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EDITORIAL

SELECTING OUR EMBRYONIC CHILDREN

NIGEL M. DE S. CAMERON, PH.D.

The scale of the questions raised by the access that in vitro and other artificial reproductive technologies (ART) have given us to the process of human procreation is hard to estimate. They have often seemed to cluster around our moral view of the early embryo, as if addressing, resolving, or evading that question would somehow set the problematics of ART to rest. Yet whatever view is taken—whether there is full human moral worth in the early embryo, no moral significance whatever, or whether we accept the studied ambiguities promoted in the Warnock Report and echoed in many jurisdictions (in which there is an acknowledged but undefined "special moral status")—two fundamental questions are left to haunt the discussion.

The first reflects the revolutionary implications of our having seized the natural process of human procreation and turned it into something better understood by analogy with the artifice and industry of humankind. The final significance of this entirely fresh modeling of the reproductive capacities of *Homo sapiens* may not be clear for generations to come.

The second reflects one single aspect of ART, an almost accidental implication, that if we have the early embryo in our hands, as it were, between the nodes of fertilization and implantation, we have an opportunity to make a selection. There is no such opportunity in the course of normal mammalian procreation. The closest analogue we may find lies of course in elective abortion, if it is employed for reasons derived from the particular nature of the embryo or fetus, though the analogy is imperfect, since abortion entails a dramatic intervention. Because implantation is a deliberate act, a work of the human will, the default would seem to be re-set the other way around. While at one level it seeks to mimic the natural process, it is in this case implantation that involves an intervention. And so, to many, there is something natural about the idea that embryos should be screened, selected, quality-tested, and subject to a fundamental assessment process derived from the wishes, beliefs, interests, and it may be tastes and predilections, of the commissioning couple, or perhaps of other parties (such as the state). You may wish a child free of inherited disease, or a girl rather than a boy, or one who will not be likely to get fat or bald or whatever trait may be unfashionable and have some basis in genetics; or, perhaps, you may be seeking a tissue donor for your other child.

I am not here commenting on these particular options.My plea is that whatever our view on this or that, we be not unaware of their implications as a totality, in shifting dramatically the balance of power between one generation and the next; and in demonstrating the mechanisms that could readily be taken up by a new eugenics.

The United Kingdom is famed for its having both the most organized regulatory regime for ART, and also perhaps the most liberal underlying policies. The United States, as is well know, has very little regulation of any

kind, and despite much recent discussion and federal funding prohibitions on destructive embryo research, there is no federal policy framework for ART. By contrast, Germany has a highly developed biopolicy that, for example, requires that all embryos created through ART be implanted, driving a stake through the heart of the selection principle with prison terms for those who break the rules. It is unclear where, within these varied options, the future policy trend may lie. As I have recently argued in the *Family Law Quarterly* (2005), the ambiguities of such vague principles as the "special status" of the embryo may in fact be necessary to the continuance of liberal ART policies, since they rightly or wrongly buffer public opinion from the perhaps more logical options—that the embryo is a mere laboratory artifact, or that it carries unique human dignity and moral worth.

There is growing awareness of the reach of embryo screening techniques, and their capacity to be used for purposes that take ART far from its original function as a means of enabling the infertile to procreate. How these matters are resolved in public policy will have profound effects on the relations between the generations, and, even beyond that, on our underlying idea of what it means to be human.

Opening remarks at the January 14, 2006, conference on Embryo Screening sponsored by the Scottish Council on Human Bioethics and the Ethics and Medicine Trust.

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GUEST COMMENTARY

HUMAN DIGNITY: STILL DEFYING DEVALUATION

MATTHEW EPPINETTE, M.A. AND ANDREW FERGUSSON M.R.C.G.P.

Is the concept of "human dignity" of any use in bioethics? Does it shed important light on the whole range of bioethical issues, from embryo research and assisted reproduction, through biomedical enhancement, to care of the disabled and the dying? Or is it, on the contrary, useless—at best a vague substitute for other, more precise notions, at worst a mere slogan that camouflages unconvincing arguments and unarticulated biases?[1]

This stark dichotomy defines the debate over human dignity. In December 2005, the U.S. President's Council on Bioethics met to consider "Human Dignity as a Bioethical Concept." The transcript of the sessions reveals that the Council quickly agreed that human dignity is useful in bioethics, and moved to questions more at the heart of the issue: What is human dignity? Where does it come from? What implications does it hold for bioethics? We give our answers here.

What is human dignity?

Dignity is, simply, "the quality of being worthy of esteem or respect."[2] Human dignity, then, is the recognition that human beings are worthy of esteem or respect. Words that come to mind here include value, worth, importance, and significance. The Encyclopedia of Bioethics defines the primary use of human dignity as "an attribute of all human beings that establishes their great significance or worth."[3] A Guest Commentary in Ethics & Medicine concludes that human dignity is: "The exalted moral status which every being of human origin uniquely possesses."[4] The same article offers the following detail:

> Human dignity is at its core an ontological reality irreducible to perceptual esthetic categories. The word "dignity" is thus appropriate to beings who are substances and not mere collections of properties. Dignity bespeaks something inseparable from human nature, something placed there, something shared by all people. One comprehends dignity less through reason and more through intuition, in a way that is comprehensible to human reflection universally. No scientist or physician has ever observed human dignity; it is an inference. Forever escaping the nets of scientific measurement, dignity defies devaluation.[5]

Why, though, is this so?

Where does human dignity come from?

At the heart of many of the complex biotechnological developments that the President's Council and others grapple with is the question of what it means to be human. Is it some capacity or some combination of capacities that makes an individual uniquely human and therefore the possessor of dignity? Is it demonstrating autonomy, rational thought, self-awareness, freedom? Or is there something innate to human beings? Is human dignity about doing or being?

If human dignity is rooted in capacities, in what humans can do, then human beings can be reduced to performance, and dignity can be gained or lost according to ability. To the contrary, human dignity is an inherent aspect of human beings, the result of being created in the image of God: "Human beings are constituted by their bearing the divine image (*imago Dei*), and from that fundamental fact flows their unique and inviolable dignity as persons."[6]

Because human beings bear God's image in this world, we are his representatives, stewards of his creation. Our stewardship extends not only to animals and plants and earth, but also, in some way, to one another. In short, we are tasked with caring for one another. Christian faith communities have a long history of involvement in medicine as a key way of fulfilling this mandate.[7]

What implications does human dignity hold for bioethics?

How do we connect the irreducible value of all human beings to specific issues in bioethics such as cloning, embryo research, access to healthcare, end-of-life suffering, and the like? This is where the hard work of bioethics lies.

The fact that all human beings have an innate and irreducible dignity means that all deserve equal respect and treatment. No human being lacks human dignity; therefore no human being should for example be subject to the risks associated with cloning or to willful destruction in the first days of life. At the same time, every human should have fair and equal access to the care his or her condition requires, and should be supported and comforted by a community of people in life's final days and hours.

Arriving at conclusions on these issues may seem easy, but connecting with integrity to human dignity requires reflection, interpretation, and translation. This is the task that the Center for Bioethics and Human Dignity, amongst other groups, has taken upon itself in its labor to educate, equip, and engage.

While all human beings have an innate and irreducible dignity, it is important that we recognize it is possible to lose sight of one's own dignity. In disability and sickness, it is the sense of dignity, not dignity itself, which is lost. It is the duty of bioethics and healthcare to restore this sense of dignity. Further, it is possible to be treated in ways inconsistent with one's dignity. The recognition that each and every human equally possesses dignity serves as motivation for treating one another properly; that is, with dignity.

Conclusion

Human dignity is the fundamental issue in bioethics and every account of human dignity is inevitably based on a view of what it means to be human. Human dignity is properly grounded in the view that humans bear the image of God. Consequently, every member of our human family is of inestimable worth and must be protected and treated with utmost respect at every stage of life. It is gratifying to see that in considering this vital issue the President's Council on Bioethics has upheld dignity, not devalued it.

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The Moral Status of the Embryonic Human: Religious Perspectives

JOHN JEFFERSON DAVIS, PH.D.

I. Introduction

"The concept of an embryo is a staggering one, and forming an embryo is the hardest thing you will ever do," states Scott Gilbert in the seventh edition of his text, *Developmental Biology*. "To become an embryo, you had to build yourself from a single cell. You had to respire before you had lungs, digest before you had a gut … form orderly arrays of neurons before you knew how to think … a machine is never required to function until after it is built. Every animal has to function as it builds itself."[1] This scientist's sense of wonder at the miracle of embryonic development was echoed long ago in a biblical text to be examined in this presentation: "I praise you because I am fearfully and wonderfully made; your works are wonderful, I know that full well" (Psalm 139:14).

The title originally suggested for this presentation was "The Status of the Human Embryo: Religious Perspectives." The title I would prefer to use is slightly but significantly different: "The Moral Status of the *Embryonic Human* : Religious Perspectives." In the first title, "human" is an adjective, and "embryo" a noun, and the focus of attention is on "embryo." In the second title—which I prefer—"human" is the noun, and "embryonic" is the adjectival qualifier, with the emphasis on *human*. The term "embryonic human" expresses the conviction that the entity at the center of the current debate is a living member of the *human* community that, for the time being, is developmentally in an embryonic state.

The "Religious Perspectives" perspectives here considered will not include the Jewish, Islamic, or Hindu traditions, but will be limited to a consideration of Christian understandings of the moral status of the embryonic human.[2] Jewish understandings of texts in the Hebrew bible are valuable resources for Christian interpretation, but it must be recognized that post-biblical, rabbinic readings of the texts have their own "halakhic" or legal agendas, and consequently, skew —from a Christian perspective—the readings of these texts. That is to say, the rabbinic readings of the texts are not so much concerned with the question of the *intrinsic value* in the sight of God of the early embryonic human, but rather, what legal obligations might be incumbent on adult women or others as the result of, say, a miscarriage or premature birth.[3] Consequently, Jewish perspectives will be taken into account when examing texts from the Hebrew scriptures, but will not in themselves be the focus of this study.

Neither will this study attempt to reflect the full breadth of "Christian"unde rstandings of this issue. The historical development of Christian understandings

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of the moral status of the embryonic human has been ably traced by David Jones and others in the excellent essay, a "*Theologian's Brief:* On the Place of the Human Embryo within the Christian Tradition."[4] This presentation is in agreement with the central thrust of the historic Christian tradition, more recently expressed in the encyclical of Pope John Paul II, *Evangelium Vitae,* that the human being is to be respected and "treated as a person from the moment of conception."[5] Rather, the limited focus of this study is to examine, from an evangelical Protestant perspective, several crucial biblical texts[6]—Psalm 139:13-16, and the infancy narratives of Luke (Lk.1:26-45)—with a view to demonstrating that these texts, rightly understood, support the "personhood from conception" understanding of the moral status of the embryonic human.

The question of the moral status of the embryonic human has been a matter of public controversy, of course, since the legalization of abortion in America by the 1973 U.S. Supreme Court decision, *Roe v. Wade.* Two other developments, however, have given the issue fresh urgency: the development of human in vitro fertilization techniques in 1978, with the unanticipated consequence of more than 400,000 "surplus" human embryos now being stored cryogenically in U.S. fertility clinics,[7] and the first isolation of human embryonic stem cells in 1998, and subsequent calls for the harvesting of such cells for research purposes.[8] These two developments give additional impetus to a fresh examination of relevant biblical texts with a view to considering what light they can shed on the moral status of the embryonic human being.

As already been noted, this study reflects a "personhood from conception" point of view, and the further conviction that such a perspective is consonant with the scientific facts of human genetics, fertilization, and embryology, as well as with a rigorous philosophical analysis of the concept of "person."[9] Before proceeding with the analysis of the biblical texts, however, it is necessary to note two objections that might seem to prevent from the outset the drawing of the conclusions that will here be argued. First, it may be objected that this project is problematic in that it proposes to read back into ancient, pre-scientific biblical texts modern scientific understandings of human embryology. This study is quite aware of the enormous gulf between ancient and modern notions of embryological development. The point is not to read a modern scientific understanding back into these texts, as though the purpose of the inspired writers was to anticipate modern science, but rather, to focus on the sacred writers' clear witness to the reality of divine involvement in the womb *from the beginning* of human life, however the mechanics of that may have been understood. The reading that will here be proposed is a *theological* reading of the texts, with awareness of ancient and current science as relevant background information.

Second, it could be objected that biblical statements such "in sin did my mother conceive *me*" (Ps.51:5) are purely *retrospective* in nature, the language of adult speakers that have no direct bearing on the metaphysical question of the (personal) status of the individual before birth, long before the actual biblical statements were made. To this objection it may be replied that the objection itself presupposes a faulty "Cartesian" concept of personhood, one that sees active, fully present *consciousness* as the defining trait of the person, rather than a characteristic that is manifested at the proper developmental stage of

the human, given proper circumstances.[10] This paper proposes an alternative understanding of personhood not based primarily on human consciousness, but rather, on the *divine* consciousness of, recognition of, and divine parenting of the embryonic human from the very beginning of the life cycle.

II. Psalm 139:13-16: Divinely Inspired "Ultrasound"

During the last several decades the development of real-time obstetric ultrasound technology has allowed expectant parents to peer inside the womb and to begin to form personal bonds with their unborn children[11] Psalm 139:13-16, one of the most important passages in the Old Testamentfor this discussion, could be thought of, as it were, as a "Spirit-inspired ultrasound" that allows us to see from a God's-eye point of view the wonder of the intrauterine development of the embryonic human. It is abundantly clear that God, the divine "parent" has already "bonded" with the child that he is making:

> 13. For you created my inmost being; you knit me together in my mother's womb. 14. I praise you because I am fearfully and wonderfully made; your works are wonderful, I know that full well. 15. My frame was not hidden from you when I was made in the secret place. When I was woven together in the depths of the earth, 16. Your eyes saw my unformed body (*golem)*. All the days ordained for me were written in your book before one of them came to be. [NIV]

Verse 13 begins with the emphatic Hebrew pronoun "you" (*ki-attah*), emphasizing the activity of God.[12] The psalmist is led to praise God (v.14) as he reflects on the mysteries of his prenatal development. The process of the formation of his embryonic body in the womb is not described in merely biological or impersonal terms, but is understood to be an expression of the creative power and direct personal involvement of God.[13] Verses 13-16 are set in the larger context of God's omniscient knowledge of all his circumstances and thoughts (vv.1-6), and the presence of the Spirit of God throughout the entire creation (vv.7-12). Those places and activities that are normally hidden from human sight—such as the inner thoughts of man or nascent life in the womb—are fully open to God, who is the Creator of all things and the Creator of man from the very first moments of his existence.

It is worth noting that certain issues of interest to the ancient Greeks and to other ancient authors are not addressed here: the respective male and female contributions to the body and physical characteristics of the developing child; the factors in determining the sex of the child; the exact length of normal gestation, and so forth.[14] By way of comparison, the author of the *Wisdom of Solomon,* perhaps a Hellenistic Jew at Alexandria during the latter part of the first century B.C., displays an interest in the more "scientific" question of the respective contributions of the man and woman to the generative process:

> I am also mortal, like all men … in the womb of mother I was molded into flesh, within the period of ten months compacted with blood, from the seed of man and the pleasure of marriage. (7:1,2)

Here the writer may reflect the Aristotelean view that the mother's menstrual blood provides the "matter" of the developing embryo's body, while the father's sperm is the active principle that gives it form.[15] The psalmist, however, is not concerned with matters of *secondary causation*, but rather, with God as the ultimate and *primary* cause of prenatal growth and development: the interests are theological rather than "scientific" in the modern sense; not just with bare facts, but with embryological facts as *valued* in the sight of God.

In verse 16 the psalmist uses the word *golem,* "embryo," which appears only here in the Massoretic text of the Hebrew Bible. The word suggests an "unshaped mass," such as a piece of clay or block of wood that has not yet been shaped into a vessel.[16] The *golem,* the "unformed" human in the womb, refers to the embryonic human in the first 40 or so days of gestation.[17] The point to be noted here is that according to v.16, during the earliest stages of human life—when the embryo does not *look* human—vulnerable human life is *seen* by God and is the object of divine awareness and concern.

The reference in v.16 to the *eyes of God* seeing the embryo is significant. In biblical theology, God's eyes or God's seeing imply not only knowledge or awareness, but can more specifically imply watchful care and concern as well. The land of Israel, for example, "… is a land the Lord your God cares for; the eyes of the Lord are continually on it from the beginning of the year to its end" (Deut.11:12). God's eyes are on the faithful in the land, that they might dwell with him (Ps.101:6). God's eyes watch over the exiles in Babylon for their good, to bring them back to the land (Jer.24:6). God saw Hagar in her distress after she was cast out of Abraham's household (Gen.16:13). God sees the misery of his people in Egypt (Ex.3:17), and determines to redeem them. God promises that his eyes and heart will always be upon the temple (I Kgs.9:3). To have God's face and eyes looking upon one can signify experiencing God's care and favor, as in the Aaronic benediction: "The Lord bless you and keep you; the Lord make his face shine upon you" (Num.6:24,25). These examples indicate that God's "seeing" can express God's personal concern for and personal, covenantal relationship with the object of his sight—in this context, his concern for David as an embryonic human.[18]

God's intrauterine creative activity in Ps.139:13-16 can be seen in the broader context of the biblical witness to the *sovereignty of God in human conception*. This is notably evident in the patriarchal narratives of Genesis. Consider the following: The Lord prevents Sarah from having children (Gen.16:1). Abraham is subsequently promised a son when Sarah is 90 years old, and he 100 (Gen.17:19). God declares that he has made Abraham the father of many nations (Gen.17:5)—the divine word calling into existence "things that are not yet"—but shall be by the omnipotent power of God (cf. Rom.4:17: "… the God who gives life to the dead and calls things that are not as though they were").[19] God closes the wombs of the women in the household of Abimilech, king of Gerar (Gen.20:18). Isaac prays for Rebekah, his barren wife, and the Lord answers his prayer and Rebekah conceives (Gen.25:21). While they are still in the womb of Rebekah their mother, God elects Jacob rather than Esau, even though Esau would be the firstborn (Gen.25:23). Jacob's wife Rachel is barren, prays to the Lord, and God answers her prayer in the conception and birth of Joseph (Gen.30:22).

Elsewhere in the Old Testament redemptive history, the Lord gives the Hebrew midwives children (Ex.1:15). God "remembers" Hannah in her barren condition, and she conceives and gives birth to Samuel (I Sam.1:19,20). The angel of God appears to Manoah's barren wife, and she is told that she will conceive—a promise fulfilled in the birth of Samson (Jdg.13:3). When Jeremiah is called to be a prophet, he is told that even before God formed him in the womb, God had set him apart to be a prophet to the nations (Jer.1:5).[20]

The sovereign *creative* power of God in the womb is to be seen, furthermore, as linked with God's power and purposes to *redeem* his people. A striking example of such linkage between God's power as Creator and Redeemer can be seen in the intertestamental text II Maccabees 7:22,23, where a courageous Jewish mother, whose seven sons are martyred during the Maccabean revolt, commends her dying sons to God with her hope in the resurrection of the dead:

> 22. I do not know how you [her sons] came into being in my womb. It was not I who gave you life and breath, nor I who set in order the elements within each of you. 23. Therefore the Creator of the world, who shaped the beginning of man and devised the origin of all things, will in his mercy give life and breath back to you again, since you now forget yourselves for the sake of his laws.

The wondrous power of God to form the child in the womb testifies the ominipotent power of God to create the world out of nothing and the first man from the dust of the ground. The creative power of God who created the child in the womb bolsters faith in the God who can raise that martyred child from the dust of death and despair.

This biblical linkage between God's sovereign power to create in the womb and his power to redeem his people is prominent in the theology of the prophet Isaiah. It is the Lord "… who created you, O Jacob, he who formed[21] you, O Israel: fear not, I have redeemed; I have summoned you, you are mine" (Is.43:1). "This is what the Lord says: he who made you, who formed you in the womb, and will help you …" (Is.44:2). God says to Israel, "I have upheld you since you were conceived, and have carried you since your birth"—in contrast to the pagan idols that can neither carry nor save (Is.46:3). The God who is the Redeemer of Israel is the one who formed Israel in the womb, who made all things, who alone stretched out the heaven (Is.44:24). Isaiah clearly testifies that God's creative activity in the womb points beyond itself to the identify of God as the one who alone can truly redeem humankind from slavery and death.[22]

Before turning to the infancy narratives in Luke, it will be worthwhile to briefly note a variety of biblical texts that attribute theological terms or personal characteristics to the unborn in the womb. The effect of such texts is to "personalize" the unborn; they contribute in a significant way to a hermeneutical framework that can help us to transcend the limitations of ordinary culturally conditioned perceptions, and to see, as it were, the embryonic human being from a "God's-eye" point of view. We note, for example, that the category of *election* is applied to Jacob while he is still in the womb of his mother Rebekah

(Gen.25:23). David confesses that he was *sinful* from the time of his conception (Ps.51:5).[23] The categories of *calling* and *consecration,* usually used of adults, are attributed to Jeremiah (Jer.1:5) and Paul (Gal.1:15). God's *steadfast love* was experienced by Job within the womb (Job 10:12).[24] John the Baptist is filled with the Holy Spirit from his mother's womb (Lk.1:15). Elizabeth conceived a *son*[25] in her old age (Lk.1:36); here the biblical text speaks not of some impersonal "products of conception," but rather "son" is the direct personal object of the verb conceive. Names are divinely revealed and given before birth to Ishmael (Gen.16:11), John the Baptist (Lk.1:13), and Jesus (Mt.1:21). These divinely appointed names are unmistakable indications that God viewed these individuals as *persons* before birth, from the very beginning of the human life cycle, inasmuch as a personal name is the crucial marker of human personal status.

In regard to this significant phenomena of divine prenatal naming, one might note the important concept of a "performative utterance" developed by the philosopher J.L. Austin.[26] Austin points out that language, as a human activity, functions not only to describe states of affairs (e.g., "Springfield is the capital of Illinois"), but can also bring new states of affairs into being (e.g., "by the authority vested in me … I now declare you to be husband and wife"). Under the right circumstances and conditions, the declaration by a speaker actually constitutes the reality of which he or she speaks.[27] The naming of Ishmael, John the Baptist, and Jesus before birth actually constitute them as persons before their lives are visible to others, while they are still in the womb. And not only God's words, his "performative utterances," but also the divine actions of calling, setting apart, electing, caring for, sustaining, and even filling with the Spirit show God can recognize and constitute humans as members of the covenant community from the time of conception.

The social learning theory pioneered by George Herbert Mead argued that the human self only develops in the context of interaction with other persons.[28] The words and gestures of the parent are clues by which the child develops a sense of herself as a person. Our sense of personhood emerges as we are recognized as persons by significant others. If the Lord of the covenant recognizes an embryonic human as a member of the covenant, then so should we; we can choose to see the embryonic human from the perspective of the Creator, rather from the perspective of fallen human culture.

III. The Infancy Narratives of Luke: Divine Kenosis, Trinitarian Enactment of Ps.139; Jesus the Blastocyst

Having examined Ps. 139:13-16 in the larger context of a biblical theology of the sovereignty of God in human conception, we now turn to a section of the infancy narratives of Luke (Lk.1:26-45), which shows in striking fashion how both Jesus and John the Baptist emerge as significant persons on the stage of redemptive history while they are yet in their mothers' womb. These Lucan texts can be seen as paramount witnesses to the miracle of divine "kenosis", and of a "trinitarian enactment" of Ps.139:13-16. The eternal Logos, the second person of the Trinity, "emptied himself" (Phil.2:7, heauton ekenosen), or "made himself nothing" by entering human history as a single, supernaturally

fertilized ovum in the womb of the virgin Mary—by becoming an embryo, a tiny, insignificant "nothing" from the point of view of human culture and common sense. The inspired description of David's embryonic development in the womb (Ps.139:13-16) is now re-enacted by the Triune God: God the Father sending the angel Gabriel to the virgin Mary in the annunciation, God the Holy Spirit giving her a supernatural conception, and God the Son—David's greater Lord (Mt.22:45)—entering into the process of embryonic development that he himself had designed as the co-creator of all things (Jn.1:3). Jesus Christ, the Second Adam, recapitulates the history of the human race, by himself participating in the human life cycle from its very beginning.

Luke tells us that in the sixth month of Elizabeth's pregnancy with John the Baptist, the angel Gabriel was sent by God to Nazareth to announce to Mary her election to be the mother of the messiah (Lk.1:26f.).[29] The angel says to her, "You will conceive in your womb (*sullempse en gastri*) and bear a son, and you will call his name Jesus" (1:31). From the time of conception, Mary is directed to view the miracle to take place within her body in very personal terms, in terms of her *son,* and in terms of the very specific personal name *Jesus,* "savior." There is no place here for some impersonal biological terminology of the "products of conception." The divine "speech-act" mediated by Gabriel confers personal status on Jesus in his embryonic state.

Gabriel goes on to tell Mary that her relative Elizabeth has conceived a son (*suneilephen huion*) in her old age and is now in the sixth month of her pregnancy with John (1:36). The word son (*huion*) is here the direct personal object of the verb conceive, again indicating that from the angelic/divine point of view, John was a *son* from the moment of conception. After the annunciation, Mary arises "with haste" (*meta spoudes*)[30] and journeys to the home of Elizabeth in the hill country of Judah (1:39). The distance involved would have been about 80-100 miles;[31] according to Josephus, it took about three days for pilgrims from Galilee to reach Jerusalem.[32] When Elizabeth hears Mary's greeting, John leaps in her womb and Elizabeth is filled with the Holy Spirit (1:41). Since the role of John in redemptive history is to be the forerunner (Lk.1:17), to prepare the people for the advent of the messiah, his leaping in the womb should be seen not primarily as a response to Mary, but rather as an intrauterine response to Jesus, newly conceived in the womb of Mary. Here is the first encounter between Jesus and John the Baptist—Jesus as an embryo, John the Baptist at sixth months gestation age, both still in the womb and hidden from human sight.[33]

Elizabeth, filled with the Holy Spirit, exclaims, "Why am I so favored that the mother of *my Lord* should come to me?" (1:43). As Bock notes, Elizabeth is here functioning as a prophetess, declaring the divine significance of John's leaping within her womb.[34] She recognizes Mary not as the mother of a thing, but as the mother of "my Lord"; the fruit of her womb was not mere tissue, but the incarnate "Lord."[35] Jesus the messiah, who is fully human and fully God, is person and Lord as a blastocyst, as a very early stage embryo. Elizabeth's Spirit-inspired, and hence divinely authorized speech-act invokes the personal status of the newly-conceived Jesus, who is already present as "Lord." The newly-conceived Jesus—as blastocyst—was at the same developmental stage now occupied by countless embryonic humans—abandoned in cold storage or

otherwise—who are now to be victimized by having their bodies dismembered for the harvesting of their embryonic stem cells.

The Christian tradition has recognized Jesus's conception by the Holy Spirit as the beginning of his human life. The Apostles' Creed states that he was "conceived of the Holy Spirit, born of the Virgin Mary."[36] The Formula of Union, 433 A.D., following the Third Ecumenical Council of Ephesus in 431, is even more explicit, affirming that "… God the Word took flesh and became man and from his very conception (*kai ex autes tes sullempseos*) united to himself the temple he took from her" [Mary].[37]

Some readers might be tempted to dismiss this reading of the Lucan narrative in support of Jesus' personhood from conception by pointing to the exceptional status of Jesus (and John) in human and redemptive history. While it is true that Jesus is the "great exception," it is more relevantly true that he is the Second Adam, the grand exemplar of humanity as it was meant to be, and the one who shared in every facet of our human existence, sin excepted (Heb.2:14; 4:15). If Jesus as the Second Adam enjoys personal status from the time of conception, the implication is that this discloses a divine intention that all the sons and daughters of Adam deserve to be regarded so as well.

IV. Some Objections; Concluding Observations

As we move this discussion toward a conclusion, a number of common objections to the personhood-from-conception position will be mentioned, together with a brief responses.

1. "Fetal Wastage": there is some evidence that perhaps 25-30% (or possibly more) of implanted embryos spontaneously miscarry.[38] This raises a theological question: If God infused the soul at the moment of conception , why would he allow so many embryonic humans to perish? This can be seen as a special case of the more general question of theodicy or the problem of evil. In a fallen world, human beings can perish for a variety of reasons at any point in the human life cycle. That God permits *X* to perish is not evidence that God considers *X* to be less than personal. The fact that the innocent can suffer is not a sufficient reason to deny their personal status, but rather, could be motivation to remedy, where possible, the causes of such suffering.

2. "Twinning": During the first fourteen or so days of gestation, it is possible for the human embryo to split and form identical twins. This may occur in about 3.5 of every 1000 live births.[39] This rare possiblility of "twinning" is said to preclude the unambiguous presence of a person or individualized human being from the time of conception. This objection, however, is based on a confusion of two related but distinct concepts: *individuality* and *indivisibility*.[40] An individual—i.e., a distinct, recognizable member of a given class—does not need to possess the property of *indivisibility* in order to be a recognizable individual. The "United States of America" was a recognizable individual member of the community of nations prior to the Civil War, even though it could have been possible for the nation to have been divided into two nations by the conflict over slavery. Some human embryos may possess the property of being able to split, but they are nevertheless still recognizalbe, living, individual members of the class of human beings of the species *Homo sapiens*.

3. "Consciousness": It is quite evident that embryonic human beings lack the conscious experiences of persons already born. This lack of consciousness is thought by some to be a compelling argument for denying personal status to the embryonic human. This could be called an example of a "Cartesian fallacy"—identifying the essence of personhood with the presence of a particular state of consciousness. If the experience of full consciousness is a necessary condition for full personhood, then such a definition denies personhood not only to human embryos, but to brain-damaged persons, and even to normal persons who happen to be asleep. On the contrary, consciousness should be viewed not as the "root" of personhood but rather as a normal "fruit," a property that manifests under appropriate circumstances and at the normal stages of the human life cycle. It is not so much the circumstantial and momentary presence of consciousness that marks the person, but rather, the *intrinsic capacity* to manifest consciousness given right circumstances. Embryonic humans possess such an intrinsic capacity.

4. "Development": It is the case that the Christian understanding of the moral status of the human embryo has developed over time; but this is no argument against the truth of its conclusions. Theologians have attempted to integrate new scientific understandings into their moral teachings. By 1869, the Roman Catholic Church had officially endorsed the position of immediate animation or ensoulment, consistent with new discoveries in embryology.[41] On the other hand, in the context of the current controversy over embryonic stem cell research, some proponents of this research have disregarded accepted scientific definitions of when human life begins for political purposes—moving backward, in effect, from the best scientific knowledge. In May of 2005, for example, the Massachusetts legislature changed the existing law that recognized fertilization as the beginning of human life, altering it to read that life begins at the moment the embryo is implanted in the womb.[42] Proponents of the bill, S. 2039, "Definition of When Human Life Begins," argued that it was important to change the definition because "… researchers need to harvest embryos up to day 14."[43] Legislatures feared that without such an alteration of the definition, such research would move to California or New Jersey, and potential jobs and revenues would be lost to the state economy.

5. "Ethnocentrism": "A human embryo does not look like a human being." This is an egregious example of ethnocentrism and cultural prejudice—where the "Other" is excluded from the circle of humanity on the basis of appearance. History is littered with examples of such ethnocentrism. The first European settlers in Australia had great difficulty in seeing the aboriginal peoples as truly human; they were frequently hunted down like animals and killed without qualms, and depicted in art as simian creatures who crawled on the earth or scampered in trees.[44] The simple reply to the objection "They don't look human" is, "This is the way human beings are *supposed* to look at this stage of development; this is normal—so adjust your perceptions to agree with the facts."

6. "Social Utility": It is frequently argued that the destruction of human embryos for the purpose of harvesting their stem cells is ethically justified by the presumed benefits they may eventually produce for patients suffering from a variety of genetically caused conditions. While the goal of alleviating suffering

is laudable, it is never ethically acceptable to destroy one innocent human being for someone else's benefit—to kill one human being to harvest their body parts in order to attempt to heal someone else. To deliver potential benefits to a future "Christopher Reeves", it is not right to kill a future "Mother Teresa". The ends do not justify the use of any and every means; right ends must be pursued through the use of right means. We must not "do evil that good may come," (Rom.3:8). The deliberate destruction of embryonic human beings is prohibited by the sixth commandment, "Thou shall not kill" (Ex.20:13); this commandment outweighs all considerations of social utility.

In closing, let me leave you with a refrain from a children's book by Dr. Seuss, *Horton Hears a Who*: "a person's a person, no matter how small."[45] Horton, a kind and sensitive elephant, hears voices from the microscopic inhabitants of Whoville, who live on a tiny speck of dust. At first, no one but Horton can hear these tiny persons, but Horton continues to advocate for them and finally succeeds in saving them from destruction. A kangaroo, who now can hear them, says "From now on , you know what I'm planning to do … from now, I'm going to protect them with you! … From sun in the summer. From rain when it's fall-ish, I'm going to protect them. No matter how small-ish!"[46]

At this juncture of history, we, like Horton, are in the minority in our culture as we advocate for the personhood of our fellow creatures who happen to be embryonic humans. But history also tells us that other classes of persons who were biologically human were long denied their just legal rights. In 1776, the Declaration of Independence declared that "all men were created equal", but American slaves had to wait until 1863 to be declared free by the Emancipation Proclamation. William Wilberforce struggled for 44 long years, from 1789 to 1833, in the cause of abolition.[47] American women had to wait until 1920 to receive the right to vote, and Native Americans received the full rights of citizenship only in 1924.[48] "Embryo rights" remains a final frontier in the ongoing struggle for human rights and the right to life.

The way may be long, but the cause is just. In the meantime, we can do what we can to encourage programs like the "Snowflake" embryo adoption program,[49] and use the terminology of *embryonic humans* rather than "human embryos" to emphasize our shared humanity. "A person's a person, no matter ow small."

Endnotes

1 Scott F. Gilbert, *Developmental Biology,* 7th ed. (Sunderland, MA: Sinauer Associates, Inc., 2003), p.3.

2 For ancient Indian embryology, see Joseph Needham, *A History of Embryology,* 2nd ed. (New York: Abelard-Schuman, 1959), pp.25-27; Arthur William Meyer, *The Rise of Embryology* (Stanford, CA: Stanford University Press, 1939), pp.17,18. For Islamic understandings of embryology and prenatal human life, see Basim F. Musallam, *Sex and Society in Islam* (Cambridge: Cambridge University Press, 1983), pp.39-59, "Conception Theory in Muslim Thought," and Abul Ebrahim, "Abortion," in *Oxford Encyclopedia of the Modern Islamic World,* v.I, John L. Esposito, ed. (New York: Oxford University Press, 1995), pp.17-19.

3 For example, Leviticus 12 specifies periods of ritual uncleanness for women after the birth of a child—seven days for a son, 14 days for a daughter. The issue arises, in the case of a miscarriage, as to what counts as the birth of a "child" . In general, rabbinic law held that "anything that has not the shape of a human being cannot be regarded as a human child": Babylonian Talmud *Niddah* 21a. For Jewish understandings of the moral status of the embryonic human, see David M.

Feldman, *Birth Control in Jewish Law* (New York: New York University Press, 1968); "Embryo," in *Encyclopedia Talmudica,* v.I, Rabbi Shlomo Zevin, ed. (Jerusalem: Talmudic Encyclopedia Institute, 1969), pp.208, 209; for recent Orthodox Jewish opinion, see Rabbi Yitzchok Breitowitz, "The Preembryo in Halacha," *Jewish Law Articles,* accessed at http://www.jlaw.com/Articles/preemb.html.

4 Accessed at http://linacre.org/atheol.html

5 *Evangelium Vitae* 60, accessed at http://www.vatican.va/holy_father/john_paul_ii/encyclicals/documents/. For the historical development of Christian and Roman Catholic understandings, see Michael J. Gorman, *Abortion and the Early Church* (Downers Grove, IL: InterVarsity Press, 1982), and John Connery, *Abortion: the Development of the Roman Catholic Perspective* (Chicago: Loyola University Press, 1977).

6 Ex.21:22-25, a passage in the Mosaic law that has received significant attention in relation to abortion, will not be dealt with in this study, since it is not apparent that this law would have had applicability in cases regarding the life of the human embryo in the earliest days of gestation. On the exegesis of this text, see Meredith G. Kline, "*Lex Talionis* and the Human Fetus," *Journal of the Evangelical Theological Society* 20 (1977) 193-201; H. Wayne House, "Miscarriage or Premature Birth: Additional Thoughts on Exodus 21:22-25," *Westminster Theological Journal* 41 (1978) 108-123; Jack W. Cotrell, "Abortion and the Mosaic Law," *Christianity Today* 17:12 (March 16, 1973) 6-9. For a history of Jewish understandings of this passage, see Mark S. Scott, "Quickening in the Common Law," *Michigan Law & Policy Review* 1 (1996) 2-6, accessed at http://www.vanderbilt.edu/SFL/quickening.htm. Other texts such as Job 10:8-13 and Ps.51:5 will be dealt with in a more incidental fashion insofar as they bear upon Ps.139 and the infancy narratives of Luke.

7 Rick Weiss, "Clinics Holding an Excess of Embryos," *Boston Globe,* May 8, 2003, p.A8.

8 For a review of current scientific practice and ethical issues see *Monitoring Stem Cell Research* (Washington, D.C.: President's Commission on Bioethics, 2004), accessed at http://www.bioethics.gov/reports/stemcell/. The public debate on human embryo research in Great Britain during the 1980s is analyzed in Michael Mulkay, *The Embryo Research Debate: Science and the Politics of Reproduction* (Cambridge: Cambridge University Press, 1997). On the status of the human embryo in American law, see Daniel Avila, "The Present Standing of the Human Embryo in U.S. Law," *National Catholic Bioethics Quarterly* 1 (Summer 2001) 203-226.

9 For current scientific embryology, see Ronan O'Rahilly and Fabiola Muller, *Human Embryology & Teratology,* 2nd ed. (New York: John Wiley & Sons, 1996); William J. Larsen, *Human Embryology,* 2nd ed. (New York: Churchill Livingstone, 1997); Bruce M. Carlson, *Human Embryology and Developmental Biology* (St. Louis: Mosby, 1994). For philosophical defenses of the personhood-from-conception position, see, notably, Robert P. George, *The Clash of Orthodoxies: Law, Religion, and Morality in Crisis* (Wilmington, DE: ISI Books, 2001), pp.317-323 ("We Should Not Kill Human Embryos—For Any Reason"); J.P. Moreland and Scott B. Rae, *Body and Soul* (Downers Grove, IL: InterVarsity Press, 2000), pp.204-206; Gabriel Pastrana, "Personhood and the Beginning of Human Life," *Thomist* 41:2 (1977) 247-294; Maureen L. Condic, "Life: Defining the Beginning by the End," *First Things* 133 (May 2003) 50-54.

10 The philosophical definition of "person" that is presupposed in this paper could be stated as follows: "A 'person' is a living, distinct, self-organizing and self-directing organism of the species *Homo sapiens,* that has the *intrinsic capacity* to manifest, under the appropriate circumstances, the developmental processes (including consciousness) that are characteristic of *Homo sapiens.*" For the author's philosophical defense of the "personhood from conception" position, see John Jefferson Davis, "Human Embryos, 'Twinning," and Public Policy," *Ethics and Medicine* 20:2 (Summer 2004) 35-46.

11 See E.K. Ji, et. al., "Effect of Ultrasound on Maternal-Fetal Bonding," *Ultrasound in Obstetrics & Gynecology* 25:5 (May 2005) 473-477; J. Lumley, "Through a Glass Darkly: Ultrasound and Prenatal Bonding," *Birth* 17:4 (Dec. 1990) 214-217.

12 J. Clinton McCann, Jr., "Psalms," in *The New Interpreter's Bible,* v.4 (Nashville: Abingdon Press, 1996), p.1236. McCann notes that vv.13-18 "… are an eloquent presentation of the biblical view that human life is not simply a natural, biological occurrence but is the result of the will and work of a benevolent creator."

13 Ibid.

14 For a helpful review of Greek understandings of conception and pregnancy, as represented in the writings of Hippocrates, Galen, and Aristotle, see Robert Garland, *The Greek Way of Life* (Ithaca, NY: Cornell University Press, 1990), pp.17-58, "Conception and Pregnancy."

15 Aristotle, *Generation of Animals,* 1. 19. In *History of Animals* 7.3 Aristotle states that the male embryo is formed by the 40th day, while the female embryo remains unformed until about the 80th or 90th day. In the Babylonian Talmud it is stated that both male and female embryos are formed by the 40th day: *Niddah* 30a. The appearance of the human embryo is described in *Niddah* 30b.

16 R. Avrohom Eeuer, *Tehillim* (Brooklyn, NY: Mesorah Publications, 1977), p.164. Delitzsch believes that *golem* is derived from *gaalam,* "to roll or wrap together," used in the Talmud of an unshaped mass: Franz Delitzsch, *Biblical Commentary on the Psalms,* v.3 (Grand Rapids, MI: Eerdmans, 1968), p.350; see also Harris, Archer, and Waltke, *Theological Wordbook of the Old Testament,* v.1 (Chicago: Moody Press, 1980), p.165, who similarly derive *golem* from *gaalam,* "to wrap up, fold, fold together" (II Kgs.2:8); cf. *gelom,* "wrapping, garment," (Ez.27:24). Dahood unconvincingly suggests a conjectural repointing of *golem* to read *gilay-mi,* "my life stages": Mitchell Dahood, *The Anchor Bible: Psalms III* (Garden City, NY: Doubleday, 1970), p.295. The references in the preceding v.15 to "my frame" (*hatzemi,* lit., "my bones") and being "woven together", however, more plausibly support the reading *golem,* "embryo."

17 Recall *Niddah* 30a (note 12 above), where it is said that both male and female embryos are formed by the 40th day.

18 In other religious traditions the concept of being "seen" by the deity in important in worship. In Hinduism, for example, the worshipper may prize the "eye contact" with Lord Krishna as represented in his visible image, since being "seen" by the god or goddess confers a spiritual blessing. Cf. Diana L. Eck, *Darshan: Seeing the Divine Image in India,* 2nd ed. (Chambersburg, PA: Anima Books, 1985), pp.6,7: "… it is not only the worshipper that sees the deity, but the deity sees the worshipper as well … The gaze of the huge eyes of the image meets that of the worshipper, and the exchange of vision lies at the heart of Hindu worship."

19 In this context, the "things that are not" (*ta me onta*) are the nations that will come into existence through Abraham's descendants.

20 When the apostle Paul writes that "God set me apart from birth" (Gal.1:15, *aphorisas me ek koilias metros*), he appears to be echoing the language of Jer.1:5. Jeremiah was called to be a *prophet* to the nations; Paul, an *apostle* to the nations. J.B. Lightfoot renders *ek koilias metros* as "from before birth, before I had any impulses, and principles of my own": *The Epistle of St. Paul to the Galatians* (Grand Rapids, MI: Zondervan, 1956), p.82.

21 The language of "forming" recalls the language of Gen.2:7, where God forms man from the dust of the ground.

22 In Christian theology it is said that the works of God *ad extra* (in time and history) are the works of creation, providence, and redemption: cf. L. Berkhof, *Systematic Theology* (Grand Rapids, MI: Eerdmans, 1941), p.101. These Isaianic texts indicate that the works of God *ad extra* are also exercised *in utero*—since God's power to create, sustain, and redeem are manifest in the womb.

23 Delitzsch comments that "David here confesses his hereditary sin as the root of his actual sin. The declaration moves backward from his birth to conception, it consequently penetrates even to the most remote point of life's beginning." *Biblical Commentary on the Psalms,* v.2 (Grand Rapids, MI: Eerdmans, 1968), p.136.

24 Delitzsch observes that God's *hesed* here means the "… divine goodness, not only in the womb, but from the beginning of life and onwards." *Biblical Commentary on the Book of Job,* v.1 (Grand Rapids, MI: Eerdmans, 1968), p.167. The term *hesed,* a prominent word in Old Testament theology, frequently, but not always, implies "covenant faithfulness"; "lovingkindness" is perhaps a more generally adequate meaning: R. Laird Harris, *"hesed,"* in Harris, Archer, and Waltke, *Theological Wordbook of the Old Testament,* v.1 (Chicago: Moody Press, 1980), p.307.

25 *aute suneilephen huion.*

26 J. L. Austin, *How To Do Things With Words,* 2nd ed. (Cambridge: Harvard University Press, 1975). For a brief but helpful discussion of Austin's philosophy of language, see Kevin J. Vanhoozer, *Is There a Meaning in This Text?* (Grand Rapids, MI: Zondervan, 1998), pp.208-209.

27 For a notable biblical example, one might think of the sovereign, creative word of God in the first chapter of Genesis ("and God said …") which brings the creation into being.

28 George Herbert Mead, *Mind, Self, and Society* (Chicago: University of Chicago Press, 1934). For discussion of Mead, see Jack O. Balswick, Pamela King, and Kevin Reimer, *The Reciprocating Self: Human Development in Theological Perspective* (Downers Grove, IL: InterVarsity Press, 2005), pp.80-84.

29 In the following discussion, I am indebted to the article of Graham Scott, "Abortion and the Incarnation," *Journal of the Evangelical Theological Society* 17 (1974) 29-44, especially pp.36-38, on Luke 1:26-56.

30 Darrell Bock comments, "Mary's departure reflects an instant response to God's leading," *Luke, v.1: 1:1-9:50* (Grand Rapids, MI: Baker Books, 1994), p.134.

31 Ibid.

32 Josephus, *Life,* 52 [269]: "… for Samaria was now under Roman rule and, for rapid travel it was essential to take that route, by which Jerusalem may be reached in three days from Galilee." The

road that ran through the district of Samaria was commonly chosen by the Jewish inhabitants of Galilee on their pilgrimages to Jerusalem: Carl Rasmussen, *Zondervan NIV Atlas of the Bible* (Grand Rapids, MI: Zondervan, 1989), p.172.

33 According to Scott, op. cit., p.37, "Assuming that the time between Mary's visitation as a virgin and her arrival as a mother at Elizabeth's was about a week, the conceptus Christ would be ready for implantation if conceived immediately after the visitation, or would still be in the most elementary stages of zygote existence [JD: the *blastocyst* stage: Larsen, op. cit., p.xv] if conceived sometime later."

34 Bock, op. cit., p.135.

35 Scott, op. cit., p.37.

36 *Qui conceptus est de Spiritu Sancto:* in Jaroslave Pelikan and Valerie Hotchkiss, eds., *Creeds and Confessions of Faith in the Christian Tradition,* v.I (New Haven: Yale University Press, 2003), p.669.

37 Ibid., pp.169-171.

38 A.J. Wilcox, et. al., "Incidence of Early Loss of Pregnancy," *New England Journal of Medicine* 319 (July 28, 1988) 189-194; cf. C.E. Boklage, "Survival Probability of Human Conceptions from Fertilization to Term," *International Journal of Fertility* 35:2 (1990) 75, 79-80, 81-94.

39 O'Rahilly, op. cit., p.46.

40 For a more complete analysis of this argument, see John Jefferson Davis, "Human Embryos, 'Twinning,' and Public Policy," *Ethics & Medicine* 20:2 (Summer 2004) 35-46.

41 Connery, op. cit., p.307.

42 This is a confusion of the beginning of a new *human life* (the embryo's) with the beginning of *pregnancy*—a condition experienced by the mother.

43 Bob Katzen, "Definition of When Human Life Begins," *Salem Evening News,* May 23, 2005, p. B5. This seems to be a good illustration of Foucault's thesis that the power of definition can be used by social elites to victimize and oppress marginalized social groups: cf. Michael Foucault, *Power/Knowledge,* (New York: Pantheon Books, 1980), p.133. Lee Silver has also candidly admitted that researchers have introduced the new term "pre-embryo"—the human embryo prior to implantation—with no real scientific justification, largely for political purposes. The term is "… useful in the political arena" when objections are made to experimentation involving human embryos: Lee M. Silver, *Remaking Eden: Cloning and Beyond in a Brave New World* (New York: Avon Books, 1997), p.39.

44 Felipe Fernandez-Armesto, *Humankind: A Brief History* (New York: Oxford University Press, 2004), p.80.

45 Dr. Seus, *Horton Hears a Who!* (New York: Random House, 1954), p.6.

46 Ibid., pp.58, 60.

47 The story of Wilberforce is told in Kevin Belmonte, *Hero for Humanity: a Biography of William Wilberforce* (Colorado Springs, CO: Navpress, 2002), and Garth Lean, *God's Politician: William Wilberforce's Struggle* (Colorado Springs, CO: Helmers & Howard, 1987).

48 Roderick Nash, *The Rights of Nature: a History of Environmental Ethics* (Madison, WI: University of Wisconsin Press, 1989), p.7, "The Expanding Concept of Rights."

49 Pam Belluck, "From Stem Cell Opponents, an Embryo Crusade," *New York Times,* June 2, 2005, pp. A1, 22

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Ethics Involved in Simulation-Based Medical Planning

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Abstract

Computational biology, including simulation and modeling, is a burgeoning field with a recent influx of mathematicians, computer scientists, and engineers. With this recruitment, significant advancement has been made in numerous biological areas. However, as is the case in almost any rapidly evolving field, innovation can move beyond ethical considerations. We discuss one specific example of a simulation-based model that impacts surgical decision making on human patients. We then discuss a recent code of ethics for simulationists and its inadequacy in addressing issues relating to human subjects research. Finally, we recommend a system of validations for computational simulations involved in research applied to human subjects.

Introduction

With the fairly recent influx of data in the areas of biology and genetics, there has been enormous growth in the field of computational biology and genomics. The National Institute of Health has promoted this growth by opening major avenues of funding to disciplines like mathematics, computer science, and engineering to augment the already well established field of computational biology. With the influx of researchers, much progress is being made as they collaborate to answer questions about human disease processes. However, in some cases ethical considerations become a background rather than a foreground issue.

First, we will discuss and define computational biology; this will lead to our focus on simulation-based medical planning. We will then discuss a fairly recent code of ethics for simulationists, which is intended to address general ethical questions for those involved in simulation. Finally, we will make suggestions of a verification procedure for those interested in computational simulations that apply to human subjects.

Computational Biology and Simulation

Computational biology is an emerging field of research for both biologists and non-biologists and includes areas such as anthropology, genomics, physiology, ecology, and evolutionary biology. Computational biology encompasses all areas of biology where computational modeling and simulation are used. In this arena

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of research, simulations are goal-driven experiments with models that vary in time;[1] and simulationists are professionals who are involved in these modeling activities.[2] Simulationists develop computational models and use these models to study and predict the behavior of physical systems. This focus on simulation and modeling has resulted in an influx of mathematics and mathematicians into the biological sciences. A good illustration of the influx of mathematicians into the area of computational biology is the work of James Keener and James Sneyd. They wrote a book in 1998 titled Mathematical Physiology.[3] This work exemplifies the tremendous diversity in computational biology. We would like to specifically examine one application of computational biology that relates to research on clinical decision-making in human subjects.

The application of computational biology to clinical decision-making in human subjects is in need of a more reflective process. Simulationists may be familiar with modeling applications that involve human physiology; however, their experience with research that directly involves human subjects may be limited. Also, while many human physiological systems are understood as mechanistic processes, humans cannot be reduced to mechanistic processes alone. Simulationists often collaborate with experts in other fields, i.e. physicians, utilizing their mathematical and programming expertise to answer important clinical questions. In these situations, simulationists may rely on physicians to deal with the ethical considerations in the interdisciplinary research involving human subjects. However, as the research advances and the mathematical and programming aspects of the simulation move beyond most physicians' abilities to assess correct methodology, it becomes important for simulationists to consider ethical issues in human subject research. Physicians—who have as their primary concern the welfare of their patients—should not be expected to shoulder this responsibility alone.

The ability to further inform physicians' clinical decisions by way of simulations is potentially beneficial for physicians and patients. This collaboration of simulationists and physicians requires a level of trust and integrity that is similar to specialty referral in the clinical setting. However, it differs in that the domains of expertise of the clinician and the simulationist are completely independent. Physicians would rarely have the expertise needed to determine if the level of accuracy of the mathematical model or the computational method utilized for a simulation is sufficient. It is imperative that the simulationist and the physician understand the advantages as well as the limitations of simulations or patients' care may suffer. We will discuss a specific example of a simulation that assists surgical decision making regarding positioning of grafts in vascular disease.

Simulation-Based Medical Planning

The simulation of blood flow in arterial bypass grafts strives to identify the optimal placement of the bypass grafts in order to improve blood flow for patients with end stage vascular disease.[4] The techniques for this type of simulation-based medical procedure include constructing a geometric model of the blood flow obstruction from three-dimensional magnetic resonance imaging (MRI) and computed tomography (CT) data. The simulationist extracts preoperative patient specific physiologic data from cine phase contrast MRI data

and builds a model of the patient's current blood flow. Then the simulationist develops models corresponding to differing bypass graft positions and estimates how the different positioning of the graphs impacts blood flow distal to the obstruction. The surgeon can utilize the models to choose the preferred location or positioning of the bypass graphs using simulation data calculated from the pre-operative MRI.

These types of three-dimensional models make many assumptions that influence the accuracy of the predictions. One assumption of the current simulation methodology that has received significant criticism is the assumption that blood vessels have rigid walls. This assumption is valid for high velocity flows, but it becomes a less suitable assumption at lower velocities. Researchers have responded to these criticisms by implementing a one-dimensional model where the blood vessels have elastic walls. Data from simulations using the one-dimensional elastic arterial wall assumptions found that the flow rates are similar to the three-dimensional rigid wall results. This is encouraging, but concern remains about what margin of error is acceptable given differing sets of assumptions.

A variety of potential sources of error highlight the importance of determining what margin of error is acceptable. Another source of potential error is the accuracy of the geometric model developed from MRI data. The procedure for obtaining detailed structural information from MRI data is still in its infancy and is being refined. Error related to geometric models developed from MRI data hopefully will continue to be minimized. That said, it is accurate to assume some small amount of initial error due to inaccuracies in the geometric models. The physician must be concerned with whether this error is significant enough to distort the potential improvement in blood flow for different placement of the bypass graft. Practically, the physician needs to be assured that a given bypass graft placement site will improve blood flow in the patient and not just in the simulation.

Many researchers and physicians believe that the benefits of simulation-based medical planning far outweigh the few concerns. The biggest potential advantage is the opportunity to assist doctors in the decision making process with pseudo-surgery that does not physically affect the patient at all. Simulations can be used as an experimental lab that may allow for innovative surgical advancement without any threat of harm to the patient. However, if physicians are to make clinical decisions based on simulations, it is of paramount importance that the simulations be carried out in a manner which maintains the highest standards of professional and ethical conduct.

Code of Professional Ethics for Simulationists

Simulationists have begun to recognize and write about the importance of ethical practice within their field. The Code of Professional Ethics for Simulationists is available in its entirety in *Proceedings of the 2002 Summer Computer Simulation Conference*.[5] The code addresses five areas: personal development and the profession; professional competence; trustworthiness; property rights and due credit; and compliance with the code.

The personal development section includes professional obligations such as acquiring and maintaining professional competence. The fair treatment

and encouragement of newcomers is emphasized; in addition, it suggests supporting members in simulation and promotion of the credible use of modeling and simulation.

The professional competence section includes a discussion of proper methodologies and technologies, the use of critical professional review, the stipulation of proper and achievable goals for any project, and the proper documentation of simulations. Full disclosure of assumptions and known limitations is discussed as well as specification about the conditions of applicability of models and results. The code cautions against acceptance of results without proper verification and unbiased interpretations of results.

The trustworthiness section includes a commitment to honesty about possible conflicts of interest and discusses the importance of honoring agreements and contracts. It identifies responsibilities and accountabilities and highlights how organizational settings should be conducive to ethical behavior. This section also calls for support of studies which will not harm humans and the environment.

The property rights and due credit section includes a call to fully acknowledge other's contributions and give proper credit for intellectual property, honoring property rights including patents and copyrights; and honoring privacy rights and confidentiality of data and knowledge.

The section on compliance with the code addresses the importance of adhering to the code and encouraging others to adhere to the code. It calls simulationists to treat violations of this code as inconsistent with being a simulationist and to seek advice from professional colleagues in ethical dilemmas. In addition, the authors advise any professional society which supports this code to be aware of updates.

The current formulation of the code represents an excellent move toward identifying professional and ethical scientific behavior for simulationists. However, it lacks any specific discussion of issues that arise when simulations are used in medical decision making for human subjects. This omission is understandable, since the domain of simulationists is only just beginning to include research that involves human subjects. It may also be the case that where there has been work with applications for human subjects it was assumed that physicians would be responsible for ethical research standards with human subjects.

We appreciate the call for input to this code, because it recognizes that in a rapidly evolving area, ethical reflection and input from many can enhance the applicability of such a code. Therefore, we will suggest additions to the code specifically in areas where simulations are a part of clinical decision making and we will discuss the possibility of verification systems for simulations that affect clinical decision making in human subjects.

Verification Procedure for Simulation-Based Medical Planning

We propose that a system of verifications is needed for simulations that seek to direct clinical decision making. The discussion on validation of predictive tools or simulations is not entirely new in medical ethics literature. The Handbook of Medical Informatics[6] has a chapter devoted to predictive tools for clinical decision support and a more recent book concerning ethics, computing and medicine has a chapter devoted to decision-support software.[7] In both of these examples, the discussions emphasize statistical data related to past medical decisions. However, statistical comparisons and simulation-based medical planning are significantly different approaches. We think that there needs to be a new system of validation for simulations.

These verifications should include, but not be limited to: (1) proper verification of the mathematical model, (2) proper understanding of the relationship between the model and actual human physiology, (3) proper verification of margins of error, and (4) proper verification of the risks and benefits of the new technology in sufficient numbers of human subjects to confirm usefulness and expose unanticipated outcomes.

Our four-fold suggestion for verification of new simulation technologies applied to human subjects is partially discussed in the current code of professional ethics for simulationists. Proper verification of the mathematical model and proper understanding of the relationship between the model and actual human physiology, (1) and (2) above, are the primary responsibility of the simulationist and they are addressed in the professional competence section of the code. There needs to be a comprehensive explanation by the simulationist of all of the basic assumptions and limitations of the model, as well as the end goals and prior applications of similar models. While these issues are addressed in the professional competence section of the code, they are not elucidated in regard to the importance in applications which involve human subjects.

The code does not discuss the margin of error of simulations or the verification of the risks and benefits of simulation technology in human subjects research. We would like to address these two issues in more detail.

Margin of Error

Despite the usefulness of simulations, an important concern is that these models are approximations based on inexact measurements. Therefore, it is extremely important to have a discussion about how much error is acceptable for simulations applied to human subjects. In the aforementioned simulation-based medical planning research, Ku et al[8] had blood flow predictions that were within 10.6% of the experimental data with an average absolute error of 5-6% for bypass-to-inlet and aorta-to-inlet blood flow ratios. Is this an acceptable error tolerance when computing future blood flow rates in humans? For these results, it is argued that when the computed pre-operative results are low, then a similar correlation is seen in post-operative results. This correlation highlights the importance of refining the accuracy of the geometric model, but does not completely answer the question of how much error tolerance is acceptable.

The potential of compounding error is another cause for concern. The error in the initial MRI data results in error in the simulation's preoperative and postoperative results. The MRI data is important, because the accuracy of the geometric model has a significant impact on the resulting computational flows.[9] When you add the error implicit in a mathematical model due to simplifications and assumptions, add the possible error from MRI and CT data, and add the margin of error of the surgeon during the procedure, there are numerous areas where the simulator can over or under approximate certain components. Therefore, a serious discussion about an acceptable margin of error is necessary when this technology is applied to human subjects.

In Vivo Validation and Clinical Trials

Simulation-based medical decision making should be subject to validation protocols which could include both in vitro and in vivo trials for each element of the simulation process. Mathematical models tend to be static and may not be able to adequately approximate dynamic physiological processes. By their nature, simulations can only estimate the real world setting. This fact represents an acknowledgment of both the assets and limitations of simulation methodology, one better understood by simulationists than practicing physicians. Since simulation-based medical planning is so new, physicians may be at risk for embracing these simulation options prior to sufficient examination. The necessary level of certainty can only be gained through extensive clinical trials. Physicians are familiar with protocols used to validate new drugs and devices such as those utilized by the Food and Drug Administration (FDA). In order for a medical device to be authorized for use in humans in the United States, a system of tests must be completed and the safety and reliability of the device must be demonstrated. We propose the development of validation protocols including clinical trials for simulation-based medical decision making so that simulations can be evaluated as thoroughly as other treatments and therapies.

The first level of validation we recommend for simulation-based medical planning is to do post hoc testing.[10] For instance, the patients' MRI and CT data can be used, both preoperative and postoperative, to evaluate the numerical results of the blood flow calculations. Post hoc testing has the advantage of causing no additional harm to the patient, limited inconvenience, no additional surgical procedures, but some increased costs.

The second level of validation would be clinical trials where simulations are used to predict and affect medical decision making. Experimental protocols with sufficient numbers of patients are needed to confirm the usefulness of simulations and expose any unanticipated outcomes. At present, there are limited protocols for these types of clinical trials and few Institutional Review Boards have experience in assessing the ethical dimensions of this type of research.

Conclusions

We desire to open the discussion about the development of validation protocols where mathematical simulations are utilized in clinical decision making. We believe the best way to verify simulations are both in vitro and in vivo

validation protocols as well as clinical trials.

We propose expanding the code of ethics for simulationists to include some of the issues raised by human subjects research. The proper verification of margins of error for the specific simulation is a very important discussion that needs to be held. We also suggest having additional items which specifically address research on human subjects. The additions should include a discussion of the value of post hoc testing as well as the importance of participating in clinical trials in which simulations are used in clinical decision making.

The goal of this paper has been to educate those in the medical community about innovative applications of computational biology which are on their way to a hospital near you. Now is the time for simulationists to address the need for a fully orbed ethical reflection on the implications of their exciting technology. The time is ripe for a discussion of the proper means of verification and validation of simulation-based medical devices.

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NORMATIVE ETHICS IN HEALTH CARE

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Abstract

The late David Thomasma insisted on "normative elements" to guide methodology for Ethics and Bioethics. "Normative elements" include moral principles from moral philosophy and theology, virtues from philosophy and religious traditions, facts and wisdom from supervised clinical experience, psychology and the history of medicine, and additional knowledge from science, phenomenology, and case material studies. These guides develop good professional teaching and practice. Such work focuses understanding and creates relationships of justice for the needy, personally and socially, from hospitals to the total environment. For example, Thomasma presented "normative elements" to guide managed care toward the patient's good. These varied comprehensive norms represent some of the rich legacy of Thomasma which can guide us today and into the future. This methodology can be a corrective to the antifoundationalism of current postmodernism.

I question whether this emphasis on the "normative elements" is being adequately recognized today in bioethics. So, I wrote to Dave on e-mail (December 3, 2001),

> Dear Dave: I want to explore with you an important issue in bioethics. The issue originates in Volume II of the Foundations of Ethics…ed. by H. Engelhardt & D. Callahan, published by Hastings Center, 1977, pp.111-168 in two articles. The first is by D. Burrell & S. Hauerwas, the second by Dr. Pellegrino. The first has become a widely accepted argument for narrative ethics which appears toward becoming dominant in bioethics. During the Philosophy affinity group of American Society for Bioethics and Humanities (ASBH), 2001, Lisa Eckenwiler, Ph.D., presented a paper, appealed to narrative ethics & referred to the Burrell and Hauerwas article. I asked her if she knew Pellegrino's response to Hauerwas. She did not. This experience is typical of my reading also. I had a brief phone conversation with Stan Hauerwas about the issue (October, 1998). He suggested that Pellegrino still represented Catholic humanism or classic humanities and old philosophy, not up to date with Wittgenstein. Am I now into your turf since you have been the philosophical wing of Pellegrino-Thomasma? I have generally accepted this literature and philosophy. Have you and/or Dr. Pellegrino made any additional response to the article, 1977? Since I am briefly exploring with you, what do you think should be the next response? Your colleague, Jack Hanford.

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Dave responded (December 13, 2001):

> This is problematic of course. Yes, Ed (Pellegrino) has responded more frequently than I to narrative ethics. Generally we are in sympathy with broadening the context of bioethics, but find its normative elements lacking in a thoroughgoing acceptance of narrative.

This response is consistent with the original response by Edmund Pellegrino (Engelhardt, 1977, p. 153), a Catholic scholar and physician who combines the rational (Kant) with the empirical and narrative without the Burrel and Hauerwas (Engelhardt, 1977) almost exclusive emphasis on the narrative which excludes the rational as understood by Kant. Pellegrino is the best known partner with Thomasma. His other partner is Jurrit Bergsma (2000), a prominent psychologist and fellow Dutchman.

Thomasma (2000, in Bergsma) responded to the problem of lacking norms by asserting his emphasis on the principle of dominion. His philosophy has consistently appealed to principles as guides to moral action. The specific principle of dominion interprets responsibility for respecting vulnerable persons when intervening into nature, the environment, the body, and clinical practice. Practice must be accountable to the goal of medicine which is healing and enhancing the good of the patient. Practitioners confront life-death decisions about their autonomy or the patient's, the power of technology or the power of consent by the patient. The principle of dominion gives priority to the vulnerable patient and considers the consequences of interventions on vulnerable populations. For example, Doctor Jack Kevorkian acted freely, assumed his individual professional autonomy, and applied his technology to assist patients in dying. They were vulnerable and in need of respect for their vulnerability. They needed the principle of dominion applied to protect their weakness, suffering, and to protect their lack of power or dominion or control.

David Thomasma thought rigorously about clinical relationships and about clinical training in bioethics with his philosophy, science, ethics, and phenomenology. Also, he wrote well and abundantly. He was a man of faith and was comfortable being humble. For instance, Thomasma and S. Hauerwas could agree on the serious danger of elevating the dominion especially of the state. Both authors are aware of the depth of evil and violence historically in Germany such as in the Holocaust, in America such as leading the Western world in purifying genetics from the 1920s, against America on 9/11/01, and in much of the rest of the world. We must find ways for dealing with this violence and bioethics can help by including its normative elements. I believe these "normative elements" comprise the basics for a methodology for bioethics.

By affirming these "normative elements", Thomasma argued against the subjectivism and relativism of the Hauerwas and Burrell exclusive use of narrative as almost the sole method in doing bioethics. Pellegrino and Thomasma (1993) blended the "normative elements" into an objective focus on narrative, virtues, and particular case material to exercise reasoned moral evaluation. Pellegrino (in Jennifer Walter 2003) describes his relationship to Thomasma "So close was our collaboration that it is difficult for me to know who was responsible for any idea, theme, or argument" (page 8).

The emphasis on "normative elements" shows a significant contribution toward developing method in bioethics from the 1970s to the present. Presently, the methodological controversy and debate is about whether the normative elements of a moral philosophy of medicine can stand up against antifoundationalism. Antifoundationalsim begins with the repudiation of the Hippocratic Oath because of its inherent paternalism such as charged by Robert Veatch, a major leader in bioethics. The paternalism of the physician is almost replaced by the appeal to the autonomy of the patient. But, Thomasma will insist that the guidance of the principle and virtue of beneficence can be balanced with autonomy. This view is convincingly presented in the book titled *For the Patient's Good: The Restoration of Beneficence in Health Care.* (Pellegrino & Thomasma 1988). Thomasma (in Pellegrino & Thomasma 1997) counters antifoundationalism by exposing the confusion in terms through the history of moral philosophy. But, he maintains focus on bioethics and shows that the normative standards from the history of medicine, the traditions of Judaism and Christianity, and natural law must prevail in spite of the competition and even threat of antifoundationalism.

Such norms can be derived from theology and philosophy according to Thomasma. He integrated theology with philosophy to interpret rules, principles, covenants, and codes to guide clinical work. But theology empowered by faith places more profound obligations on the practitioner to be faithful, to act with a fiduciary sense of responsibility to meet the needs of the vulnerable patient. The exercise of autonomy from this faith, specifically Christian faith for Thomasma, was an act of freedom in responsibility. Some secular practitioners view autonomy to give them power to act only for adequate remuneration, act when convenient, pass responsibility on to a manager who might review the health insurance contract to see if the patient is entitled to services. This kind of practice threatens the inclination toward trust in the professional. Instead, Thomasma insisted that trust is necessary for healing. The burden for being worthy of trust is placed on the Christian physician and others.

Although Thomasma's appreciation of the emotional, affective dimension of personhood was expressed in his books, his early work also developed the cognitive dimension. By cognitive, he included philosophy, ethics, religious studies, psychology, sociology, anthropology, and the study of law. Dealing with the cognitive fits well into the academic preparation of health professionals. We know how to evaluate cognitive competence. This work was advanced by Thomasma along with Don Self (1996) and others. Thomasma used philosophy to analyze cases and provide rigorous arguments in forging moral, just policies in health care.

Thomasma contributed significantly toward guiding bioethics toward the patient's good. An important test for ethics was whether it contributed toward effective professional clinical practice. This test went beyond thinking. It went toward the end or goal of medicine which is to enhance the good of the patient. Thomasma, linked with a practicing physician, kept his focus on the needs of the patient. The patient by definition is needy and even vulnerable. He usually presents for help and the practitioner is challenged to enter a healing bond for the good of the patient. The practitioner must be technically competent. This means she practices in the manner of other capable physicians, nurses,

and other workers for the health of the patient. But in addition the test of the practice must be shown in the quality of care which produces the patient's good or health.

What is a source of this commitment to the patient's well being? One obvious source is the history of medicine, broadly conceived. Thomasma embodied this historic tradition along with religious tradition; Jewish, Christian, and inclusive of other traditions devoted to healing and comforting the suffering. Western medicine emerged from Christian and other cultural inheritance. History shows a continuity of practice by clergy and physicians especially psychiatrists and clergy in the Confessional and counseling functions. Here we have a rich heritage of motivation for healing and caring for those in need. This heritage was represented in the thinking and practice of Thomasma.

Thomasma's clinical and religious ethical approach led to a relational ethic. The practitioner would need to relate and dialogue with the patient to know the patient's needs. The health professional would probe not only about the nature of the disease but how the patient felt about the illness which might be changing the patient's life. Such depth analysis was facilitated by European philosophy of phenomenology and existentialism. In simple terms the phenomenologist assumed if we want to know what goes on inside a person we ask them and we listen very carefully. The existentialist probed personal experience and existence, anxiety, and death. This approach meant the practitioner treated not only the disease but the person, not only gave medications but also therapeutic words and a caring relationship. The therapist, broadly conceived, not only cured but cared. Ethics was not relegated to questions of who stole the coffee money but rather ethics was central to the therapeutic process of healing.

During the National Endowment for the Humanities Health Care Ethics Summer Institute of 1983, Thomasma trained us to think with the normative elements as we analyzed case material. This work required a formal process of reasoning relevant to specific clinical problems. Thus, Professor Thomasma provided leadership in creating bioethics as a discipline which insisted first on knowing the medical facts of a case, knowing the concerns of the persons involved, considering the values that were relevant, reconciling conflicts between values and persons, prioritizing values and principles, and coming to a responsible decision. This course of study included ethical norms, metaphysical assumptions, and a critique of this process of work. This work contributed to effective teaching and practice of ethics in health care, some of which is presented in (Hanford, 2002).

Thomasma's normative perspective of justice and care is important for analyzing the current crisis in delivering mental health and health in general through managed care. This perspective may provide guidance for the future development of managed care delivering mental health services. Thomasma specifically provided a broad Christian perspective from which to examine managed care. The changing face of health care needs guidance from a Christian perspective to provide focus on the emergence and development of managed care. In the following I identify the nature of his perspective, sketch an outline of a position on managed care, on care of the elderly, and show the crucial importance and complexity of exercising true consent.

From his healing perspective, we can see that delivering health care requires sensitivity well beyond simply producing a commodity, which is a general emphasis in managed care. The issue of fairness demands rethinking the economic system and procedures at work here, where economic structure needs especially to serve the healing relationship. The duties of the healer ought to be motivated by a professional relationship stimulated and defined by Christian vocation.

Thomasma was a strong critic of some managed care because too often its concerns threaten beneficence to the patient, and trust and charity toward poor patients in particular. For example, inappropriate use of the role of gatekeeper may result in a decision for financial profit over the greater good of the patient. He justified this criticism by his appeal all at once to Christian theology, the history of medicine, and the vulnerable predicament of the patient and what this all means or should mean to a medical professional. It is in these terms that the quality of the professional relationship ought to be sustained, according to Thomasma.

Moreover, a physician should advocate the most equitable and just system and work toward its implementation in a social setting that sets fair priorities for the good. To do this, society must define goods as ends in themselves that provide guidance and incentives for managed competition to become real managed care. Whether a society achieves this end can be evaluated by the Christian and humane standard of how the society treats its most vulnerable, its children, poor, sick, and elderly. This is an appropriate end for the means of the economics of managed care, and we must guide the system directly to its end—the good of the patient. This guideline must be understood and followed because many health concerns go beyond or transcend market principles.

The business system for managed care needs its norms to be understood in their historical context. The supervening issue throughout this history is how to design an economic system for the humane delivery of health care. Most of this history for the last 100 years has been the story of the fee-for-service contract. This system created powerful incentives for progress but has come under criticism for over treatment, such as the indiscriminate dispensing of medications, thereby escalating costs and sometimes producing harm. Managed care has already provided a means for curbing costs by controlling referrals and related methods. But managed care has also been seen as "mangled" care by its threat of under treatment. This criticism is especially relevant to mental health because history shows that lack of treatment is tolerated more in mental illness than in physical illness. Such criticism can lead us toward creating a better system; a more just, humane, and loving approach.

We need a system that will control costs, but not at the expense of quality care, which must include norms for appropriate care for persons with mental illness, and especially chronic illness. To achieve this goal, Thomasma created a system of education that enhanced the quality of professional relationship. This required the expertise of mental health professionals. They represent an ultimate source or ideal for quality in relationships; they specialize in creating and developing such encounters. They must have legal, political, and economic support for reinforcing fiduciary duties and responsibilities.

The importance and value of Thomasma's emphasis on normative bioethics can be specifically shown in his work toward ethics in the care of the elderly. The elderly comprise one of the vulnerable populations which should receive preferential treatment according to Thomasma. Thus, all of his writing about the special needs of vulnerable patients would be normative in caring for the elderly. In fact, focus on the vulnerable is a foundation pillar in Thomasma's beginning methodology.

Thomasma (2001) has edited and contributed to a 450 page volume titled PERSONHOOD…which argues for the concept of "Person" as a normative reality.

This means our approach to the elderly must not stereotype but approach each older patient as a valuable individual entitled to dignity and respect. Specifically, their autonomy must be sustained. For example, the clinical case of Ty shows the loss of consent perhaps because of some dementia in old age.

The story of Ty shows the frequent conflict between the elderly patient and even his or her own family. The conflict is serious involving hard decisions about whose rights and entitlements should trump especially in long term care decisions and judgments of dementia.

The Case of Ty at 90 Years of Age and the Absence of Normative Elements

I will describe the historical context and introduce the family. The family appeared united but real unity is questionable because of Ty. Ty's consent was absent and so he was invisible because of his apparent dementia. I say "apparent" because there was no evidence of his doctor being called or consulted. Therefore Ty had neither test nor diagnosis. His strong wife, Lois, avoided doctors all her life but Ty had not. In fact, no medical practitioners were involved as he grew less capable; therefore no referrals back to his physician or relationship with any physician. Yet we know that medication might have helped Ty. Instead, a family member volunteered that he had adequate past expertise to deal with dementia.

Ty and his wife were in their early 90s. They had been successful and industrious in their life's work. After Ty's retirement from his profession he had continued to be productive in profession-related activities and volunteer work. He also took up new hobbies. He was admired for his fine mind. Lois started and led several volunteer projects, also.

Ty and Lois moved several times after retirement. In each location they were adept at making new friends and engaging in new activities. They finally settled in a condo at a retirement community which would provide a continuum of care as they grew older and their needs would change. This was a firm plan for living until their deaths.

No Serious Consideration of Ty's Consent

Ty's mind continued to decline and Lois had increasing difficulty in caring for Ty and managing the household. Ty and Lois had outlived most of their friends, and their closest family member was their son who lived many hundreds of miles away in a different state. Lois was very lonely without friends and the companionship of her husband who was increasingly confused and unable to recognize her at times. The family was informed by personnel at the retirement community that it was time for Ty and Lois to move to Assisted Living and gave them a deadline. At that point Lois refused to move to Assisted Living but insisted that she and Ty remain together. Ty could not understand or process what was going on and the decisions that had to be made.

After Lois stated that she did not want their money to go to the residential community, the family moved Lois and a very bewildered Ty to a home near theirs. This decision went against Ty's life plan which should have been his consent or normative guide. The family (not Ty) decided to leave the center without consultation even though the couple had been there for about 12 years. Lois was angry because Ty did not consistently recognize her. She attributed mental illness stigmas to his apparent dementia and he was taken to a state where he and his wife had never lived. After the move, Ty and Lois lived in several different living situations but none of them were therapeutic to Ty and his decline was rapid. After just a few months he and Lois moved into different wings of a nursing home facility and Lois could visit him a couple times a day. Ty was constrained and after a couple of weeks, he died. His funeral was in a strange place with only close family present. These were good and virtuous people but they did not think with the "normative elements" of consent and autonomy.

This case illustrates in conclusion the tragic results of not including normative elements of the rules for consent (specific guidelines) and the principles of autonomy, beneficence, and justice (general value guides and motives for action).

Democracies are vulnerable communities for normative ethics because freedom can breed subjectivism, personal and cultural relativism. In America, we guard against this danger by reference to our Constitution and by our effort to create professions with integrity. One example of the latter is the historical development of the medical profession. Its success is attributed to science as a method of acquiring objective knowledge, to the academic process of higher education, and to supervised clinical practice with structures for holding the profession to normative standards embedded within Greek Hippocratic medicine and the Abrahamic faiths and others. This seems to be our history and the continuing promise for our future.

Thus, Thomasma and Pellegrino emphasize that biomedical ethics must emerge from and yet guide especially the medical and nursing professions but also other health professions. Simultaneously, these professionals and others must be accountable to the normative elements of moral philosophy, theology, and other traditional sources of the good and right.

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Supporting Organ Transplantation in Non-Resident Aliens Within Limits

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Abstract

It is common knowledge that the supply of cadaveric organs does not meet demand. This shortage is often used as ethical argument against transplantation in Non-Resident Aliens; however, this fact in isolation does not present a comprehensive picture of organ allocation in USA. Even though approximately 153 cadaveric livers, kidneys, and hearts are transplanted into Non-Resident Aliens each year, roughly another 85 livers, kidneys and hearts are recovered as usable for transplantation but are not transplanted due to inability to find a recipient. These organs are also unable to be exported due to logistics or lack of patient matching. Because usable, recovered allografts are discarded on a yearly basis, there is no justification to use "allograft scarcity" as argument against transplantation in Non-Resident Aliens. Further, consistent with other countries, a system of two waiting lists which allocates organs to US Residents with the first right of refusal (with Non-Resident Aliens having access to organs refused by or not matched to US Residents) is ethically appropriate. Justification for this two-list system lies in deconstructing "who" is the transplant community, and who are "guests" of the transplant community.

Keywords: transplant, organ allocation, ethics, justice, discrimination, foreign national

Introduction

Allograft scarcity across all organ types continues to be documented by the United Network for Organ Sharing (UNOS).[1] In general, attempts to increase organ donation have not been very successful, with the number of organ donors increasing by only 3% each year.[2] There is concern that the number of organs needed will never meet demand, thus there is an ethical imperative to allocate them fairly to patients with the capacity to benefit from them.[3] Currently, UNOS permits Non-Resident Aliens (NRA) to be registered on the transplant waiting list and to receive allografts under the same allocation policies as that of United States (US) Residents.[4] UNOS considers NRAs as those individuals "granted permission by the US Government to enter the US on a temporary basis as a non-immigrant alien for purposes which include tourism, business, education, medical care, or temporary employment".[4] Residents are those who have the legal right to live permanently in the US.

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UNOS allows each transplant center to allocate up to 5% of cadaveric transplants to NRAs.[4] Approximately 153 cadaveric livers, kidneys, and hearts (total) are transplanted into NRAs each year.[1] Most of these cases never receive media attention; however, when this does happen, the spotlight shines directly on US transplant policy. Emotions range from anger that NRAs "take" organs that "should" go to US Residents, to compassion for these needy individuals who are frequently poor, very sick, and unable to access transplant services in their own country.[5,6,7]

US Transplant Data

As of 27 May 2005, patients registered on the UNOS transplant waiting lists are in need of 95,618 organs (some patients need more than one type of organ). Sorted by citizenship, there are 88,656 US citizen registrations, 3483 Resident Alien registrations, and 851 NRA registrations. Specifically, NRA registrations comprise 0.89% of all registrations, 0.98% of kidney registrations, 0.91% of liver registrations, and 0.38% of heart registrations (www.unos.org). Between 1996 and 2003, NRAs were the recipients of 661 liver transplants, 399 kidney transplants, and 161 heart transplants. During this same period, US Residents were the recipients of 35,660 liver transplants, 64,479 kidney transplants, and 17,580 heart transplants (Table 1).[1] Donated livers, kidneys and hearts that were clinically suitable for transplant but were unused during this period totaled 679 (Table 2).[1] These organs (approximately 85 per year) may have either been unmatched (no suitable donor found), or matched, but the potential recipient was unable to be contacted to arrange transplantation.

Organ Exporting v. NRA Transplants

In addition to allowing NRAs to receive organ transplants, UNOS also allows cadaveric organs donated in the US to be exported to other countries.[8] These exports are distinctly separate from using organs for research in that the exported organs are for human transplant. UNOS policy allows such export to occur as long as no suitable UNOS waiting list matches are identified. Not unexpectedly, the primary export location is Canada, as logistics prevent export to distant countries. In the 10-year period between 1994 and 2003, 78 hearts, 29 kidneys, and 5 livers were exported to transplant centers in foreign countries.[1]

The practice of organ export raises the question, *Is there an ethical difference between exporting organs to other countries and keeping the organs in the US and giving them to NRAs?* Both the NRA and the patient who receives the exported organ are non-residents of the US. While the NRA is physically present in the US, he/she is subject to living outside of the US (due to voluntary return to their home country or deportation) just as the export organ recipient resides outside the US. The latter patient is not receiving transplant management care in the US, and the NRA patient will not have US medical management when he/she leaves. Notably, US Residents don't bear the surgical and medical costs of transplantation when organs are exported; however, they often do in the case of NRAs, as these patients receive their transplant in the US and often require financial assistance to pay for their expenses. Another matter is the fact that

NRAs compete for cadaveric organs on equal footing with US Residents (until the 5% quota is reached), whereas organs that are exported to other countries are the result of not finding suitable matches in the US. This said, recipients living in foreign countries take second place to US Residents and NRAs who have priority for the organs in an equal manner.

Appropriate organ allocation must reflect on both pre- and post-transplant issues. While UNOS and US physicians have no control over the psychosocial assessment of patients receiving exported organs, facilities receiving these organs are approved by UNOS via "formal organ exchange agreements".[8] Optimally, these approvals should reflect on post-transplant treatment quality and accessibility. In the case of NRAs receiving organ transplants in the US, the transplant facility should conduct a thorough psychosocial assessment that reflects upon the transplant management services available in the country that the NRA would return to if he/she left the US. This investigation should identify what transplant-related medications are available in the patient's home country, as well as the financial costs and accessibility (private insurance versus national health care). NRA patients are of special concern, as often their country of origin lacks appropriate facilities and medications for post-transplant care. In such settings, these patients are at risk for substandard medical care (or no medical care), thus putting the donated organs at risk for rejection, and ultimately, clinically preventable patient death.[9]

Illegal Aliens

Illegal aliens ("undocumented aliens") are those who have entered the US illegally without the proper authorization and documents, or who have entered the US legally but have since violated the terms of the status in which they entered or have overstayed their permitted time limit (www.irs.gov). UNOS organ allocation policies do not address the matter of transplantation of illegal aliens.[4,5] Specifically, the policy dealing with foreign nationals addresses allocation to NRAs and does not mention illegal aliens at all. It is unclear why UNOS does not discuss this group. By default, one could assume that organ allocation to illegal aliens is not allowed just as employment of illegals is prohibited,[10] but UNOS policy is silent on this matter. Indeed, transplantation of illegal aliens is ethically problematic as these individuals frequently lack the financial means to pay for their surgical and post-transplant care, as well as a stable support system to assist them post-transplant. Also, they are subject to deportation at any time, disrupting post-transplant care. Such deportation often occurs to countries that lack appropriate medical services for transplant patients,[9] or the care is not accessible due to high cost.

Further complexity is found when one considers that NRAs can become illegal aliens after they are placed on the transplant waiting list. It is unclear if these individuals have their immigration documentation routinely reviewed by anyone (UNOS, transplant center) to ensure that NRAs who are wait-listed maintain legal status or if these individuals get removed from the waiting list if determined to be illegal aliens, rather than NRAs. Have individuals who were listed with NRA status but shifted to illegal status while listed been transplanted anyway? UNOS does not keep such statistics. Also, there is the matter of people

entering the US "legally" with a formal determination of NRA that is based on a false premise of tourism or education, when in fact, these individuals are seeking organ transplantation. Should UNOS or the transplant team become the "Immigration Police"? Should they inform the US Government if they suspect or identify fraud? In Los Angeles (CA), San Diego (CA), Stockton (CA), New York (NY), Chicago (IL), Miami (FL), Austin (TX), and Houston (TX), no hospital or physician can report immigration violators to the Department of Homeland Security's Bureau of Immigration and Customs Enforcement".[11]

While allocating organs to illegal aliens can result in poor resource stewardship, Beth Israel Medical Center (NY) takes the controversial position that they will allocate organs to these individuals. Under their policy, however, they will not subsidize the individual's inpatient or outpatient clinical expenses or medications. Further, the hospital requires that these individuals provide a deposit to cover all anticipated costs, unless they can provide prove that they are entitled to State or Federal healthcare funds.[5] In the past, the publicity about organ allocation to foreign nationals has been shown to reduce organ donation rates,[9] thus the practice has the potential to negatively impact US Residents who are in need of transplant (by reducing the number of organs available to them). This negative potential is likely further fueled by the inclusion of undocumented aliens in the construct of "foreign national" as these individuals reside in the US illegally, and have little, if any, healthcare funds.

Waiting for a Transplant

Patients waiting for a transplant are often troubled by many fears including anxiety about not knowing how long their wait will be, or if they will die before getting a transplant.[12] Some patients experience clinical deterioration while they await a donor organ, and decline to a state in which they are no longer considered transplant candidates. In the case of NRAs, when these individuals receive media attention about their organ need there can be a perception that the extra focus will facilitate transplantation of the NRA sooner than others [US Residents] who are waiting for an organ. Review of UNOS heart transplant data for the six-year period of 1998-2003 finds that the median time to transplant for US Residents was 297 days (+/- 69 days), whereas the median time to transplant for NRAs was 43 days (+/- 15 days).[1] During this period, US Residents waited nearly seven times longer for a donor heart than did NRAs (39% of whom were children). This data alone does not provide reasons for the significant disparity among waiting times for heart transplant recipients, but the matter warrants further research. It is possible that there is a preponderance of NRAs living in geographic regions that are known to have shorter waiting times compared to other regions,[13] that these individuals are less likely to be sensitized,[10,14] and/or that media attention is occurring and playing a role in directed donation to identified NRAs.[15]

A Proposal

As shown, dozens of donated organs are discarded each year in the US, as these organs are unmatched to US Residents, NRAs, or patients on Canada's transplant waiting list, or the organs are matched but the patients cannot be contacted to arrange transplant. The fact of organ discard, and the issues surrounding organ allocation to foreign nationals raises two philosophical questions, Who is the transplant community and Who are guests of the transplant community?

There are several ways to define "transplant community". This community could be seen to comprise those explicitly permitted by regulations to be organ recipients (NRAs and US Residents), people willing to be organ donors (living or cadaveric) regardless of their residency status, or anyone (regardless of their willingness to be an organ donor or their residency status). If one takes the position that non-US Residents should not be allowed to receive organ transplants in the US because these individuals don't donate to the organ pool, this fails to acknowledge the fact that many US Residents are also not organ donors. In the US, willingness to be an organ donor is not a transplant eligibility criterion; however, UNOS does give kidney organ allocation preference to individuals who have been living donors of any organ (rather than those who consent to be cadaveric donors).[16]

An argument that only taxpayers should be allowed organ allocation is faulty because it assumes only US Residents are taxpayers. NRAs who have the legal right to work in the US and who are employed are often subject to income and Medicare taxes, and they do pay tax on consumer goods. Illegal aliens do not have the right to work (and do not pay the associated taxes) but they do contribute to the local tax base through their daily consumption of taxed consumer goods. While their contributions do not equate to the taxes paid by US Residents, to say that foreign nationals do not make economic contributions is false.[17]

Having made these assertions, I pose that it is appropriate to consider the "transplant community" as US Residents because in general, this is the community from which organ donation arises and from which the majority of financial input is received.[18] This does not mean, however, that foreign nationals should be excluded from transplant; rather, they should be viewed as "guests" of the community. As guests, these individuals should not be on an equal playing field for access to allografts, but rather they should have access only after it has been determined the no suitable allocations can be made to US Residents. A similar policy is standard practice in Australia and New Zealand.[19]

Formally, this organ allocation system should be comprised of two waiting lists, one for US Residents and one for NRAs.[20] The second list should not include illegal aliens as this group has the highest risk of deportation, the highest risk of disrupted post-transplant care (due to issues of cost and access), and the lowest potential for contributing to the US transplant community as donors. Both standard and extended criteria organs (marginal organs)[3] should be allocated using the two list system. Both NRAs and US Residents should demonstrate the ability to pay for their pre- and post-transplant care either via their own financing, access to insurance, or verified charitable donation. All hospitals should provide a small amount of charity care[18] for transplant patients

on a yearly basis, as they do for other medical specialties. The amount should consider their current and projected case load, costs, and funding, as well as the worthy goal of assisting the stewardship of donated organs.

NRA transplants should be allowed; however, these should occur only if the organs are unable to be used by US Residents or are refused by them—essentially giving US Residents priority on the UNOS waiting list due to residency status. In this manner, donated organs belong to the community from which they were donated. They can be shared with guests outside of the community only after it is determined that the community cannot benefit from the donations, and it is confirmed that the guests can respect the gifts (access to suitable follow up medical care). The practice of medicine has a compassionate nature in that it seeks to reduce suffering and improve quality of life, thus a person's national origin itself should not be an exclusion criterion for the provision of care. However, in a setting where finances are limited and allografts are scarce (and require significant maintenance), allocation must reflect on many variables.

For the reasons discussed, it is not unethical to give US Residents first priority for organ transplantation, or to deny organ transplants to illegal aliens. In fact, untamed allocation can have a net effect of harming the transplant community by reducing organ donation.[9] Further, if US educational efforts eventually succeed in significantly increasing the rate of organ donation, the group that should reap the benefit is the "transplant community"; that is, the community from which the donations originated. If there is an excess, such should be shared with those outside the community. Lacking excess, the "community" should be served first by having priority access to cadaveric organs. Additionally, the number of "unused" organs should be reduced to zero; that is, any usuable organ that is unmatched amid the two-list system, as well as for export transplant, should be used for research or educational purposes. No donated organ should go to waste.

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NATURE'S END: THE THEOLOGICAL MEANING OF THE NEW GENETICS

RICHARD SHERLOCK, PH.D.

Ever since the ancient Greeks, the ethical tradition of the West has been powerfully dominated by claims about human nature. Such an intellectual orientation has an eminently practical value. If we can indicate features common to all humanity as the basis of moral principles, we at least have a common point of reference with which others can conceivably come to agree. Moral and political deliberation may then be reduced to a debate about the precise meaning and application of shared moral principles—and not the much more contentious question of the ultimate ground of such principles. We can see how prevalent the western appeal to human nature is by considering two quite different thinkers.

Aristotle

In the *Nichomachean Ethics* Aristotle views human beings teleologically. Human beings possess a specific nature, one that is purposefully directed to a specific end, the good. This human good represents the flourishing of a set of distinctively human capacities. These are natural human desires, the fulfillment of which constitutes the good life for human beings. Such "moral passions" are the natural dispositions to moral activity that can be fully sufficient. Aristotle calls this supreme and self-sufficient good eudemonia or happiness. Almost immediately, however, he recognizes that this claim seems little more than a platitude. In order to make it intellectually plausible his assertion needs to be more clearly specified.

Thus, Aristotle analogizes his search for the human good to the search for the more particular goods of craftsmen or artisans like tanners, carpenters, or flute players. There are characteristic features of a good carpenter or flute player. They are good insofar as they perform well the activities required of their art or craft. They fulfill well the functions inherent in their activity. Similarly, we may speak of good sight or hearing when the eye or ear performs well their natural tasks of hearing or seeing.

Aristotle believes that human beings have a specific nature whose flourishing is analogous to the flourishing artisan who pursues his art with skill. This good will be unique to human beings—though it will require the lesser goods that human beings share with other forms of life. Nutrition and growth are shared with plants, so that will not be specific to human beings. Perception seems to be shared with animals, so it would likewise not be the basis of the good we are searching for. The good we are seeking is one proper to man and only to man. Hence, Aristotle defines this peculiarly human good

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as an activity of the rational soul, a feature that other forms of the life lack. The soul is said to have a characteristic set of "natural functions" and proper actions in accordance with these functions represent the good for man. "For all things which have a function or an activity, the good or the well is thought to reside in the function, so it would seem to be for man." In short, we find the distinctive human good by examining what contemporary academic philosophers call the "species-specific functioning" of a human being. Since a rational soul is unique to man, Aristotle concludes that "the function of man is an activity of soul which follows or implies a rational principle."

The rest of the *Ethics* represents Aristotle's attempt to develop this in sight by specifying the virtues or qualities of soul that represent human flourishing. In accordance with Aristotle's distinction between theoretical and practical wisdom, both moral and intellectual virtues are necessary for happiness. This is not the place to give a comprehensive treatment of Aristotle's teaching on the complicated matters. Suffice it to say that Aristotle grounds his whole enterprise in a detailed account of human nature and the flourishing to which that nature is directed.

Hume

Hume's appeal to fixed regularities in human nature is less direct than that of Aristotle. It is also not connected to a teleological biology and metaphysics. But it is still an appeal to human nature as the grounding for ethics.

Hume's moral philosophy is deeply rooted in his moral psychology, a psychology that is central to his discussion of the "moral sense" which, he asserts, is common to all human beings. Hume begins his celebrated discussion of ethics in the *Treatise of Human Nature* with a criticism of eighteenth-century moral rationalism, a view which held that moral principles could be intuitively grasped by speculative reason alone. Moral principles, Hume holds, are not derived from percepts of fact, nor from a rational intuition of things in the world or the relations among them.

It is in this context that Hume raises the question of the relationship between matters of fact and matters of moral principle—the celebrated is/ought problem—around which so much debate has revolved. Hume is not arguing for moral irrationalism or emotivism. Rather, he is locating the source of morality in a feature of human nature more readily appealed to, and more obvious than the rationalist alternative: the moral sense.

Since, for Hume moral distinctions do not represent a rational judgment of ideas his alternative explanation is that "It must be by means of some impression or sentiment they occasion that we are able to mark the difference betwixt them." Morality is based on a natural feeling or sensation such that "we do not infer a character to be virtuous because it pleases; but in feeling that it pleases after such a particular manner we in effect feel that it is virtuous."

Hume's account of the root of morality is fully natural. It is directed against both rationalism and religious theories of conscience. Though superficially similar, seventeenth-century Calvinist or Puritan theories of conscience were fundamentally different. The theological writers understood conscience as a

witness of the Holy Spirit directly to the human soul. Conscience, whether an idea or feeling was not natural: It was supernatural. Hume, however, locates morality in a natural feeling of sympathy for others, a point he drives home with an extensive discussion of the meaning of the word "natural" and its application to the question of morality.

A century and a half after the publication of Hume's *Treatise*, Charles Darwin returned to this theme with a late work on the evolution of "moral emotions" in man and animals. Especially in human beings, fellow feeling (Hume's sympathy) would have evolutionary value. Human beings require parental affection and care for a long period of time. Since in Darwin's view, as well as Hume's, parental affliction of sympathy is the most basic form of sympathy, those humans who had a better-developed natural moral sense would be selected for in the course of evolutionary development. Hume's and Darwin's naturalized morality can form a formidable basis for ethics, one that has many attractions. It preserves the distinction between morality and the exact sciences, articulates a natural (and therefore universal) human ground for ethics, and finally, accounts for the common experience of the right and wrong even by those with no formal training in such matters from philosophers or theologians. Once again, ethics is a mater of human nature.

II

In the face of the new genetics, however—cloning, gene-therapy, genetic engineering, and such—nature would seem to have played out its string. Technological mastery has proceeded to the point that we now face unprecedented moral questions, ones which the philosophical tradition of the west may simply not be equipped to answer.

Aristotle, for example, referred frequently to the natures of animals for insights into biological patterns that could ground an understanding of human moral relationships. But in an area when animal transgenics (i.e. the genetic engineering of animals to create completely new hybrids) has moved so far and so fast, is such an appeal to animal regularities plausible?

It is not the case that animal transgenics does no more than what animal breeders and domesticators have been doing for millennia. Such an assertion might have been possible if transgenics had stopped at identifiable species boundaries. Transgenics however, regularly crosses species boundaries. And there is no more troubling example of this than the use of animal organs for transplants into human beings. Attempted sporadically for three decades this effort has proven to be a failure. The human body's natural defense mechanisms almost immediately recognize that an animal organ does not belong in a human body. The biological wholeness of the human body does not include a baboon heart or a pig liver.

But human sympathy for thousands of our fellow creatures dying on waiting lists for a human organ transplant combines with science to develop a transgenic solution. For reasons of organ size and morphology pig organs are the candidate of choice. Two companies have therefore developed transgenic pigs that are modified by the insertion of two human genes. The human genes

will, it is believed, allow the pig organs to "fool" a natural defensive process of the human body which protects its human integrity.

Critics of transgenics usually appeal to two concerns. First they point to the risks of disease coming into humans from animals. Second they focus on the moral standing of animals independent of human welfare. Though significant these intellectual objections avoid the most profound issue. Has science brought us to the point where the idea that species are natural kinds, each with its own proper good is no longer a useful theoretical concept? If it is so questioned as a concept, can the appeal to nature, as Aristotle and many modern sociobiologists believe remain the starting point for serious moral reflection?

Our nature as sympathetic beings concerned about hunger, disease, and physical deformity has brought us to the ultimate form of domination over other sentient creatures. Once thought to be independent kinds seeking to flourish themselves they are on the verge of being fully created as dependent beings servicing the flourishing of human beings in the most profound way possible. To bring a sick human being to normal functioning we must destroy the normal functioning of some animals which will now have human genes.

Human beings are afflicted with many illnesses caused by defective genes. Many others have some genetic component. Consider only those like cystic fibrosis that are specifically genetic and where the genetic abnormality has been well identified. Could we not use transgenic technologies to relieve the suffering and early death of thousands afflicted with such a disabling and fatal condition?

For the last decade a number of researchers have attempted precisely that with a process known as somatic cell therapy. The process aims to cure a genetic disease in an afflicted individual by attaching a good gene to a carrier (called a vector) and then inserting the vector into the afflicted organ. The theory has been that the vector, typically a virus, would spread throughout the afflicted organ; the good gene would do what the malfunctioning gene was supposed to do. Unfortunately this process has not worked well. It now appears that somatic cell therapy is very difficult and major drug companies that once invested heavily in the process have pulled back.

In this form of genetic change one did not propose altering the human species or even just one genetic line of a species. All one was proposing was "fixing" a broken part of one individual. If somatic cell therapy could work, we would avoid the troubling questions of the right of one generation to choose the genetic destiny of its progeny for generations to come. But this therapy has not worked.

When somatic cell therapy begins to look difficult, the moral impulse that gave rise to gene therapy in the first place remains: the desire to help the unfortunate and the suffering. Consider a family with retinoblastoma in their history. Retinoblastoma is an inherited eye disorder that causes blindness in children, typically only in one eye. Half of all those who carry the defective gene will have affected children.

The obvious technical answer to the tragedy of retinoblastoma is to extract the DNA that might be abnormal and insert a healthy replacement at the embryonic stage of human development. After all, as the neo-Aristotelian

language widely employed in discussions of genetics would have it, blindness is not part of the "species typical functioning" of Homo sapiens. In doing so scientists will have insured that retinoblastoma will never appear in the progeny of this family. We have given the gift of sight that keeps on giving. In order to fulfill the demand given by the moral sensitivities which seem innate in humanity, we must, it is said, take our given nature in our hands and alter the destiny that God or fate has left us. What supposedly will provide the moral limits to our use of such biotechnology is a ubiquitous appeal by ethicists to that phrase "species typical functioning."

The idea is that genetic transformations are morally acceptable and indeed praiseworthy when they restore an individual (and perhaps his progeny) to the typical functioning of an ordinary human being. A particular patient's liver is not producing and essential enzyme. Perhaps a pig liver would do the job. Perhaps somatic cell therapy can inject genes that would code for the production of the missing chemical. When the specific genetic problem and inheritance pattern are identified, we can use nuclear cell transfer to prevent the birth of infants whose genetic destiny would not have been typical.

But the very science that has brought us to a potential cure for one family's retinoblastoma calls into question the limits that commentators try to set to its use. The same technology that can be used to target one genetic sequence and replace it in a fertilized human egg can be used to target any genetic sequence—from those more loosely correlated with diseases such as alcoholism or gender preference to those controlling eye color, height or body build. As our knowledge of the precise genetics that control some parts of our bodies and influences both body and behavior increases, the seemingly neutral and conventional appeal to species typical functioning increasingly appears as a chimera. It cannot bear the weight that its advocates place on it, and this for two reasons.

First what was originally a physiological or biological claim about a species is now employed as a moral limit to science. As a purely biological claim this won't work.

To be sure we can claim that "genetic repair" as it can be called will benefit the patient and the patient's progeny. Hence genetic repair of a missing function might be generally considered good. But what about enhancing functions? Might someone not consider it better for him and his progeny to be taller than average, less prone to shyness, or less sensitive to the effects of alcohol? If repair is likened to typical functioning these three and literally thousands of other possibilities do not look as neatly like repairs. But they are beneficial nonetheless. So they seem to follow from the same rationale as that given for repairs more narrowly conceived.

The new genetics has brought us to a point where any appeal to the fixed regularities of human nature for moral principles may no longer be persuasive. We are then left with a challenge. The tradition that has provided the context and limits for human activity in ethical and political matters for millennia may no longer be adequate. Insofar as human beings now take their own nature as an object to be crafted rather than a pattern to be followed, they have left behind both Aristotelian teleology and Humean naturalism.

The second difficulty with the appeal to species typical functioning is that, as such, it is only partially a teleological claim about final causes. Philosophers have long believed that the most persuasive view of Aristotle's discussion of final causes sees teleology immanent in the individual but not tied to a cosmic plan. In this way commentators have tried to save Aristotle from the discredited fate of natural theology. In this view final cause represents the individual creature's irreducible potential for a specific form of life. Final cause gives order and meaning to an otherwise disparate batch of natural parts. One of the greatest biologists of the twentieth century, Ernst Mayr, explicitly used Aristotle to articulate how the teleological ends of living entities are prefigured in the genetic *eidos* inherent in their being. The *eidos* is the blueprint that gives form to the growing being. In such an understanding we assume that DNA represents the organizing principle of a living being that sets forth its potentialities understood as final cause. Even granting that it is only necessary but not both necessary and sufficient for flourishing, our ability to rewrite the program points to the limits of such an immanent teleology as a moral guidepost for the new genetics.

One recent commentator on the moral meaning of Aristotle's teleology holds that " Aristotle's biological teleology cannot be cosmic because to explain natural occurrence through its final cause is to explain why it was better this way, not absolutely but relative to the substance of each thing." This is an extremely plausible reading of Aristotle and it shows why Aristotelian (and neo-Aristotelian) teleology is not adequate to the task of articulating the proper limits of the new genetic technology that is now upon us. Flourishing is relative not to a cosmic purpose but to the specific substance of each thing. But when we can deliberately change substances, even our own, we can no longer appeal to the immanent telos of such substances for the limits to change.

One solution might bed to throw the baby out with the bathwater: to reject genetic technology altogether. There is now a substantial literature developing this moral view. But for all its appeal to a natural way of being, such writing fails give any account of one of the most elementary parts of human nature: or feeling of sympathy for those afflicted with severe genetic diseases And our desire to help families avoid such diseases or cure them if possible.

On careful analysis it would appear that we need the intellectual resources to make a delicate judgment about planned genetic change. Our natural concern for our fellow human beings leads us to consider as morally acceptable or even required some such changes. Yet our wariness toward or even revulsion at many such schemes, a revulsion born of moral concern and an awareness of the dismal history of eugenic schemes, remains. Still it is the capacity of the moral tradition of the west that once provided the resources for such a judgment which biological science now calls into question.

III

It seems therefore that we must take a road less traveled, the road that modern science rejected and modern ethical and political philosophy viewed with suspicion. Science has brought us to the point where we must question the sufficiency of philosophy itself to continue to provide the meaning and context for science. To understand the meaning of, and limits to, human genetic

change—to even make sense of its claims of better or worse – we must conceive of human beings in a cosmic, or to put it plainly a theological context.

One of the least developed of Saint Thomas Aquinas' arguments for the existence of God is relevant here. Aquinas appeals to our common experience of judging or grading things as more or less virtuous, wise, or noble. Such an activity in the world presupposes a perfect standard of wisdom, nobility, or virtue that itself is beyond the world. Just like the activity of attributing a chain of causality, the activity of grading implies a transcendent being whose existence alone makes our common activities such as grading or comprehending a chain of natural causes coherent. Though this is the beginning of a natural theology whose limits are evident in the newest genetics, I believe that it is significant that Aquinas' proofs for the existence of God are only a very small part of a much larger theological work. They are not meant to stand alone in the fashion of enlightenment natural theology. They are meant as a first engagement with theology proper. The argument we are considering here only leads to the conclusion that a transcendent standard is required by the common activity of normative judgment. It is theology proper which displays in full form what the divine standard is. This not the place to develop a full theology of any sort, let alone one adequate to the task I have set for it here. However, we can establish three elements that such a theology must include.

First it must reject a reductionistic view of human beings as no more than a collection of molecules. The qualities that matter to human beings are qualities that are traditionally thought of as virtues of the soul, not the body. Embodiment may be necessary for human existence but it cannot be sufficient. This is especially true if embodiment is given a standard "flesh and bones" understanding. Those philosophers and theologians who speak of a sort of matter that is different from our common understanding or of a materialism that is anomalous or non-reductionistic, have not actually solved the difficulties with standard accounts of personhood. It may be better to admit frankly the poverty of materialism as such, and to work out a fully alternative account of the holistic nature of human beings as embodied souls. The alternative account will need to include qualities of embodiment as part of a comprehensive view of human beings, but it cannot reduce qualities of soul to qualities of body.

In other words, while the needed account of human beings' transcendent end must speak of the soul and its temporal embodiment, it may remain neutral with respect to the nature of this ultimate state of transcendence. To put the matter in terms of Christian theology, the theology which I believe is now required does not need to solve the problem of the difference between a concept of bodily resurrection and the concept of the immortality of the soul.

Second, this theology must be incarnational in the strong sense. Much of modern Christian theology has been ambivalent or worse regarding a strong view of the incarnation. It has preferred to regard the founder of the Christian religion as a superior human being whose superiority is noted by conformity to whatever standard a given author prefers: authenticity, "God consciousness", or love of neighbor are familiar alternatives. This intellectual standpoint cannot meet the current need. It selectively extracts some part of the world as normative and then reads the Christian story in this light, finding what was presumed all along—the superiority of the founder. Such intellectual moves start at the

wrong end. They read eternity in light of the *humanum* and not, as serious theology should, the *humanum* in light of eternity. As the *humanum* becomes ever more an artifact, this has the ultimate effect not of "playing God" but of making God.

All readings of human nature are selective, but in this perspective, those who select some part of human nature for theological purposes are correct. They have started, however, at the wrong end. Given our limited position in the process of becoming, we cannot finally and fully grasp the terminus of our becoming by looking only at features of our existence at this point. We cannot pick out those features that are existentially appealing and simply throw away the rest. We must have a vision of the final end of our existence in light of which we can do the selecting.

Third this theology must be revelational. The principles that it sets forth to guide practice must be rooted in a grasp of divine and not merely natural law. The appeal to natural law has been an honorable enterprise for much of Christian history. Like the philosophical counterpart, theological variations have many attractions for political and moral practice in a complex and religiously diverse world. Its most persuasive theological defenders have made appeals to specifics about human nature such as the sensation of pleasure or the teleological structure of human sexual intimacy to ground moral practice. But cloning, the most immediate and troubling result of human scientific mastery, promises asexual reproduction for those who either cannot or do not want the heretofore "natural" variety. This science, however, leads directly back to the difficulty of appealing to human nature for guidance about changing once stable features of our natural existence.

Divine law has always been thought to clarify the more obscure elements of natural law. It has long been held to show more clearly the moral features of human existence, amplifying natural law and supplementing it where necessary. Even if one regarded natural law as moderately useful for practical purposes, this revelatory feature of traditional theological morality must be reinvigorated to meet the deepest needs of the present.

We may return to the problem of human cloning for an illustration of this need. Critics of human cloning have often referred to its asexual character as deeply disturbing. The concern is that asexual reproduction is unnatural because it divorces the expression of sexuality from the natural telos of marital union, if not actually reproduction. Setting aside the way this critique intersects with problem of deliberate technological reproductive control in other ways, the appeal to the natural telos of sexuality is problematic. We might well ask: why is asexual reproduction wrong? We are then told that it distorts a natural telos. Probing further we are pointed to towards stable regularities of human biological existence that the very possibility of human cloning calls into question.

In rather traditional fashion we might return to the biblical account to clarify the manner in which asexual reproduction in unnatural. It might be because sexual distinction, not asexuality, is coequal with human existence seen theologically. God it is said, " created man in his own image… male and female created he them." Sexual distinction is not only a product of biology it is a product of humankind's status as divinely created. This creation may

be expressed biologically and evolutionary biology certainly may offer some explanation of how we got to the biological and social point that we are at. But a fuller comprehension of biology is only given in a theological context.

Sexual union is also understood in a context of divine creation. Reproduction is the first task given to Adam and Eve (not to one alone) and in the second creation story in the second chapter of Genesis it is noted that human beings are created such that they leave the families of their birth and unite with one another whereby "they will become one flesh". My reading of Genesis in relation to cloning is of course contestable. I claim for it no authoritative status. The point has not been to offer a full account of this highly complicated question. I have only used the issue to exemplify the way in which revealed theology provides the richer context that is required to fully comprehend developments at the frontiers of the biological sciences today. The discussion of cloning illustrates the way in which divine law amplifies and makes clear the ultimately significant features of our biological existence.

IV

At the foundation of modernity was a self-conscious desire to establish a political order divorced from the theological concerns and conflicts of the past. Scientific mastery would turn human attention to the sturdy realities of this world and away from the always concerns about salvation in the next. The success of the modern project is everywhere evident. No one would wish to return to those ages in which human life was actually "nasty brutish, and short."

But the advance of modern science, especially in the area of genetics, has now called into question the sufficiency of the classic liberal attempt to keep questions of ultimate purpose from intruding on public life. The liberal tradition of narrowing the focus of the questions addressed in the political order and the reasons that may be offered in the public square was a noble endeavour in which religious communities fully played their part. Since the enlightenment, religion has largely spoken the language of liberalism and when it did not it was ignored. Christian communities in America, for example, have frequently addressed public issues such as slavery, civil rights, the Vietnam War, and abortion. When Christian communities have addressed these problems, however, they frequently relied in large measure on reasons that met a liberal or Enlightenment test of acceptability. Abortion, for example, is usually opposed not because of the corruption of the soul that is involved in assenting to the practice but because of the apparently positivistic claim that " science has proven that human life begins at conception."

For the mosts part this taming of theological claims has been pragmatically beneficial. In public debate a most effective strategy is to show an opponent that even on grounds that he or she accepts, your own conclusion follows. In the case of recent advances in genetics, however, this tradition of liberal theology is no longer adequate. What is required is not a tamed and muted quasi-religious voice but a robust expression of a theological vision of the nature and destiny of mankind.

To be sure theology must be informed about the issues posed by the new science. But its speech must be vigorous in response to questions that arise from the scientific manipulation of the *humanum*. Theology's most constructive role in the discussion is to be itself not a weak version of sociology or political science, or even philosophy.

This undertaking will require theology to give cogent reasons for its conclusions, reasons which follow from its grounding vision of human existence. Theology's role in the present discussion, however, is not limited to giving specific reasons even reasons rooted in a robust theological commitment for this or that moral view. More fundamentally theology must bear witness to its complete vision of reality. To bear religious witness is different that giving a discursive reason for a conclusion. No one is convinced to be a Christian by studying Aquinas' "five ways" – but a deep engagement with Augustine's *Confessions*, the most powerful testimony of God's love for a lost soul in all literature just might.

In bearing witness, theology points to certain features of our existence which it is convinced are intimations of immortality or dimly lit parts of our experience that show a transcendent purpose. Theology shows how disparate parts of our existence can be brought together coherently in one unified picture. Recognizing this truth may not be a matter of reasoning to a conclusion but a matter of recognizing oneself in the "story" thus presented. One says at the end not " I accept your reasons" but " Ah, now I see." Conversion, not persuasion may be the proper goal of our efforts.

If these tentative remarks are sound, then theology's role in our time is best fulfilled not by appealing merely to natural law of liberal values, but by bearing full and vigorous witness to the truth that it alone holds sacred. This is the truth that allows us to see the deepest and most profound view of human nature as ordained toward a transcendent destiny. This is the story that theology alone tells. It is also the story that alone can face the challenge of the present and future of man's technological mastery.

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BOOK REVIEWS

One of Us: Conjoined Twins and the Future of the Normal

Alice Dreger

Baltimore, Maryland: The Johns Hopkins University Press, 2004

ISBN 0-8018-8070-X; 342 PP., PAPERBACK, $26.95 (HARDCOVER $49.95)

As a historian of science, Alice Dreger presents several challenging theses regarding conjoined twins and public policy. Though the subtitle of the book refers to conjoined twins, much of Dreger's analysis has a wider agenda: to change society's views regarding abnormal and normal anatomy. While most of the book examines policies for conjoined twins, Dreger interacts with issues such as cleft palate, intersex (hermaphroditism), slavery, and homosexuality.

One of Dreger's theses is that normalizing surgery is often simply assumed to be the best route for conjoined twins. She challenges the notion that "conjoined twins are born to be separated." In order to prove her point she notes that there is a lack of follow-up studies that analyze the real benefits of normalization procedures (both physically and psychosocially). She also cites several cases of surgeries that have failed in order to disprove the notion that separation should be done at "any cost."

Secondly, she challenges the driving force behind normalization and separation procedures. She notes that it is extremely rare to find adult conjoined twins who want to be separated, even after one has died. Her research indicates that most conjoined twins felt at ease and comfortable with how they lived. Ultimately she suggests the surgeries may be more about the well being of parents than the children. Such surgeries involve more risk than acknowledged and may be based on a desire to avoid a society with "abnormal" people.

Thirdly, Dreger calls into question so called "sacrifice" surgeries wherein one conjoined twin is killed for the sake of the other. She raises important questions about the methods used for determining which twin is killed and which twin lives. She laments that issues such as financial and social obligations have overshadowed the more important fact that both twins have a right to life.

Dreger's solution is radically different than the solution posed by so many in the wider medical community: to simply abort conjoined twins. She suggests alternatives to separation surgeries if the case is not life-threatening. These include: therapy, group and parental support, postponing operations and accepting that conjoined twins may indeed live a dignified and satisfying life together.

As a philosopher of science, Dreger does not fair as well and her book is riddled with unsubstantiated claims. One of these underlying philosophical assumptions is that homosexuality and intentional transgenderism are anatomical issues that are parallel to having a minority skin color, dwarfism or conjoined twinning. She wants society to approve of and support homosexuals in the same way that we support conjoined twins. This is fallacious as it equates the *actions* (sexual or otherwise) of a person with *physical anatomy*.

In conclusion, Dreger's short volume provides a good entry point to the ethical issues surrounding conjoined twins. Though her claim that conjoined twins are "oppressed" by "singletons" is perhaps a stretch, she wants to force the medical community to look outside the box and consider whether long held assumptions about separation surgeries are valid. This challenge is perhaps all the more important within a Western Judeo-Christian ethic that places great value on autonomy, individuality and freedom. Dreger's suggestion is worth consideration: perhaps the most freedom for conjoined twins is to be found in their union.

David Wenkel, M.A.

Ending Life. Ethics and the Way We Die.

Margaret Pabst Battin.
New York: Oxford University Press, 2005

ISBN 0-19-514027-3; 344 PP., PAPERBACK, NO PRICE QUOTED

The author is Distinguished Professor of Philosophy and Adjunct Professor of Internal Medicine, Division of Medical Ethics, at the University of Utah and this book is a sequel to her 1994 *The Least Worst Death*. It is an eclectic but almost always interesting collection of her writings around "Ending Life: The Way We Do It, the Way We *Could* Do It", as she titles her Introduction.

One quote could summarize her theme. She describes "the Stoic/Christian divide about the individual's role in his or her own death: whether one's role should be as far as possible active, self-assertive, and responsible and may include ending one's own life—or, on the other hand, acceptant, obedient, and passive in the sense of being patient, where 'allowing to die' is the most active step that should be taken."

The descriptions, discussions and debates that follow make her position clear. Indeed, she (presumably) chose for the front cover Rubens' 1615 painting *Death of Seneca*, a grisly reminder of that Roman Stoic philosopher and statesman who died in 65 AD when Nero ordered him to commit suicide and he obligingly opened his veins.

Part I, "Dilemmas about Dying", begins with a useful historical review that ends with an unconvincing plea for a consensus on "Can the Dispute over Physician-Assisted Suicide Be Resolved?" We are either going to have doctors killing patients legally or we are not. There is no middle ground. Chapter 2 uses the Netherlands, the U.S., and Germany to illustrate three different approaches to dying, and makes a generally fair critique, though discussion is not about 'if' but 'how' we intervene to end life. A chapter on the rationality of physician-assisted suicide in AIDS contains useful insights, and I disagree totally with her conclusion to the question "Is a physician ever obligated to help a patient die?" A short case consultation seems out of place, and Part I ends with a lengthy piece of creative fiction she wrote in 1981 but has never published previously. Interestingly, while as a philosopher her assumption is always that autonomy trumps (almost) everything, it is here and in another fictional piece that she records a genuine ambivalence about what ending life would mean in practice. Perhaps philosophers should listen more to their intuitions?

Part II examines "historic, religious and cultural concerns" and is scrappy. I wasn't sure what a chapter on collecting primary texts added; enjoyed some speculations on why former U.S. Presidents John Adams and Thomas Jefferson died on the same day, July 4th 1826, the 50th anniversary of the signing of the Declaration of Independence; agreed with almost everything about "high-risk religion" (her views on snake handling being the most obvious example!); was gripped by the narration and implications of her account of killing experimental animals; and would have been interested in a longer treatment of suicide bombing.

Part III, "Dilemmas about dying in a global future", is helpfully provocative about questions we must all face, whichever side of the Stoic/Christian divide we sit. Genetic information will indeed enable many of us to predict more accurately when we might die, though if Battin succeeds in legalizing doctor killing, some will know exactly when they will die. We do need to consider, now, the ethical aspects of increased life span, and while I applaud the emphasis on global life expectancies and international justice (the United States has 5% of the global population, but accounts for 50% of health spending), I deny there is any consequent "duty to die". Was there deliberate irony in the title "New Life in the Assisted-Death Debate", about so-called Nu-Tech methods of killing patients without recourse to scheduled drugs? She helpfully advocates "oppositional collaboration" to encourage dialogue within empirical research in bioethics, and ends by borrowing the phrase attributed to President Clinton

on abortion—"Safe, Legal, Rare"—to re-emphasize her conviction that, because of cultural change, physician-assisted suicide will be legalized.

So, has this editorial experiment bringing together thirty years' worth of writings worked? Yes it has. I gathered new material about end-of-life issues. I valued her analyses of religion's mistakes but on the evidence choose to be a Christian with hope and not a Stoic without. Perhaps the author will revisit her assumptions about autonomy and listen to the intuitions so helpfully recorded in her two fiction pieces.

Physician-Assisted Dying

Timothy E. Quill and Margaret P. Battin, Editors
Baltimore, Maryland: The Johns Hopkins University Press, 2004

ISBN 0-8018-8070-X; 342 PP., PAPERBACK, $26.95 (HARDCOVER $49.95)

Timothy Quill M.D. is a professor of medicine, psychiatry, and medical humanities at the University of Rochester and Margaret Battin Ph.D. is the Distinguished Professor of Philosophy and an adjunct professor of medical ethics at the University of Utah. Both are well known advocates of what they here call "physician-assisted dying" and this multi-author book is a reasonably useful collection of views which seek to justify the editorial position summed up in the words of the conclusion: "Excellent palliative care as the standard, physician-assisted dying as a last resort".

The whole book is a counterpoint to *The Case against Assisted Suicide: For the Right to End-of-Life Care*, edited by Kathleen Foley and Herbert Hendin. That volume seems to have inspired, if not incensed, some of the authors here and clearly any reader of this review who wishes to read either should read both.

There is much overlap between chapters and the quality of the 21 pieces in the four Parts is very variable. Part I gives perspectives on mercy, non-abandonment, autonomy and choice. Reading here the arguments on just one side of the case, it is frustrating then to have to agree mercy is a good thing—but what does that actually mean in practice? Non-abandonment is of course "a central obligation for physicians" and I love the concept but why isn't killing the patient, even if their choice is fully deliberated, abandoning them? Does autonomy always trump (almost) everything? And what limits must a truly just society set on choice?

Part 2 considers clinical, philosophical and religious issues and while often agreeing with analyses, I was also provoked to wonder: Does any of us really expect to avoid *all* suffering? Or is that which remains after all legitimate responses (and that should be very little suffering in the wealthy world to which this book is addressed) a necessary part of the rich condition of being human? I disagreed with much in Beauchamp's piece "When hastened death is neither killing nor letting die" but the real lowlight was Bishop Spong's attempt to justify doctor killing from a Christian perspective. It ignored much Biblical material, misinterpreted the rest, and was frequently blasphemous.

Part 3 gives a one-sided account of current practice in Oregon and the Netherlands where, as just one criticism, the issue of under-reporting is never taken seriously. And there is an obvious answer to the sentimental descriptions of distress experienced by doctors who perform euthanasia—don't do it. Work to care and not to kill. Reverse your law.

Part 4 describes political and legal positions. We could learn a lot from the professional strategies employed in Oregon that changed law there when similar approaches had failed or were to fail in the states of Washington, California, Michigan, Maine and Hawaii. The Oregon experience, both pre- and post-legislation, is going to be very relevant in the intense debate going on in my own country, the U.K. Many of the arguments in this section and throughout

are tired ones, even if slickly re-presented, and any reader should keep asking what data and objections have been omitted. No clinician would recognize some of the arguments made by some of the J.D.s as bearing any relation to real medical life, and terminology is always at issue. For example, the reader needs to understand that "compassion and patient choice at the end of life " means doctors killing patients.

This is a depressing book. Of course "excellent palliative care" has to be the standard but like the overwhelming majority of professionals in palliative care worldwide I deny that "physician-assisted dying" ever has any place. A vocal minority of healthy autonomaniacs may indeed want "physician-assisted dying" but it is not needed as "a last resort". Doctor killing should be rejected by every healthcare system and society in the world that claims to be civilized. Thankfully, almost all do.

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BIOTECHNOLOGY UPDATE

BY AMY MICHELLE DEBAETS, M.A.

Korean Cloning Scandal and Scientific Fraud

The recent discovery that the claims made by Hwang Woo-Suk to have cloned human embryos and developed lines of stem cells from those embryos was entirely fabricated has sent shock waves around the world, particularly for researchers and patients who had pinned their hopes on cures coming from stem cells derived from cloned embryos. The scandal reaches far and deep, including fabricating the results of cloning and deriving stem cell lines and publishing them in major scientific journals, *Science* and *Nature*, coercing junior researchers within the department to provide their own eggs for the research, claiming that the number of eggs used was far less than actually used in the research, and including an American scientist as a primary author on the papers who was either an accessory to the fraud or knew so little about what was going on with the project that he should not have been included as an author at all.

Over the past few years, Hwang had become a national celebrity in Korea and more recently an internationally-famous scientist, receiving both fame and fortune in exchange for promising cures to desperate patients. The Korean government had even named him the nation's "top scientist." Hwang, apparently feeling the pressure to deliver results, created claims to have succeeded in cloning human embryos using a "gentler" method of cloning than was used to create Dolly the sheep. The photos, supposedly of the cloned stem cells, have now been shown to have been doctored by the team. This has raised significant questions about the validity of other work in which Hwang has participated, the relative frequency of scientists falsifying data in cases like this, and the need for regulation or restriction on scientists who receive public funding and may have conflicts of interest regarding their financially lucrative work.

The scandal has also raised serious questions about the coercion of women, particularly researchers who worked under Hwang, to donate their own eggs for use in the research. According to these scientists, they were expected to undergo hormone injections and surgery to remove their eggs for use in the cloning research. Investigations have also uncovered the fact that, contrary to published claims, many more eggs were used in the experiments than had been reported, and despite the use of hundreds of eggs, not a single cloned embryo resulted. The publicity generated over Hwang's experiments led many people in Korea to undergo risky experimental trials involving untested stem cell treatments, some of whom are now far worse off than they had been. This is largely because of problems with the rushed and underregulated processes through which the experiments had been approved amidst all of the hype surrounding stem cells.

Lest it be thought that this is solely a Korean issue, Gerald Schatten, a biologist from the University of Pittsburgh and a primary author of the papers published by Hwang and his team, has claimed no knowledge of the fraud. Two scenarios are then possible, neither good for Schatten: either he really had no knowledge of the fabrications that were so widespread in this research, and thus should not have been included as an author of the papers at all, or he did know about the fraud and should be liable for it. Schatten is now trying to patent the process that the team used to supposedly create the cloned stem cells; the decision is pending in the US Patent and Trademark Office.

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State Of The Union Address: Biotech statement

In the United States, the past three years now have been marked by the war in Iraq and bitter partisanship in Congress. A comprehensive ban on human cloning has been passed In the 2006 State of the Union address, US President Bush reiterated his opposition to the abuses of biotechnology, stating:

"A hopeful society has institutions of science and medicine that do not cut ethical corners, and that recognize the matchless value of every life. Tonight I ask you to pass legislation to prohibit the most egregious abuses of medical research – human cloning in all its forms … creating or implanting embryos for experiments … creating human-animal hybrids … and buying, selling, or patenting human embryos. Human life is a gift from our Creator – and that gift should never be discarded, devalued, or put up for sale."

Gamete Donors for IVF Clinics – should they remain anonymous?

The assisted reproductive medicine industry has grown since the first baby was born using in vitro fertilization in 1978. In the United States, the industry is almost entirely unregulated and is highly profitable for hospitals and independent clinics alike. As the first generation of children born through the use of IVF and related procedures reaches adulthood in large numbers, a movement is arising to regulate the clinics, and particularly to make gamete donor information available to people who would otherwise have no knowledge of their genetic heritage. Clinics have long held that such donor information is and should remain anonymous, but this has also led to questions of the truthfulness of the clinics' claims about the background of the donors as well as information on how many children were born using a particular donor's gametes, etc. Children born through IVF often want to meet their genetic parents, just as children who have been adopted typically now have the option to meet their birth parents. They also want to ensure that they do no accidentally marry or have children with people who may be closely related to them, which they may not know because of clinics' privacy policies. All of these concerns and more are leading both people who have used fertility clinics to have children and children born through assisted reproduction to regulate the industry in the United States as is done both in other areas of medicine and in nearly all other industrialized nations.

Harmon, Amy. "Are You My Sperm Donor? Few Clinics Will Say," *New York Times*, January 20, 2006. http://www.nytimes.com/2006/01/20/national/20donor.html?ex=1138424400&en=7241e5c97b8dc90e&ei=5059&partner=AOL

Human-Rabbit Hybrids: The Key to Cloning?

Following up on the 2003 published research in which Chinese researchers claimed to derive stem cells from hybridized embryos using human nuclear DNA and rabbit eggs, British scientists are now seeking to conduct cloning and embryonic stem cell research using the same technique. This allows the scientists to conduct cloning research without the need to harvest human eggs – a costly and difficult process, but it instead creates embryos that are 98% human, with the remaining DNA and the cytoplasmic material coming from the rabbit. Some of the researchers are claiming that this solves the problem of creating human embryos for research, but the creation of human-animal hybrids poses other significant questions: How human must one be to be considered "fully human"? If one of the hybrid embryos was to be implanted in a womb and born, would it be human? Animal? Something else entirely? History has shown that people have a strong tendency to justify degrading others by claiming that they were, for reasons of race, gender, etc., not fully human. Is this another instance of the same argument being used to treat these embryos as less than human in order to justify their treatment as mere laboratory experiments? Or does the argument hold? These questions have yet to be answered, but the research marches on toward the development of human-animal hybrids.

Sample, Ian. "Stem Cell Experts Seek Rabbit-Human Embryo," *The Guardian*, January 13, 2006. http://www.guardian.co.uk/science/story/0,3605,1685534,00.html

Nanotechnology Update

According to the National Nanotechnology Initiative, "Nanotechnology is the understanding and control of matter at dimensions of roughly 1 to 100 nanometers, where unique phenomena enable novel applications. Encompassing nanoscale science, engineering and technology, nanotechnology involves imaging, measuring, modeling, and manipulating matter at this length scale. At the nanoscale, the physical, chemical, and biological properties of materials differ in fundamental and valuable ways from the properties of individual atoms and molecules or bulk matter. Nanotechnology R&D is directed toward understanding and creating improved materials, devices, and systems that exploit these new properties." Products currently on the market that utilize nanotechnology or nanoscale materials include sunscreens and cosmetics, stain-free clothing, dental bonding agents, and ink.

President Bush's budget proposal for FY 2007 includes over $1.2 billion dollars for the National Nanotechnology Initiative and was hailed by him in the State of the Union address as the key to American competitiveness in the rapidly changing technological world. Of this, only $14.3 million dollars are being spent (over the next five years) on projects to understand the ethical, legal, and societal implications of nanotechnology, less than one-tenth of one percent of the total annual budget. In comparison, the Human Genome Project had 3-5% of its annual budget devoted to the study of these implications.

For more information on the US National Nanotechnology Initiative, see www.nano.gov. To read the latest news on developments in nanotechnology, see www.smalltimes.com. Practical information on nanotechnology for the non-specialist is available at www.howstuffworks.com/nanotechnology.htm. Research and information on the ethical, legal, and social implications of nanotechnology can be found at www.nano-and-society.org.

Embryonic Stem Cells help Patents, Not Patients

A recent article written by an advocate for spinal cord research details the scientific and therapeutic differences between adult, or somatic stem cells, and embryonic stem cells. Nonembryonic stem cells have now been used to treat 65 different medical conditions, while the volatility of embryonic stem cells, their tendency to form tumors and cause tissue rejection, has meant that they have not been used or approved for any human trials and are not expected to be approved for some time to come. The article details the financial rationale behind much of the support for embryonic stem cell research: embryonic stem cell lines are patentable under US law, whereas stem cells derived from a patient's own body (adult stem cells) are not.

Swenson, Jean. "Embryonic Stem Cells Help Patents, Not Patients," *St. Paul Pioneer Press*, January 3, 2006. http://www.twincities.com/mld/twincities/news/editorial/13535335.htm

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