other animals) in the same way, and, indeed, we are often invited to think of them as collections of genes (or as collections of organs possibly available for transplant), but we might also wonder whether doing so loses a sense of ourselves as integrated, organic wholes.

Even if we think of the human being as an integrated organism, the nature of its unity remains puzzling in a second way. The seeming duality of person and body has played a significant role in bioethics. As the language of "personhood" gradually came to prominence in bioethical reflection, attention has often been directed to circumstances in which the duality of body and person seems pronounced. Suppose a child is born who, throughout his life, will be profoundly retarded. Or suppose an elderly woman has now become severely demented. Suppose because of trauma a person lapses into a permanent vegetative state. How shall we describe such human beings? Is it best to say that they are no longer persons? Or is it more revealing to describe them as severely disabled persons? Similar questions arise with embryos and fetuses. Are they human organisms that have not yet attained personhood? Or are they the weakest and most vulnerable of human beings?

Related questions arise when we think of conditions often, but controversially, regarded as disabilities. Perhaps those who are deaf and have learned to sign create and constitute a culture of their own, a manualist as opposed to an oralist culture. If so, one might argue that they are disabled only in an oralist culture, even as those who hear would be disabled if placed in the midst of a manualist culture. So long as the deaf are able to function at a high level within that man-

ualist culture, does it matter what way they function? Notice that the harder we press such views the less significant becomes any normative human form. A head, or a brain, might be sufficient, if it could find ways to carry out at a high level the functions important to our life.

Such puzzles are inherent in the human condition, and they are sufficiently puzzling that we may struggle to find the right language in which to discuss that aspect of the human being which cannot be reduced to body. Within the unity of the human being a duality remains, and I will here use the language of "spirit" to gesture toward it. As embodied spirits (or inspirited bodies) we stand at the juncture of nature and spirit, tempted by reductionisms of various sorts. We have no access to the spirit—the person—apart from the body, which is the locus of personal presence; yet, we are deeply ill at ease in the presence of a living human body from which all that is personal seems absent. It is fair to say, I think, that, in reflecting upon the duality of our nature, we have traditionally given a kind of primacy to the living human body. Thus, uneasy as we might be with the living body from which the person seems absent, we would be very reluctant indeed to bury that body while its heart still beat.

In any case, the problems of bioethics force us to ask what a human being really is and, in doing so, to reflect upon the unity and integrity of the human person. We must think about the moral meaning of the living human body—whether it exists simply as an interchangeable collection of parts, whether it exists merely as a carrier for what really counts (the personal realm of mind or spirit), whether a living human being who lacks cognitive, personal qualities is no longer one of us or is simply the weakest and most needy one of us.

Finitude and Freedom

In one of his delightful essays, collected in *The Medusa and the Snail*, the late Lewis Thomas explores the deeply buried origins of our word "hybrid." It comes from the Latin *hybrida*, the name for the offspring of a wild boar and a domestic sow. But in its more distant origins the word, as Thomas puts it, "carries its own disapproval inside." Its more distant etymological ancestor is the Greek *hubris*, insolence against the gods. That is, buried somewhere in the development of our language is a connection between two beings unnaturally joined together and human usurping of the prerogatives of the gods. Thomas summarizes his excursion into etymology as follows: "This is what the word has grown into, a warning, a code word, a shorthand signal from the language itself: if man starts doing things reserved for the gods, deifying himself, the outcome will be something worse for him, symbolically, than the litters of wild boars and domestic sows were for the Romans."

That is only one side of the matter, however. For Thomas can also write in a provocative paragraph:

Is there something fundamentally unnatural, or intrinsically wrong ... in the ambition that drives us all to reach a comprehensive understanding of nature, including ourselves? I cannot believe it. It would seem to be a more unnatural thing ... for us to come on the same scene endowed as we are with curiosity ... and then for us to do nothing about it or, worse, to try to suppress the questions. This is the greater danger for our species, to try to pretend ... that we do not need to satisfy our curiosity...

Using some old religious language, we might say that Thomas sees how, given the duality of our nature, we may go wrong in either of two ways: pride or sloth. As prideful beings, we may strive to be all freedom—acknowledging no limits to our creativity, supposing that our wisdom is sufficient to master the world. As slothful beings, we may timidly fear freedom and ignore the lure of new possibilities. Either is a denial of something essential to being human, a reduction of the full meaning of our humanity. Clearly, Thomas is inclined to fear most the dangers of sloth, but that may be only the mark in him of a passing modernity.

In any case, the duality of body and person is clearly related to what we may call a duality of finitude and freedom. The human being is the place where freedom and finitude meet; hence, it will always contravene something significant in our humanity to act as if we were really only free personal spirit or only finite body. Yet, because of the two-sidedness of our nature, we can look at a human being from each of these angles.

Drop me from the top of a fifty-story building and the law of gravity takes over, just as it does if we drop a stone. We are finite beings, located in space and time, subject to natural necessity. But we are also free, able sometimes to transcend the seeming limits of nature and history. As I fall from that fifty-story building, there are truths about my experience that cannot be captured by an explanation in terms of mass and velocity. Something different happens in my fall than in the rock's fall, for this falling object is also a subject characterized by self-awareness. I can know myself as a falling object, which means that I can to some degree "distance" myself from that falling object. I cannot simply be equated with it. I am that falling object, yet I am also free from it. Likewise, I am the person constituted by the story of my life. I cannot simply be someone else with a different history. Yet I can also, at least to some degree, step into another's story, see the world as it looks to him—and thus be free from the limits of my history. The crucial question, of course, is whether there is any limit to such free self-transcendence—whether we are, in fact, wise enough and good enough to be free self-creators or whether we must acknowledge destructive possibilities in a freedom that refuses any limit.

Understanding our nature in this way, we can appreciate how hard it may be to evaluate advances in medicine, claims about the importance (or even obligatoriness) of research, attempts to enhance our nature in various ways, or efforts to master death. If we simply oppose the forward thrust of scientific medicine, we fail to honor human freedom. The zealous desire to know, to probe the secrets of nature, to combat disease—all that is an expression of our freedom from the limits of the "given." Yet, of course, if we can never find reason to stop in this restless attempt at mastery, we may fail to honor the finite limits of our wisdom and virtue. In fact, it may trivialize freedom to think of it as limitless.

There is probably no cookbook that gives the recipe for knowing how best to honor—simultaneously—both our freedom and our finitude. That there ought to be limits to our freedom does not mean that we can easily state them in advance. But a truly human bioethics will recognize not only the creative but also the destructive possibilities in the exercise of our freedom.

The Relation Between the Generations

Because we are not only free but are also embodied spirits, the biological bond that connects the generations has moral meaning for us. We occupy a fixed place in the generations of humankind. Both Jews and Christians inculcate a command that calls upon us to honor our father and mother. It is a puzzling duty: to show gratitude for a bond in which we find ourselves without ever having freely chosen it. Yet, of course, insofar as the child is a "gift," we might say that father and mother have also not chosen this bond. They too simply find themselves in it. A truly limitless freedom to make and remake ourselves, to pursue our projects in the world, would divorce us from the lines of kinship and descent that locate and identify us. Would that be the fulfillment of our nature? Or alienation from it?

It is, I think, fair to say that several different aspects of medical advance—in reproductive technologies, in psychopharmacology, in genetic screening, and one day perhaps in techniques for genetic enhancement or cloning—have made it more difficult for both parents and children simply to honor and affirm the bond between the generations and accept as a gift the lines of kinship that locate and identify them.

We are given a captivating image of the child as gift in Galway Kinnell's poem, "After Making Love We Hear Footsteps."

For I can snore like a bullhorn
Or play loud music
or sit up talking with any reasonably sober Irishman
and Fergus will only sink deeper
into his dreamless sleep, which goes by all in one flash,
but let there be that heavy breathing
or a stifled come-cry anywhere in the house
and he will wrench himself awake
and make for it on the run—as now, we lie together,
after making love, quiet, touching along the length of our bodies,
familiar touch of the long-married,

and he appears—in his baseball pajamas, it happens, the neck opening so small he has to screw them on, which one day may make him wonder about the mental capacity of baseball players— and flops down between us and hugs us and snuggles himself to sleep, his face gleaming with satisfaction at being this very child. In the half darkness we look at each other and smile and touch arms across his little, startlingly muscled body— this one whom habit of memory propels to the ground of his making, sleeper only the mortal sounds can sing awake, this blessing love gives again into our arms.

This image, of the child as a gift that is the fruition not of an act of rational will but an act of love, can be contrasted with an image of the child as the parents' project or product. For the latter way of thinking, having a child becomes a project we undertake to satisfy our purposes and make our life complete. And, of course, our desire may be not simply for a child but for a child of a certain sex, with certain characteristics or capacities. Human cloning, were it possible, would from one angle bring to completion this image of the next generation as a product of rational will, undertaken to fulfill our desires. From another angle, of course, cloning might be thought to break entirely the bond between the generations, since in the instance of cloning we do not even know how to name the relation between progenitor and offspring.

Pondering how best to think about the relation between the generations, we are driven once again to questions about when we should use our freedom to seek mastery or control and when, by contrast, we should accept certain limits inherent in human bodily life. The twentieth century began with considerable confidence in the possibility for eugenic control of the relation between the generations. That confidence suffered eclipse in the face of revelations of Nazi eugenic experiments, but it has reemerged in quite different ways. Today, any state-sponsored eugenic ideology would surely face considerable opposition, but instead we have (to use the barbarous locution now common) "privatized" eugenic decisions.

Here again, there is no simple recipe for making decisions. Parents must indeed exercise reason and will to shape their children's lives. They do not and should not simply accept as given whatever disabilities, sufferings, or (even just) disappointments come their children's way. Still, as every child realizes at some point, the conscientious parent's effort to nurture and enhance can be crushing. It can make it difficult to accept the child who has been given, impossible to say simply "it's good that you exist."

The implications for the bond between the generations become still more far-reaching when we consider that research may make possible alteration of the human germline. More than fifty years ago, without any precise knowledge of such intervention, C. S. Lewis contemplated such eugenic efforts, and he noted the salient point that relates to my theme here: "What we call Man's power over Nature turns out to be a power exercised by some men over other men with Nature as its instrument." Alterations in the human germline would be an awe-some exercise of human freedom, and, if used in the struggle against disease, might promise (over time) a cure not only for individual sufferers but also for the human species. Yet, of course, the exercise of freedom is also an exercise of power, and just as—synchronically—parents need to allow the mystery of humanity to unfold in the lives of their children, so also—diachronically—one generation needs to allow others their freedom. How we sort out these competing goods will reveal much about how we understand the character of human life.

Suffering and Vulnerability

Part of the sadness of human life is that we sometimes cannot and other times ought not do for others what they fervently desire. With respect to the relief of suffering, the great quest of modern research medicine, this is also true. Some relief we are unable to provide, a fact that only gives greater impetus to our efforts to discover causes and cures. It is precisely the fact of our inability to help in the face of great suffering that fuels the research "imperative" of which we are all beneficiaries. Nevertheless, it is important to ask how overriding this "imperative" is—whether there are means to the possible relief of suffering which we ought not take up, and whether it would be good if we were not vulnerable to suffering.

So great is our modern concern to overcome suffering, we may almost forget that there are perspectives from which this goal is deliberately made secondary. For anyone drawn to Stoic philosophy, for example, bodily suffering could not finally be of great significance. It can harm us only if we are deceived into supposing that anything other than one's own inner self-mastery really counts. Thus, Seneca tells the story of Stilbo, whose country was captured, whose children and wife were lost, and who "as he emerged from the general desolation alone and yet happy, spoke as follows to Demetrius, called Sacker of Cities because of the destruction he brought upon them, in answer to the question whether he had lost anything: 'I have all my goods with me!'" And Seneca's comment demonstrates the power of Stoicism.

There is a brave and stout-hearted man for you! The enemy conquered, but Stilbo conquered his conqueror. "I have lost nothing!" Aye, he forced Demetrius to wonder whether he himself had conquered after all. "My goods are all with me!" In other words, he deemed nothing that might be taken from him to be a good.

While it may be hard sometimes not to be repelled by the harshness of such Stoic vision, it is equally hard not to recognize the nobility of an outlook that makes

how we live more important than how long. And if it seems to denigrate too much the goods of everyday life, we can detect a similar nobility in another ancient worldview that does not think these ordinary goods of no account.

Discussing some sermons of St. Augustine, first preached in the year 397 but newly discovered only in 1990, Peter Brown notes that Augustine was often required to preach at festivals of the martyrs. At Augustine's time the cult of the martyrs continued to be of profound importance to average Christians, for persecution was still a recent memory. The martyrs were the great heroes, the "muscular athletes" and "triumphant stars" of the faith. But, Brown suggests, one can see Augustine quite deliberately making the feasts of the martyrs "less dramatic, so as to stress the daily drama of God's workings in the heart of the average Christian." For that average believer did not doubt that God's grace had been spectacularly displayed in the courage of the martyrs. What he was likely to doubt, however, was whether such heroism could possibly be displayed in his own less dramatic and more humdrum day-to-day existence. So Augustine points "away from the current popular ideology of the triumph of the martyrs to the smaller pains and triumphs of daily life."

An example of how he does this is instructive. "God has many martyrs in secret," Augustine tells his hearers. "Some times you shiver with fever: you are fighting. You are in bed: it is you who are the athlete." Brown comments:

Exquisite pain accompanied much late-Roman medical treatment. Furthermore, everyone, Augustine included, believed that amulets provided by skilled magicians ... did indeed protect the sufferer—but at the cost of relying on supernatural powers other than Christ alone. They worked. To neglect them was like neglecting any other form of medicine. But the Christian must not use them. Thus, for Augustine to liken a Christian sickbed to a scene of martyrdom was not a strained comparison.

Here again—though in a way of life that will be, in some respects, quite different from Stoicism—one sees an outlook for which relief of suffering, however desired and desirable, is not the overriding imperative of life.

The Stoics remind us that an authentically human life may prize goodness more than happiness and, indeed, that true virtue may be achieved precisely when we seem most vulnerable to suffering. The ancient Christians remind us that one might value competing goods (such as faithfulness to God) more highly than relief of suffering.

In the modern world we may admire such views, but we tend to keep our distance from them. The quest for health (or is it Health?), the attempt to master nature in service of human need and to refuse to accept the body's vulnerability to suffering, has characterized the modern period. If such a world offers less occasion for the display of nobility, it does not despise the sufferings of countless ordinary people—and that is no small gain. The research that makes such gains

possible is greatly to be desired, but is it also imperative? Many questions of bioethics, especially of research, invite us to try to determine the difference between the desirable and the imperative.

One of the now classic essays in bioethics, first published in 1969, was Hans Jonas's "Philosophical Reflections on Experimenting With Human Subjects." It articulated at the very outset of the development of bioethics a difference between the desirable and the imperative. Jonas noted that sometimes it is imperative that a society avoid disaster; hence, we conscript soldiers to fight. The fact that we do not (ordinarily) conscript experimental subjects indicates that, however much we value the improvements to life made possible by medical research, we do not think of ourselves as having an obligation to make such improvements. Research brings betterment of our life; it does not save our society. It serves health—not Health.

Because this is true, we seek volunteers, not conscripts, in the cause of medical progress. And because this is true, far from using those who might be most readily available as handy research subjects, we should be most reluctant to use them. Indeed, Jonas defended "the inflexible principle that utter helplessness demands utter protection." That is, the vulnerability that ought to concern us most is not our own vulnerability to illness and suffering but, rather, the vulnerability of those whose very helplessness might make them seem all too readily available to us in our never-ending struggle to make progress. If "utter helplessness demands utter protection," we will have to ask ourselves whether it is right to build our medical progress upon the sacrificed lives of those—such as spare embryos—who seem expendable because doomed to die anyway.

Finally, we must also ask ourselves whether there might be research that is neither imperative nor desirable. If goodness is to be prized more than happiness, the endless quest to remake and enhance human life, to overcome vulnerability, may destroy other, equally important goods of an authentically human life. We recognize this truth, for example, in our role as parents. Conscientious parents want with all their heart to give their children what they need, to make them happy. They also know, however, that some goods cannot be given but must be developed and achieved in the child's own life. We cannot simply give our children the happiness that comes from finding a vocation, a spouse, or inner strength. Trying to give such goods would, in effect, subvert and undermine them. So too we have to ask whether there might be research aims which, however well-intentioned, would seek to bestow traits of character and skill that have no value apart from the process whereby they are developed and achieved. We are, that is, forced to ask hard questions about projects aimed at "enhancing" human nature.

Where do such ambivalent reflections lead? Bioethics directs our attention to *Bios*—to human bodily life in all its vulnerability and with all the goods (bio-

logical, rational, cultural, spiritual) that characterize it. For that life we seek health, and in that life we seek to avoid suffering. These are great goods of bodily life, but they sometimes compete with other, equally human goods. Relief of suffering is surely of great importance; yet it remains only one desideratum of a truly human life. At a few times and places it may seem imperative; at many times and places it is desirable; in some times and places, because we judge other, competing goods to be even more fundamental to human life, it may be neither imperative nor desirable.

In Search of Wisdom

Many of the threads of this discussion come together in one of the most famous passages in Dante's *Divine Comedy*. In Canto XXVI of the *Inferno*, with Vergil still his guide, Dante encounters the "false counselors," those who had used their gift of great intellect in ways that ultimately led others astray. Here it is that Dante meets Ulysses (Odysseus) and hears his story. In a passage that Dorothy Sayers called "perhaps the most beautiful thing in the whole *Inferno*," a passage that is evidently Dante's own invention and is certainly found neither in Homer nor in Vergil, Dante describes the last voyage of Ulysses.

Ulysses has made it safely home from years of wandering after the Trojan Wars. He has returned to his home—and to Ithaca, which he is to rule. But, in this invention of Dante's, he does not remain there.

No tenderness for my son, nor piety To my old father, nor the wedded love That should have comforted Penelope

Could conquer in me the restless itch to rove And rummage through the world exploring it, All human worth and wickedness to prove.

And so, Ulysses gathers together a crew to set sail once more. They reach the very boundary of the inhabited world as they know it, and Ulysses urges his shipmates on that they may have the new experience

Of the uninhabited world behind the sun. Think of your breed; for brutish ignorance Your mettle was not made; you were made men, To follow after knowledge and excellence.

They forge ahead, only to sail into a storm which whirls the ship around three times, then lifts the poop high and plunges the prow down into the water.

And over our heads the hollow seas closed up.

When we remember that Ulysses is in hell, that as a false counselor he has used his great intellect to lead others astray, the point of the passage might seem clear. As a warning to Dante's readers it depicts, in the words of John Sinclair, "an eternal and insatiable human hunger and quest after knowledge of the world." The restless desire to know without limit, the will to sail uncharted waters, disastrously overcomes even the deepest loyalties of our finite life: to home, to father, to wife, to son. The passage is, I said, a warning; yet, Sinclair immediately adds: "and as we read it we forget the sin in contemplation of the sinner's greatness."

It is evidently one of the puzzles Dante scholars face: that Ulysses' proud and dignified description of his last voyage, a tale told quite literally by one who is damned, should have been made so enticing and compelling an account of the human need "to follow after knowledge and excellence." But that, perhaps, is the truth we have to ponder. Our finitude and freedom are not easily reconciled. The goods of life compete with each other, and if we do evil it may be done with great dignity and appeal—done even in the service of some good. The wisdom bioethics seeks is the wisdom to discern right order among such competing goods.