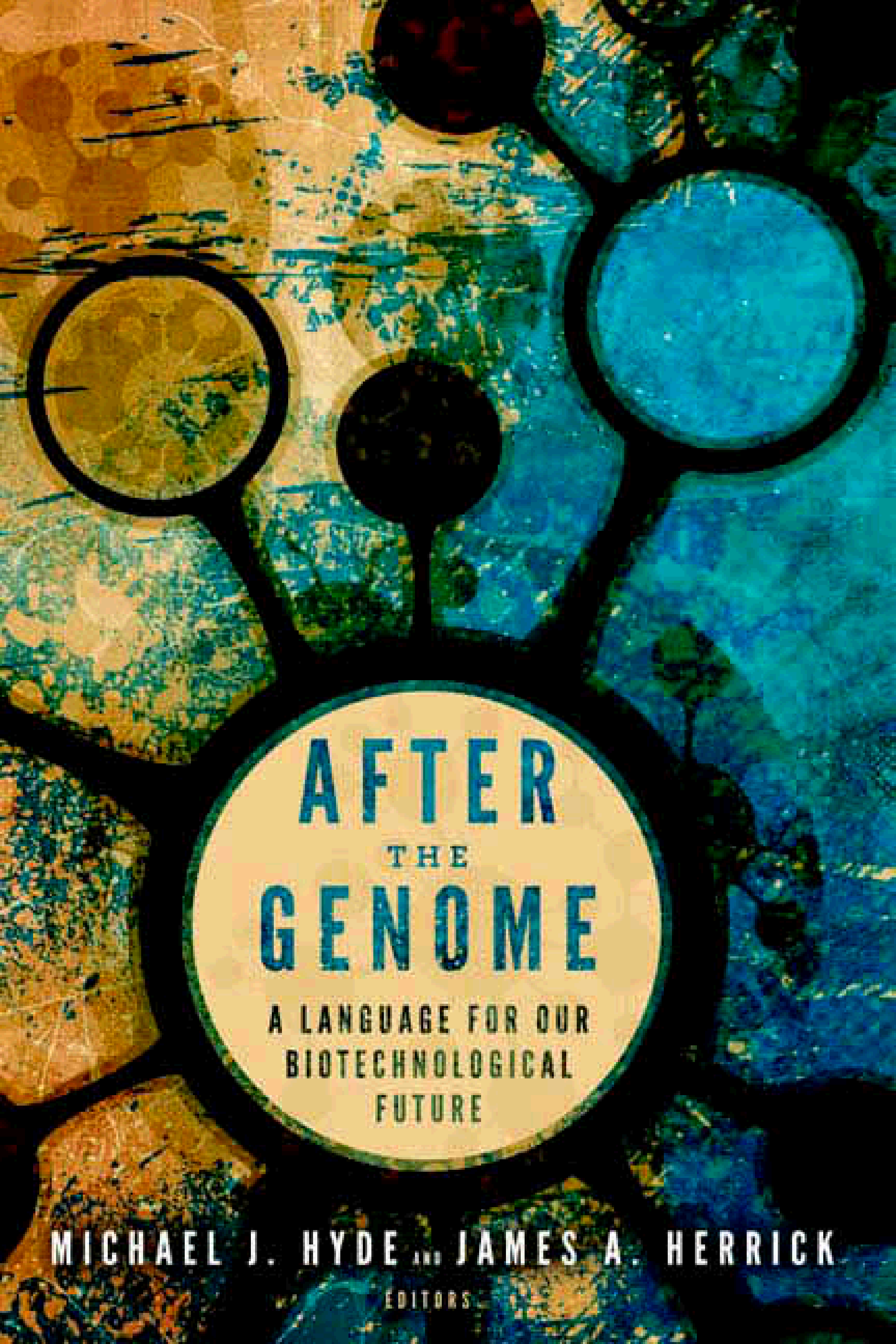

AFTER THE GENOME

A LANGUAGE FOR OUR BIOTECHNOLOGICAL FUTURE

MICHAEL J. HYDE AND JAMES A. HERRICK

EDITORS

AFTER THE GENOME

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Editors' Introduction

A LANGUAGE FOR OUR BIOTECHNOLOGICAL FUTURE

Rhetoric, Religion, Science, and Ethics

Michael J. Hyde, James A. Herrick

The rapidity with which biotechnological advances appear and make their way into our lives is changing not just the ways we experience life, but also how we understand ourselves. Many of these same technologies promise, or perhaps threaten, to change the nature of what it means to be human. In its 2003 report titled *Beyond Therapy: Biotechnology and the Pursuit of Happiness*, the President's Council on Bioethics (PCB) would thus have us keep in mind two related questions: "Does our ability to flourish as human beings depend on our ability to improve upon the human form or function? Or might the contrary be true; does our flourishing depend on accepting—or even celebrating—our natural limitations?"[1] Ontological urgency marks the debate over the benefits and burdens of today's biotechnology revolution.

The language that informs and is informed by this debate is itself a biotechnology. Rooted in the physiological workings of the brain, language functions first and foremost as a tool, an instrument, a means to an end whereby it facilitates meaning and understanding and in so doing demonstrates what the cultural and literary critic Kenneth Burke terms its "perfectionist" capacity: "The mere desire to name something by its 'proper' name, or to speak a language in its distinctive ways, is intrinsically 'perfectionist.' What is more 'perfectionist' in essence than the impulse, when one is in dire need of something, to so state this need that one in effect 'defines' the situation?"[2] The language of the biotechnology debate certainly displays a perfectionist impulse: be it directed toward improving the form and function of human being or celebrating our natural limitations.

So, for example, in its first report, *Human Cloning and Human Dignity* (2002), the PCB abides by this impulse in making much of its use of "fair and accurate terminology"—"especially because the choice of terms can decisively affect the way questions are posed, and hence how answers are given. We have sought terminology that most accurately conveys the descriptive reality of the matter, in order that the moral arguments can proceed on the merits." The PCB also emphasizes that "we have resisted the temptation to solve the moral questions by artful redefinition or by denying to some morally crucial element a name that makes clear that there is a moral question to be faced."[3]

A wonderful illustration of such linguistic behavior is found when, expanding on its understanding of "human dignity" in a later report, the PCB associates the phenomenon with what it terms the "the giftedness of life." The PCB's fair and accurate definition of this gift reads as follows:

> Acknowledging the giftedness of life means recognizing that our talents and powers are not wholly our own doing, nor even fully ours, despite the efforts we expend to develop and to exercise them. It also means recognizing that not everything in the world is open to any use we may desire or devise. Such an appreciation of the giftedness of life would constrain the Promethean project and conduce to a much-needed humility. Although it is in part a religious sensibility, its resonance reaches beyond religion.[4]

With this definition, however, certain questions come to mind: Who or what else is at work here? How is it that its presence requires us to recognize "that not everything in the world is open to any use we may desire or devise" and that "humility" is thus called for? What else is called for? Indeed, there seems to be a "religious sensibility" associated with the giftedness of life. But this gift "reaches beyond religion." To whom, what, where? Are there normative standards for perfect behavior to be found at the gift's source? Religion makes much of how what is beyond itself is the basis of its existence: God. Science, on the other hand, is content with the otherness of nature in its search for truth. Who or what is the ultimate giver of the giftedness of life?

When it comes to associating human dignity with the giftedness of life, the PCB's discourse becomes somewhat ambiguous, rather than straight-out fair and accurate. Why coin a phrase that begs to be associated with religious transcendence and redemption when you insist that your terminology is objectively oriented? The PCB denied that it had a religious agenda up its sleeve. Still, the phrase oozes a metaphysical and perfectionist impulse. Various members of the PCB associate the giftedness of life with God: respecting our natural limitations should have priority over the perfectionist goals of biotechnological progress.

Whether one agrees or disagrees with the members of the PCB, as well as many others who seek involvement in the bioethics debate, they warrant credit for encouraging the rhetorical practice of "public moral argument" in an effort to educate the citizenry about the benefits and burdens of biotechnology. Scientific medicine was born with the help of this democratic practice. Trained by the Sophists of their day, Hippocratic physicians involved themselves with the orator's art when defining and defending their *techne* during public debates and while treating patients. For these first men of scientific medicine, the biotechnology of language served the important purpose of calling into being a "medical public" that, owing to its new scientific education, could stand with the Hippocratic physicians in their initial fight against traveling sophistic lecturers and those quack doctors whose practice still admitted the use of magical charms.

Plato commended this rhetoric of science in his *Laws* (IV, 720c–e), believing like his mentor Socrates that scientific medicine is a model for the ethical practice of rhetoric. Socrates and Plato argued that as medicine was currently developing a rational understanding of the body and its diseases, so must rhetoric develop a rational understanding of the soul and of any topic that is discussed to influence it. Hippocratic physicians employed the art, however, so as to be done with it. The author of the Hippocratic and rhetorical treatise *The Art* gives testimony to this fact when, in concluding his defense of scientific medicine, he willingly discredits what he has been engaged in by noting with approval that "the multitude find it more natural to believe what they have seen than what they have heard."[5]

The true wisdom of medical science is based on understanding what is actually going on with the body when it is both healthy and ill. Once this understanding demonstrates itself, not in words but in actions that prevent or at least curb the pain and suffering of illness, rhetoric becomes superfluous for the Hippocratics. At best rhetoric represents utterances to patients whose opinions and fears bespeak their ignorance about the truth of medicine and about the trust they should have in their healers' diagnostic and prognostic abilities. As noted in the Hippocratic text *Decorum*, the wisdom that these healers possess and that they must constantly seek as their first priority makes them "the equal of a god. Between wisdom and medicine there is no gulf fixed."[6]

In response to recent biotechnological developments, some have taken talk of "the equal of a god" quite literally. The discipline of rhetoric would teach us that how we talk has a major impact on how we think and act. When J. Craig Venter's research group replaced a bacterium's DNA with synthetic DNA in 2007, it was widely reported that a new form of life had been created. Noting that Venter's group had both created a new life form and sought to patent the new bacterium, Canadian biotechnology monitor Patrick Mooney summed up these startling developments in the memorable phrase, "For the first time, God has competition."[7] In his blog for the *Guardian*, Andrew Brown asked, "Has Venter Made Us Gods?"[8] The connection between the creative work traditionally attributed to God and the creative work of biologist Venter was unavoidable. For the first time in human history the words "create life" were now meaningfully associated with a person.

There is a rising awareness in scholarly circles that the language deployed to discuss science is not neutral but conveys values, shapes perceptions, and suggests agendas. Identifying and deciphering the important role played by narratives, metaphors, and other linguistic strategies in shaping public expectations of science defines an important social and political endeavor. Biotechnology promises to renew damaged organs, restore lost vision or mobility, and greatly extend life itself. Do such medical miracles put us in the place of God and challenge the limits of life taught us by our faiths? While we try to accommodate in our language fundamental changes to the human condition, we may also be breaching the rhetorical walls erected around traditionally religious concerns, including what it means to be human.

It has often been assumed that religion and science represent separate and even opposed domains, but the discourses of the two undertakings have long shown signs of merging. Even before talk of synthetic life and posthumans took on religious qualities, end-of-life decisions, the spiritual care of patients, and concern for what constitutes a meaningful human life suggested a confluence of the languages of biotechnology and of religion. The rhetoric at work here suggests something deeper going on than journalistic exuberance. Are we on the brink of a more religious science, or perhaps a scientific religion? If one believes, as does the philosopher and Talmudic scholar Emmanuel Levinas, that the "purist" form of religion (not yet biased by dogma) begins with a heartfelt concern for the well-being of "the other," and that such concern is a major factor motivating the moral potential of religion and medical science, then the possibility of a religious science or a scientific religion makes good sense.[9]

Aligning biotechnology with religion has already been seriously proposed. Journalist Joel Garreau has suggested that resistance to enhancement technologies might be addressed by creating a transcendent aura around medical procedures. Arguing that the "stories we tell do not match the facts," Garreau suggests looking to our devotional life for a means of navigating these uncharted waters. Boundary-breaking refashioning of body and mind might be cloaked in religious ritual to enable a graceful threshold crossing into a new era of human nature. "Can we picture devotions marking the great significance of a young person receiving her first cognition piercing, awakening her mind to the Web of all meaning? . . . Should we have a liturgy of life everlasting as a person receives her first cellular age-reversal workup?"[10] Such suggestions should perhaps come as no surprise; only an unassailable value system akin to a religion, only a connection with the infinite through ritual and sacred language, will allow us to cross unimpeded the threshold of the gods.

Biotechnology's religious language reflects the fact that human beings remain spiritual creatures in a scientific age. Even as we uncover the very foundations of life and consciousness, we still care about the meaning of that life, seek purpose in that consciousness. We still prefer compassion to efficiency, seek to live morally, and desire insight into our ultimate destiny. Biotechnology, like religion, offers us its assistance as we pursue these preferences. But in the process these technologies of life itself are acquiring their own distinctive quality of transcendence, an aura of participating in a timeless plan, the hint of belonging to something higher even than science. Biotechnology now holds out to us the redemptive future religion once promised; the potential for significant clash or productive cooperation is apparent. The clash is more likely to happen to the extent that a certain attitude of science dating back to the Hippocratic physicians dominates the discussion: "There is science and there is opinion; the first begets knowledge, the latter ignorance."[11]

Throughout its over twenty-five-hundred-year tradition, the practice of rhetoric has had to contend with this commonplace of equating the art with opinion and ignorance. Hence, throughout this period those who wished to speak more favorably of the orator's art would have had to answer to charges of sophistry by clarifying how the art had a necessary and thus legitimate role to play in cultivating the moral ecology of the body politic. Aristotle, of course, was an essential respondent as he worked out in the *Rhetoric* the artistic nature (*logos*) of a practice whose essential purpose is to deal with what is, in the main, contingent: those matters (e.g., the giftedness of life) that we recognize as pressing and that require careful deliberation and judgment, but whose meaning and significance are presently ambiguous, uncertain, and contestable. The contingency of human existence stares us in the face every day. It is a fact of life, one that constantly tests our moral ability to make right and just decisions. Rhetoric is necessary, given this fact of life. The point is repeated throughout the rhetorical tradition. "Lacking definitive evidence and being compelled to act are the prerequisites of the rhetorical situation."[12]

The language of our biotechnological future is bound to be filled with rhetoric. Definitive evidence about ethical guidance regarding how "godlike" we have the right to become in developing our biotechnologies is, at this point, conspicuously absent from the discussion. Nevertheless, we are compelled to act in ever more inventive ways in our fight against disability, disease, and death. Indeed, the life-giving capacities of medical science warrant the highest respect and support. Without medical science, the potential for advancing our understanding of what it means to be a human being would be tragically limited. Lacking definitive evidence for answering this question, science would be wise, however, to develop its rhetorical competence.

The scope and function of today's biotechnological revolution defines an immense rhetorical situation. We are beyond the point at which medical science can present itself as a rhetorically neutral method of inquiry, or biotechnology as simply providing a set of therapeutic tools. What foundational ethical principles will guide our uses of miraculous new technologies? How will these technologies affect the theory and the practice of medicine? What discourse will we employ to describe ourselves and our technologies? Such questions suggest that an exploration of the language of our biotechnological future is both timely and critically important; hence, the commissioned chapters contained in this volume.

These chapters put biotechnology *to work* in order to assess biotechnology *at work*; they thus engage in both the practice and the critical assessment of rhetoric in the realm of science. It is a perfectionist thing to do, especially as these related actions promote public moral argument and thereby affirm the classic spirit of democracy. The rhetorical scholar David Zarefsky is quite eloquent in describing this spirit:

> A democratic society is grounded in the assumption of human fallibility. . . . We commit ourselves to certain beliefs; we think we are right; but we cannot know *for sure.* This human imperfection may be the result of unfinished evolution or of original sin, but the fact is that we could be wrong. . . . The virtue of democracy is that it permits and encourages the correction of error. . . . [I]n a democratic society, moral authority comes

> from the ability to make arguments, grounded both in moral principle and in the circumstances of a specific case, and to gain the assent of one's fellows. The tension between democracy and morality is thereby both persistent and productive.[13]

With its wide range of disciplinary and methodological perspectives, the present volume is intended to cultivate this vibrant tension. Early on in the writing process the contributors were sent a working draft of this introduction to help them with the task of advancing the critical conversation about the language of our biotechnological future—a language that influences our thinking and acting, shapes public expectations of science, and generates ideas about what it means to be a human being. We think it is fair to say that this language is robust in scope and function.

The chapters composing this volume are arranged so as to help readers begin working their way through this language and its consequences. Along the way we are told that we should have faith in, not phobias about, science. We are also told how this faith is called into question by a host of social, political, economic, and religious factors that influence the situation at hand.

Tristan Keys, Nancy King, and Anthony Atala begin the narrative with a detailed discussion of the science and language of regenerative medicine. They thus make clear the difficulty of educating the public about the benefits and burdens of this medicine, with all of it hopes, dreams, and realities. Moreover, they provide a type of test case for gauging readers' scientific literacy regarding one of the major medical developments of the twenty-first century.

The next four chapters, by Ronald Green, Thomas Lessl, Jean Bethke Elshtain, and Leah Ceccarelli, expand on the topic of the public's understanding of science. Green worries about how certain historical and political developments in science and technology over the past eighty-five years have led unfortunately to a misunderstanding and disrespecting of science on the part of the public. Lessl, however, argues that scientists share some of the blame here, for they often manifest communication habits that promulgate ethical confusion and that are rooted in science's institutional history.

Elshtain goes a significant step further than Lessl with her critique of how we currently are being influenced by a "transhumanist" rhetoric that offers very questionable promises regarding how the biotechnological revolution will "perfect" humankind. Elshtain worries that we are currently "in the throes of a form of genetic obsession that can be best called genetic fundamentalism." Ceccarelli offers a case study that occupies a middle ground. She provides a critical analysis of crucial metaphors advanced by President George W. Bush and genome scientist Francis Collins in their respective efforts to reconcile the tension between science and religion.

Science, religion, and the biotechnological revolution interact dynamically, and often the relationship is strained. Tod Chambers investigates this problem by examining the rhetoric of Christian and Buddhist responses to the spiritual challenges posed by SSRIs (selective serotonin reuptake inhibitors). Special attention is given to the way that this particular biotechnology is described or redescribed in relation to contemporary biochemical understandings of the self. Bill Leonard's chapter on the tension between science and religion introduces us to the isolated world of Appalachian serpent handlers. Here we witness how an idiosyncratic religious rhetoric provides sanctuary for those who do not trust the progressive language of our biotechnological future.

Chambers and Leonard direct us toward specific narratives that advance, question, and dismiss this language. With Arthur Frank's chapter, the rhetorical and ethical workings of various other biotechnological narratives are examined in terms of their "biovalue": how they promote biotechnology as a commodity that "promises" to benefit our well-being. Frank examines the validity of such a promise as he explores the central role of narrative in shaping how we understand ourselves in the new world of techno-medicine. So, too, does Ezra Griffith, who examines how African Americans—"a distinctively stigmatized nondominant group"—have "life stories" to tell that are not acknowledged by the clinical language of biotechnological progress. Such progress can marginalize people who, for various reasons, are denied access to its products or who find its biovalue to be too costly. Howard Brody writes of the financial, social, and political costs of biotechnology as they are informed by what he terms a "rhetoric of economism": a dominating and unexamined regime of discourse that shapes hospital policies and eventually patient care. Once again, the issue of biovalue comes to the fore.

The final two chapters, by Lisa Keränen and Judy Segal, center on how the burgeoning world of biotechnology affects the language and communication practices of the doctor-patient relationship. Keränen focuses on the use by hospitals of advance care planning documents, which she categorizes as well-intentioned but sometimes ill-functioning "technologies of the self" that lack sufficient "pastoral power." Segal discusses how the meaning of "care" has been transformed by the language of our biotechnological future and how the doctor-patient relationship is being affected by this transformation. Segal witnesses some unsettling things.

Caution is noticeable in what Segal has to say about her topic, a characteristic of all of the chapters in this volume. Caution is a reasonable state of mind to have when dealing with technology that is changing what it means to be a human being. Caution is a defense against allowing ourselves to become rotten with perfection as we work to improve the human condition. With too much caution, however, we risk the danger of becoming rotten with imperfection. The language of our biotechnological future is still in need of development and careful tuning.

1

FAITH IN SCIENCE

Professional and Public Discourse on Regenerative Medicine

Tristan Keys, Nancy M. P. King, Anthony Atala

Despite public and media fascination with the concept of regenerative medicine, it is essential that its progress from bench to bedside proceed methodically, with care and circumspection. Five scientific strategies for regenerative medicine are described and discussed in the first part of this chapter. The second part considers two issues. One issue is whether the implications of these methodologies could alter consensus notions in our understanding of health and disease with respect to conditions that might merit intervention—in particular, the meanings of "normal" and "preventive," and what should count as a "successful" intervention. The other issue is the risk that faith in science can exacerbate the therapeutic misconception in early-phase research. The third and last part of the chapter recommends that regenerative medicine scientists, bioethics and communication scholars, and media professionals work together to increase the public's scientific literacy and to encourage public engagement with the ethical, social, and policy implications of research in regenerative medicine.

THE SCIENCE

In its endeavor to treat diseased and deficient tissues and organ systems, the multidisciplinary field of regenerative medicine has rapidly progressed and now finds itself squarely in the forefront of health science. As one of the newest branches of medicine, regenerative medicine has several subcomponents, including tissue engineering and stem-cell-based therapeutics, that have themselves recently blossomed as research furthers our understanding of basic biological mechanisms. Other elements of the field, such as whole-organ transplantation, have been in practice for decades, thus providing a solid foundation for growth and development. Perhaps more than other fields, regenerative medicine relies not only on clinical research, but also on research addressing many aspects of basic science, such as cell and molecular biology, biochemistry, biomedical and chemical engineering, and biomaterials science. Collaborations among these discrete and varied disciplines help to spur the expansion of strategies and technologies that advance regenerative medicine's ability to translate its laboratory successes into the clinical arena.

The roots of regenerative medicine date back to the first attempts at keeping organs in culture over the long term for possible transplantation. Alexis Carrel, a Nobel Prize recipient for his pioneering work making possible the suturing of blood vessels, worked for many years at the Rockefeller Institute in New York, beginning in the 1930s, with Charles Lindbergh, the first pilot to fly solo across the Atlantic Ocean.[1] The first successful kidney transplant between identical twins, in 1954,[2] was soon followed by the initiation of cell therapy with bone marrow transplantation, beginning in the late 1950s.[3] The unifying principle underlying these procedures is the replacement of a damaged or diseased condition with appropriately functioning cells, tissues, or organs. Regenerative medicine thus can be broadly defined as the repair or replacement of diseased tissues and organs using cell-based therapeutics, transplantation, and tissue engineering methodologies as vehicles for restoration.[4] One of the essential elements of regenerative medicine is the human cell, capable of being harvested from living tissue and grown outside the body in a controlled laboratory setting. Once this has been accomplished, there are several different systems by which cells can be readministered to the patient in order to augment or replace poorly functioning or nonfunctioning tissue. To date, there have been several successful human applications of these techniques, ranging from simple to complex, including transplantation of newly fabricated skin,[5] blood vessels,[6] urethras,[7] tracheas,[8] and bladder wall segments.[9]

The multidisciplinary nature of the field allows for the collaboration of experts from very different branches of science. Regenerative medicine can thus become a complicated and diverse system of tools, materials, strategies, and techniques. One way to organize and simplify it conceptually is to stratify the products of regenerative medicine based on their structural composition and complexity. The associated scientific and ethical challenges of each level can then be addressed. The structural designs of human tissue that regenerative medicine attempts to replicate are (1) flat sheets of cells, (2) tubular structures, (3) hollow, nontubular, viscous structures, and (4) complex solid organs. Within these levels, there are several different scientific strategies employed to achieve restoration of function where needed. These are (1) cell-based therapeutics, (2) in situ regeneration, (3) wafer or cartridge techniques, (4) decellularization of donor organs, and (5) bioprinting. We briefly review these levels and strategies, as well as the cellular and biomaterial components required for tissue regeneration.

Cellular Component Overview

In order to engineer biological constructs for the purposes of regeneration, donor cells, which are the basic functional units of a living organism, must initially be obtained. There are several sources from which these cells can be harvested; each has unique advantages and disadvantages in cell-based therapeutics. The first major classification is whether the donor cells are retrieved from the individual who will be the recipient—an autologous source—or from a completely different individual—an allogeneic source. Autologous cells have the major advantage of being genetically identical to the recipient, or host; thus they are not labeled as a foreign body by the immune system upon reintroduction to the host.[10] Regenerative medicine's use of autologously derived cells circumvents the necessity for the immunosuppressive medications required, for example, in whole-organ transplantation.

The next classification comes in grading the cells based on their ability to either uniformly produce one cell type (unipotent) or dynamically differentiate into multiple cell lines (multipotent). The former are called native targeted progenitor cells and are inherent for each tissue type. Native cells are terminally programmed to perform the functional tasks of each unique tissue. Thus, they provide a simple model that does not require further differentiating steps or manipulation in the laboratory. However, several factors limit their use. In some instances, it is not possible to harvest enough cells from the diseased organ to begin controlled laboratory growth (called cell culture). Even when sufficient tissue can be harvested, these cells have proven difficult to culture and expand in vitro in order to yield the vast quantity of cells required for cell-based therapeutic techniques.[11] Recently, though, newly designed cell culture protocols have enabled researchers to maintain these cells in their growth phase, permitting better self-renewal and propagation characteristics. Unfortunately, these methods have not been successful with all tissue types, such as pancreas, liver, and nerves. As these limitations prevent native cells from being extensively used, scientists must rely on the field of stem cell biology as a surrogate source.

Investigators have identified several types of stem cells, each derived from different sources and having variable functional capacities. In general, stem cells are characterized by the ability to self-renew, to form large colonies from one cell, and to differentiate into multiple cell types. *Pluripotency* is a cell's ability to become any of the three primary germ layers (endoderm, ectoderm, and mesoderm) from which all tissue is derived. *Multipotent* cells are, in essence, one step further down the differentiation pathway, and so are more limited in the cell lineages they can become.

The most dynamic stem cells to be identified, and the most controversial, are embryonic stem cells (ESCs). Discovered in mice in the early 1980s,[12] and then successfully harvested from a human embryo in 1998,[13] they represent a rich source of self-perpetuating cells that could provide for continued advances in regenerative medicine.[14] More than any other stem cell source, ESCs are extraordinarily characterized by unrivaled self-renewal and differentiating properties. The most significant scientific limitation is that their application would most commonly be as an allogeneic source, thereby potentially inducing the host's immune system to respond. They have also been shown to develop tumors in animal models, indicating the potential for deranged and unanticipated growth patterns.[15] The ethical and religious implications associated with the means by which they are acquired also prevent them from being fully utilized. These ethical dilemmas go beyond concerns about the destruction of embryos, as human ESCs can be obtained from arrested embryos after failed in vitro fertilization,[16] as well as from single cell embryo biopsies, which allows acquisition without known harm to the embryo.[17]

Another natural source of stem cells can be derived from amniotic fluid, obtained during amniocentesis or chorionic villi sampling, and from placental tissue after birth (AFPS cells).[18] Although these cells are not as robust in their differentiation capabilities as ESCs, they are multipotent,[19] have been found to be stable during culture expansion,[20] and do not form teratoma tumors in vivo.[21] Another advantage over ESCs is the possibility of biobanking AFPS cells, allowing them to be used autologously but also permitting allogeneic uses. With a sufficiently large AFPS cell bank, human leukocyte antigen matching could reduce significantly, though not eliminate entirely, the amount of anticipated immune incompatibility.[22]

A third natural group of stem cells is niche-specific adult stem cells (ASCs). Initially discovered in bone marrow in the 1960s as hematopoietic cells,[23] ASCs have since been discovered in other organs, such as neuronal tissue,[24] skin,[25] and muscle.[26] They are tissue-specific progenitors with the ability to differentiate into various cell types found in the tissue from which they are derived. All cells in the body naturally age or acquire defects and die at varying rates, and must be consistently replaced. ASCs are believed to function as a reservoir for new cell formation, acting as an inherent system for repair.[27] Interestingly, several sources of ASCs have been shown to have the developmental capacity to produce non-tissue-specific cell lineages. These include mesenchymal stem cells (MSCs), found in bone marrow,[28] and adipose tissue–derived stem cells (ADSCs).[29] All of these ASCs can be autologously implemented in regenerative medicine strategies, and as the method by which they are harvested is noncontroversial, they offer excellent research potential despite their more limited differentiation capabilities. That is where their advantage stops, however. ASCs are not highly populated in sources of tissue, and thus are difficult to harvest and identify. Moreover, they have demonstrated poor growth capacity in vitro, and limited divisional and self-renewal properties; they can also accumulate genetic changes over time.[30]

Beyond these naturally derived stem cells, there are alternative techniques to generate cells with pluripotent qualities. Somatic cell nuclear transfer (SCNT), popularly referred to as cloning, occurs when the nucleus of a female germ line cell, called an oocyte, is replaced with a somatic cell nucleus from another individual. In reproductive cloning, the new cell can be successfully reimplanted in the uterus, thereby creating a fetus that is genetically identical to the donor; in essence, a clone. These procedures have been successful in producing cloned animals from several species.[31] This use of SCNT techniques is controversial, however, and human reproductive cloning is widely acknowledged to be morally impermissible. In contrast, research cloning uses the same SCNT into an oocyte, but the product is then cultured in the laboratory and allowed to propagate and generate ESC lines.[32] Because these stem cell lines are autologous, that is, genetically identical to the somatic cell donor,[33] the use of organs engineered from SCNT cells may preclude the need for immunosuppressive therapy.[34]

Although significant advances in using SCNT technology for research cloning have been made, many questions remain, and there are liabilities that must be addressed.[35] First, the oocyte receiving the donated nucleus retains its mitochondrial DNA, which could lead to immunoincompatibility when the progeny of the oocyte are reintroduced to the original somatic cell donor. In addition, the process is extremely complicated and has not proven efficient in producing pluripotent cells able to survive over time. The need for large numbers of oocytes and ethical controversy regarding their acquisition also represent barriers to SCNT research. Finally, it is difficult to produce high-quality cells that do not contain genetic or chromosomal abnormalities. These scientific and ethical dilemmas require further investigation and consideration before SCNT can progress to clinical research.

Another cell demonstrating pluripotent properties has been generated by reprogramming the gene expression profile of somatic cells.[36] Called the induced pluripotent stem cell (iPS cell), it is created using retroviruses to alter expression of genes controlling life and replication cycles and phenotype characteristics. In this sense, the somatic cell can be induced to dedifferentiate into a stem cell. Initial experiments with this technique produced cells that demonstrated features similar to ESCs, yet were found to not be fully reprogrammed, failing to completely replicate all of the stem cell's capabilities. Further research, though, has developed better reprogramming methods, producing human iPS cells whose functional capacity more closely mirrors the properties of ESCs.[37] Ideally, iPS cell techniques could be used to generate autologously derived stem cells without ethical predicaments. Despite the scientific achievements to date, however, the technologies used to induce pluripotency are very new, and iPS cells show signs of early senescence or apoptosis, thus continuing to fall short of the dynamic nature of human ESCs.[38] Much is still uncertain and unknown about the cellular and molecular mechanisms of inducing pluripotency, and the clinical applicability of iPS cells has yet to be determined.[39]

Biomaterials Overview

While the cellular elements define the basic functional features of regenerative medicine systems, the area of biomaterial science is another crucial ingredient in the process of constructing tissues and organs. In most examples where regenerative medicine could be clinically applied, direct injection of cells into the body does not suffice. Rather, a structural arrangement by which host or transplanted cells are allowed to organize and be incorporated by the host tissue is often required. The field of tissue engineering seeks to remedy this by providing either artificially engineered or naturally derived biomaterials to function as scaffolding for cell delivery. The natural architecture of native tissue, called the extracellular matrix (ECM), plays a critical role in establishing and maintaining biological structure and function. Each tissue and organ system has its own unique ECM, which establishes a highly specific microenvironment, allowing the intricate network of individual cells to function as a whole. Research into the intimate relationship between ECM and cellular components has enabled an improved understanding of the interactions required for successful tissue development, and biomaterials science seeks to replicate these conditions.[40] Constructs can be fabricated to provide three-dimensional mechanical support and to deliver bioactive substrates needed for cell growth.[41] Of course, this knowledge base is still far from complete.

There are three broad classes of biomaterials; each can either be used as an acellular scaffold that allows for infusion of host cells or can be preinfused, or seeded, with autologously derived cells before implantation. The first class is naturally derived materials, such as collagen and alginate, which are biologically recognized by the host tissue.[42] Collagen, obtained from human or animal tissues, and alginate, isolated from seaweed, can be modified to exhibit varying properties of degeneration or strength. A second class of biomaterials is tissue matrices, such as small intestine or bladder submucosa, which can be harvested from xenographic (animal) or allogeneic (human) donors and leached of any living cells, leaving the ECM architecture behind.[43] Neither tissue matrices nor collagen/alginate constructs have been shown to elicit an inflammatory response by host tissue. Last, synthetic polymers of naturally occurring substances, such as polyglycolic acid (PGA), polylactic acid (PLA), and polylactic-co-glycolic acid (PLGA), can be used to generate customized three-dimensional scaffolds.[44] Although there have been some issues with lack of biological recognition of these polymers, their use is advantageous as large quantities can be consistently produced while controlling their structural properties. However, unlike the first two classes of biomaterials, these synthetic biomaterials cannot grow along with developing tissue, and so are not ideal for use in pediatric populations. Overall, research has shown that these biomaterials are not interchangeable in different engineered constructs, although they may be used together in a composite manner, as each has unique characteristics allowing it to function well in certain situations.

General Scientific Limitations

There have been many scientific advances in the field of regenerative medicine, which have helped to bring about several landmark clinical achievements. Nevertheless, there are still significant obstacles and limitations to be encountered at each step in the regenerative process. As previously mentioned, low bioavailability, difficulty with cell culture, unstable and uncontrolled epigenetic expressions, and immunoincompatibility are all issues that require close examination with each new proposed intervention. In addition, it is essential to attend carefully to the sequential steps of successfully organizing and distributing cells into the transplant environment so as to permit host incorporation and global tissue function. For instance, providing an appropriate microenvironment for optimal cell expansion and organization in preparation for transplant presents challenges that are specific to each organ. Bioreactors were therefore developed to replicate the in vivo physiological environment by supplying oxygen and nutrients in vitro, submitting the expanding cells to mechanical stress while removing cellular waste products and monitoring pH.[45]

One of the most significant and persistent limiting factors has been the ability to deliver oxygen and nutrients to the engineered tissue and organs immediately after implantation, during the time period in which a new blood vessel supply is being developed in the host body. Nutrition and gas exchange is restricted to a maximal diffusion distance of three cubic millimeters,[46] and therefore any implanted constructs larger than this volume may undergo central cell death and necrosis unless additional oxygen and nutrients can be at least temporarily supplied. This is not a significant problem for flat, thin structures, but it is the major challenge for more complex solid tissue and organ designs. Vascularization of these synthetic structures is crucial to their success, and solutions to this problem are currently being developed. For example, the use of temporary mechanical or chemical sources of oxygen could allow enough time for the implant to undergo vasculogenesis from the host tissue.[47] Another strategy is "pre-vascularization"—engineering channels into the architectural layout of the biomaterial scaffold to facilitate vascular network formation.[48] Embedding pro-angiogenic factors into the biomaterials could also be used to assist the host tissue in developing a new vascular supply. Variations of these concepts are employed by the five different scientific strategies detailed below.

FIVE STRATEGIES OF REGENERATIVE MEDICINE

The two principal elements of regenerative medicine, cell-based therapeutics and tissue engineering, can each be utilized in varying degrees to achieve the goal of tissue regeneration. Overall, the five basic strategies used to approach restoration of tissue function cover every aspect of both cellular and biomaterial sciences. As evidenced in the normally functioning human body, the different tissue and organ systems to be replaced are characterized by very different functional and structural properties. An important implication of this variety is that a diseased organ may not require complete replacement to provide effective treatment for the patient. Thus, no one technique can be applied to every situation.

Cell-Based Therapeutics

One of the most basic strategies is simple cell-based therapy. Theoretically, properly functioning cells, when introduced into defective tissue systems, will replace nonfunctioning native cell populations. The same theory undergirds gene transfer research, whereby normal genes are introduced in order to supplement or replace mutated gene variants and restore normal function. Mechanisms of delivery include intravascular infusions and direct organ injection. Depending on the tissue being addressed, either native adult cells or native stem cells can be injected. When either of these sources is used, they first need to be obtained by tissue biopsy from the patient and expanded in the laboratory using cell culture before they are readministered. For systemic administration, this method relies on a cell's ability to auto-locate to similar tissue. For example, intravenous injection of stem cells has been used in animal models for ischemic heart disease and Duchenne muscular dystrophy.[49]

When cells are directly implanted into an organ or tissue, carrier materials such as alginate hydrogels can help contain the injected cells in the desired location. These materials should be nonantigenic, nontoxic, volume stable, and bioabsorbable. In this manner, autologously harvested cells have been used as a bulking agent in pediatric patients with vesico-ureteral urinary reflux,[50] or to act as a reservoir of testosterone, thus replacing nonfunctioning testicular tissue in animal models of testicular dysfunction.

In Situ Regeneration

A second strategy is referred to as in situ regeneration. It is similar to the methods by which cells can be genetically corrected in gene transfer research. In this case, substances are introduced to the cellular microenvironment to induce the cells within the tissue to auto-regenerate. Small molecules, nucleic acids, genes, proteins, cells, and biomaterials can all be used to this end. For instance, a technique similar to the one used to generate iPS cells has been used to reprogram adult pancreatic exocrine cells into cells resembling the insulin-producing β-cells in vivo in a mouse model.[51]

Cartridge Techniques

When regeneration of an entire organ is not necessary and only a small area of replacement tissue is needed, a synthetic wafer or cartridge could be created instead. In certain organ systems, our bodies do not require complete function in 100 percent of tissue in order to accomplish all the vital biological processes that are essential for life. In these instances, only a segment or portion of synthetically engineered functioning tissue could be implanted, staving off complete organ failure. For this to occur, cells would be harvested and expanded in vitro. These cells could then be seeded into a biomaterial, such as a sponge or wafer construct. Once the cells have differentiated into their designated phenotype after incubation in a bioreactor, this cartridge could be inserted into the target organ. This model is advantageous as the cells populating the thin cartridge would not be subjected to lack of oxygen and nutrients, which could easily diffuse in from surrounding tissue.

Tissue Decellularization

Another strategy employed to engineer sections of tissue or even regenerate entire organs is the use of decellularized tissue matrices. There are many applications of this approach, ranging from experiments that are still being developed in the lab to constructs that have already been used in human clinical trials. The first use in humans of acellular materials for tissue regeneration dates back to 1996, when the first patient-subjects with urethral strictures received decellularized bladder matrices.[52]

Xenographic or allogeneic donor tissue is harvested and subjected to mechanical and chemical processes that remove all cellular material, leaving behind an acellular collagen matrix. Studies have shown that these acellular ECM structures can sometimes still be invested with native growth factors despite the decellularization process.[53] The scaffolds can be as basic as mono-layered samples from bladder or intestinal tissue. These acellular matrices can then be seeded with autologously derived cells, incubated until there has been sufficient cell growth and development, and transplanted back into the patient. Researchers have been able to apply cell-seeded scaffolds to large defects greater than thirty centimeters (about twelve inches), whereas nonseeded scaffolds are limited to about one centimeter.[54] However, even more daring attempts at decellularizing entire organs are under way. It is possible to remove cellular matter with mild detergents, but reintroducing cells into the remaining acellular organ scaffold is a very complex task. There are numerous cell types that must assemble and organize themselves, communicate, and interact in order to have a functioning organ. This method may provide a means to assist in the vascularization process by providing a preexisting vascular tree, but there are still many challenges to overcome.

Bioprinting

A final strategy used in regenerative medicine to manufacture organs is bioprinting. This is a unique concept that has been developed exclusively as a result of regenerative medicine's ability to incorporate other specialties, particularly the fields of computer science, biomaterials science, and biochemistry. This novel use of technology had a very rudimentary beginning when the ink in a standard ink cartridge of an unassuming desktop printer was replaced with cells and a liquid matrix, enabling the "printing" of a very basic structure. This format has evolved into several different bioprinting systems, each device having specific capabilities and clinical applications. One design employs laser scanners to three-dimensionally map out injuries or defects in planar tissue, after which a computer program controls a stepwise multilayered printing process to fill in the defect.[55] Collagen and cell layers are distributed by specialized needles as directed by the computer program.

Another device is envisioned to be capable of printing a complex and detailed acellular matrix in the form of a whole organ, which would then be seeded with cells and incubated in a bioreactor, theoretically providing whole-organ regeneration. Alternatively, it is possible to bioprint living cells into three-dimensional designs. This technology relies on collagen or alginate substrates that have been chemically modified to provide a support system for the cells. A computer program controls the pattern in which individual cells or clusters of cells are deposited onto a collagen or alginate "bio-paper" that helps support the three-dimensional structure. The "bio-ink" consists of specified cells, proteins, and enzymes, which are precisely directed onto the bio-paper, dropped or sprayed in a point-by-point manner, like an ink jet printer, or dispensed as a line, referred to as direct-write.[56] There have been several successes in printing basic structures such as blood vessels, but printing an entire organ that has multiple cell types and ECM properties is a difficult mission to undertake.

Finally, a subtype of bioprinting is the physical science of electrospinning. A high-voltage charge is applied to a liquid formula of collagen, inducing the formation of very small fibers, which can be directed at a grounded structure to fabricate scaffolds of varying shapes. The physical properties of these fibers, such as the diameter and their spatial arrangement, can be controlled. These constructs can then be utilized as cell-seeded scaffolds.[57]

The development of these state-of-the-art technologies has enabled regenerative medicine to make significant progress in the laboratory, and has also brought about landmark clinical achievements. The advances that have been made in regenerating a majority of the cell and tissue types in the human body serve to encourage further research and expansion of this promising potential therapeutic option. Most of the progress has been accomplished in animal models, but several human clinical studies are under way. In order to easily understand the task that regenerative medicine has set out to fulfill, we next describe the individual tissues and organs being replicated according to their level of organizational and functional complexity.

FOUR LEVELS OF TISSUE COMPLEXITY TO REGENERATE

Flat Tissue

Sheets of cells consisting of multiple layers of one cell type represent the simplest architectural subtype in the body. This level of tissue complexity is primarily exemplified by the integument system, or skin, which represents one of the earliest attempts at culturing autologous cells in vitro for repair purposes.[58] The most superficial surface of skin, the epidermis, consists of numerous cell layers, effectively creating a barrier against external insults such as microorganisms, temperature variations, and physical contact. The layered epithelial cells also protect against extravascular water losses and serve sensory and metabolic functions. The effects of significant losses of skin surface area are devastating, as can be seen in burn victims. In addition to the large inflammatory response induced by such a significant injury, burn victims are more susceptible to microorganism infections and are unable to regulate their body temperature or water balance. Survivors of such injuries depend on traditional treatments, such as skin grafts harvested from unburned portions of their own bodies, or allogeneic grafts that provide only temporary protection until native tissue grows back in the form of extensive scars.

Regenerative medicine, however, may provide a significantly better chance for burn victims to recover without the use of allogeneic grafts or painful autograft harvesting. Bioprinting techniques may prove to be a viable option for patients with both minor and major thermal injuries. Collagen or alginate matrices would first be laid down over the wound. Autologously derived adult stem cells, initially harvested from small skin biopsies, would be cultivated in vitro to ultimately be readministered to the patient. This application would require the efficient and rapid expansion of autologous cells to decrease the time between injury and treatment, but current knowledge and methods of autologous cell culture may not be sufficient. Another complicating factor may be the extent, severity, and location of the injury. With deeper burns comes more complex tissue organization beyond the simple multilayered cells of the epithelium, so the regeneration of nerves and microvascular structures may depend on the body's own capacity to regrow.

Tubular Structures

The next classification of tissue complexity can be described as hollow tubular structures. Regenerative medicine has been able to successfully replicate many types of tubular structures in both animals and humans. In general, these are subcomponents of larger organ systems, and consist of two different cell types arranged as sheets of cells. These sheets form into circular, bilayered tissues, which usually serve as means of transporting fluid throughout the body. These structures are histologically composed of an inner layer of epithelial cells that prevent fluid from escaping the conduit and an outer layer of smooth muscle and connective tissue to provide support. The first example of tubular engineered tissue implanted into patient-subjects dates to 2005, when a scaffold was seeded with muscle and epithelial cell types from an individual with an injury to the urethra, which takes urine from the bladder and excretes it. The tissue needed to bridge the defect resulting from the injury was successfully created and implanted.[59] Other examples include engineered blood vessels and tracheas. Since these are thin tissues, and porous scaffolds are used in their design, their implantation is not significantly restricted by lack of oxygen and nutrients. When these tubular structures are bioengineered in the laboratory, the fabricated tissue is not an exact replica of natural tissue, and yet there has been success in both animal and human studies.

Whereas the simple cell-layered construct of skin does not require a complex foundation, these tubular structures must incorporate a matrix of synthetic or naturally derived scaffolding for support. Multiple formulations combining different biomaterials and either seeded or non-cell-seeded constructs have been tested. For blood vessels, autologously derived cells cultured from peripheral vein biopsies have been grown in both biodegradable collagen and synthetic scaffolds and successfully used as pulmonary artery transplants.[60] Using a different method, vascular access grafts for patients with end-stage renal disease requiring hemodialysis have been engineered and implanted in humans. To accomplish this, fibroblasts and endothelial cells were harvested from patients, separately expanded as sheets of cells, and then wrapped around a stainless steel cylinder to allow for fusion. In both situations, clinical trials yielded functioning implants.[61]

Other types of decellularized scaffolds have been used to create functioning tracheas. In animal models, autologous chondrocytes cultured from cartilage biopsies have been seeded in biodegradable collagen scaffolds and successfully implanted in the pulmonary tree.[62] Perhaps even more clinically significant, however, is the use of a human donor trachea, processed and transplanted into a human patient-subject suffering from a disease affecting the structural integrity of the lung's bronchioles. Autologously derived chondrocytes were differentiated from mesenchymal stem cells obtained by bone marrow biopsy, and epithelial cells from the patient-subject were isolated from a bronchial mucosa biopsy. These cells were seeded in the decellularized donor trachea and cultured in a bioreactor. Even though an acellular allogeneic source provided the scaffolding for autologous cell expansion, the patient-subject did not experience any rejection reactions, and was doing very well eighteen months afterward.[63] This accomplishment was exciting because, for the first time, stem cells were successfully differentiated into a particular tissue type. Although this was only a single case with short-term follow-up, these results embody what regenerative medicine techniques are capable of achieving.

Hollow Viscous Structures

Stepping up to the next level of tissue complexity is not necessarily accompanied by major changes in structural and histological organization. Instead, organs in this class have greater functional demands upon them and must be able to withstand the stresses of their normal functioning. Like tubular structures, hollow viscous organs generally consist of an inner layer of epithelial-type cells surrounded by an outer layer of smooth muscle and/or connective tissue to provide some minimal functional capacity and to anchor the structure in place. However, whereas tubular structures tend to play more passive roles, these viscous, nontubular organs have wider functional parameters, higher metabolic requirements, and more complex intracellular interactions. The hallmark organ that has been successfully regenerated in humans is the bladder, but efforts are also under way to bioengineer organs from the female reproductive system. These organs participate in more active bodily functions, and are more anatomically and functionally dynamic than tubular structures. Although they have slightly more complex histological features than tubular structures, their biofabrication process similarly depends on a scaffold seeded with at least two different cell types.

Congenital malformations and neoplastic growths can affect the normal development and anatomy of the female reproductive tract, precluding normal sexual or reproductive function. While current methods of reconstruction are very limited by the bioavailability of tissue, in situ regeneration of these organs may prove to be possible. Several animal studies have shown promise. Biopsies of vaginal or uterine epithelium and smooth muscle are used to isolate and expand cell lines in the laboratory. The cells are then seeded into biodegradable organ-shaped synthetic scaffolds. Total vaginal replacement and subtotal uterine replacement in rabbit models have yielded organs that were successfully integrated by the host animal after implantation, and subsequently demonstrated histological characteristics similar to natural tissue after several months of growth.[64] As a result of these experiments, functional and breeding studies to test the reproductive capacity of bioengineered uteri and human clinical trials for vaginal regeneration are under way.

Regeneration of bladder wall segments has been accomplished using similar techniques. Both pediatric and adult patient populations can suffer from diseases in which their bladder function and volume are decreased. Current standard surgical treatment uses intestinal segments to augment bladder volume, but these procedures are lengthy and have significant operative risks and lifelong digestive and metabolic side effects. Regenerative medicine may be able to offer these patients a chance for a less invasive procedure. Initial animal experiments evaluating acellular scaffold configurations generally yielded poor results, especially when large-area bladder segments were constructed. Mechanical failure and urinary stone formation were observed with permanent synthetic matrices. Scarring with graft contracture occurred when some degradable biomaterials were used. Non-cell-seeded grafts showed appropriate native urothelial cell ingrowth in vivo, but did not produce a well-developed or functional muscle layer. However, recent advances have led to success in a small human clinical study.[65] Autologously derived urothelial and smooth muscle cells from pediatric patient-subjects were harvested, cultured in vitro, and then seeded into collagen alone or combination collagen–polyglycolic acid scaffolds. These segments were then used for bladder augmentation, and were either covered with the patient-subject's omentum (a large, highly vascularized sheet of adipose tissue in the abdominal cavity) or left bare. Ultimately it was shown that patient-subjects receiving the collagen–polyglycolic acid scaffold with omental coverage design had the best results. Albeit small, this landmark clinical study exemplifies regenerative medicine's great potential to provide alternative therapeutic and surgical treatment options for patients.

Solid Organs

For organs in this highest level of tissue complexity, the traditional treatment for end-stage disease is either temporary supportive treatment with drugs or devices or whole-organ transplantation. Conventional transplantation allows select patients to regain a functional organ, yet it is exceptionally complicated to obtain a histocompatible match that does not require the use of immunosuppressive agents. The ultimate goal of regenerative medicine is to bioengineer and transplant complex, solid organs composed of cells derived from the patient in need. This objective, however, presents an exceedingly difficult and challenging task given the tissue complexity and developmental process of organs such as the kidney, heart, pancreas, and liver. Complete regeneration of these whole organs requires incorporation of extensive vascular networks as well as precise organization of multiple cell types, two challenges not faced in the biofabrication process of simpler tissues. Whereas creation of tubular structures and hollow viscous organs primarily utilizes decellularized scaffolds, replication of solid organ function must incorporate other methods in order to be successful.

Patients with end-stage renal disease suffer significant medical sequelae secondary to loss of the many physiological duties carried out by the kidneys. With complete renal failure, these patients must undergo mechanical dialysis to replace the waste disposal function of the kidneys, and must be closely monitored for electrolyte and acid-base derangements, among many other medical complications. Interestingly, though, 100 percent renal functional capacity is not required for survival. With this in mind, creation of a wafer or cartridge consisting of autologously derived renal cells may be a realistic technique employed to prevent a patient from needing dialysis. Renal anatomy is in fact amenable to the insertion of a thin, cell-seeded collagen scaffold that would not require an extensive vascular network and could provide appropriate physiological function. Current laboratory investigations are under way to construct such a renal cartridge. Other regenerative medicine strategies are also employed to engineer kidneys. Decellularization of porcine kidneys can be easily accomplished, and initial attempts at repopulating the remaining ECM architecture have revealed some organizational capacity of the intravascularly circulated endothelial cells. Furthermore, although it is still in preliminary experiments, bioprinting may ultimately be able to fabricate an entire kidney including the vascular network and functional parenchyma components.

Beyond the kidney, varying complexities of modular organs have all been decellularized, followed by attempts at recellularization in animal models. In a rabbit model, the ECM architecture of a phallus was preserved, and the scaffold was infiltrated with both muscle and endothelial cells. The erectile organ was replaced, and the rabbits were able to show successful reproduction with viable offspring.[66] In a rodent model, the preserved ECM architecture of a heart, including walls, valves, and blood vessels, was perfused with harvested endothelial cells, and then injected with neonatal cardiac cells. Macroscopic contractile function was observed.[67] Similarly, livers from animal models were decellularized and repopulated with hepatocytes and endothelial cells, resulting in histologically viable cells that secreted albumin and urea, two products of normally functioning liver parenchyma, and were able to metabolize drugs.[68] Finally, harvested pancreatic islet cells can be seeded into a decellularized pancreas matrix and observed to secrete insulin.[69]

Looking forward to human studies, the lack of available autologous scaffolding for these solid organs represents a significant limitation. However, semi-xenotransplantation, in which the decellularized donor scaffold is an animal source yet the cells used to populate it are obtained from the human patient-subject, may represent a solution. Studies evaluating transmission of animal-based infectious agents and rejection potential have shown promising preliminary results.[70] Despite these advances, not enough progress has yet been made to translate these laboratory studies into the clinical realm.

Conclusion: The Science

Extensive research and development in many scientific arenas over the past few decades have positioned regenerative medicine to bring exciting new treatment options to clinical reality. The ability to generate replacement tissues and organs in a laboratory setting without inducing many of the negative sequelae associated with conventional organ transplantation would be a giant leap forward in medical technology and health science standards. These techniques can be applied to just about every field of medicine, providing therapeutic options for any number of mild to severe diseases. Despite these advances, there are still significant scientific hurdles that must be overcome before further translation from bench to bedside can proceed. As these treatment methodologies continue to evolve, they must follow strict scientific guidelines in order to produce credible, high-quality results that are accurately reproducible. Researchers must create a thorough fund of knowledge by conducting extensive investigations at the basic science level in the areas of cell and molecular biology, biochemistry, biomedical and chemical engineering, and biomaterials science. There are still many gaps in our fundamental understanding of biological processes, and much more laboratory, animal, and clinical research is needed.

SCIENCE IN SOCIETY

The Language of Regenerative Medicine

As we have described, most regenerative medicine research is still in its early stages; thus, it is contributing to the growing literature and lively scholarly discussion about translational research, also referred to as "bench-to-bedside" research and, when it is time to begin clinical studies, as "first-in-human" trials. The terminology used to name and describe translational biotechnology research can give rise to an unexpected ethical issue when it appears to signal successful treatment instead of research on novel interventions of unproven efficacy. Even the term *regenerative medicine* is likely to be viewed by the public in a different way from what is understood by the scientific community. The term is intended to describe research interventions, but it also carries the implicit connotation of standard, approved, successful treatment, as did the term *gene therapy* when it was introduced over twenty years ago. This therapeutic terminology has influenced media discussions and public perceptions about the field ever since, even though *gene transfer research* is by now the preferred, nontherapeutic term.[71] Similarly, *cell therapy* is currently the language of choice to describe the type of regenerative medicine research devoted to the development and use of what are better termed *cell-based interventions*.[72] For example, the leading professional society for gene transfer researchers, the American Society of Gene Therapy, recently changed its name to the American Society of Gene and Cell Therapy in order to signal the close relationship between gene-based and cell-based interventions.

The problem of treatment-oriented research terminology and its potential effects on patient-subjects and the public is by no means new, and extends far beyond novel biotechnologies.[73] We note it here simply because it represents an important manifestation of the faith in science that is the focus of our interest.

Challenging and Changing Concepts

One of the promises of regenerative medicine technologies is that, once perfected, they are more likely to have long-term efficacy and to be curative than are many standard but "halfway" technologies. In addition, at least some are more likely to be less invasive, with fewer comorbidities, than standard treatments. A number of regenerative medicine techniques, such as cell-based interventions, in situ regeneration, and cartridge and wafer techniques, are anticipated to share both of these characteristics. When a novel biotechnology shares these characteristics in comparison to standard treatments, decisions about its use may have subtly pervasive effects on common, important, and often invisible systemic factors, including but not limited to shifts in consensus about when intervention is medically indicated and for whom. Kidney failure provides an example of how regenerative medicine technologies sharing these characteristics could not only shift consensus about medically indicated intervention but also, in consequence, alter current medical and social understanding of fundamental concepts like prevention and treatment, normal and abnormal.

When an individual's kidneys fail to function, the available treatments include dialysis and transplantation. Both are classic "halfway technologies": invasive, expensive, complicated, noncurative, and accompanied by a range of adverse effects.[74] It is obvious that total lack of kidney function counts as kidney failure. It is also obvious, however, that individuals with only one functioning kidney are able to live normal lives with no adverse effects. Somewhat less obvious, at least to nonphysicians, is what should count as kidney disease in individuals whose kidneys are failing but who are not perceptibly ill.

Several measures of kidney function are commonly used to diagnose kidney disease. In fact, chronic kidney disease is sufficiently common that there are degrees of loss of function that correspond with categories of disease severity. However, it is important to recognize that several distinctions, including the point at which a diagnosis of kidney disease is made, the percentage of function that is less than 100 percent and more than 0 percent that corresponds to a disease diagnosis, and categories of disease severity, are all nontransparent and not necessarily agreed upon. The key measurement point that divides *disease* from the normal range of function often precedes symptoms of *illness*, and may even precede other biological measures of functional impairment. For example, kidney function is usually assessed by a measure called creatinine clearance. A value that falls below the agreed-upon normal range may not be accompanied by any protein in the urine (an important sign of impaired function) until the value has fallen significantly. Individuals with impaired kidney function may feel perfectly well until creatinine clearance is very low and the urinary protein level is very high.

Nonsymptomatic disease measures have clear medical and scientific rationales. However, this type of line drawing between "normal" and "abnormal" function, and disease versus nondisease states, is also determined in part by many other factors, most notably by value-laden judgments that may be either explicit or largely hidden. Indeed, philosophical and sociocultural debate about the concepts of "health" and "disease" have spawned an enormous literature.[75] For our purposes, however, we need note only that the identification of a condition that should be labeled "disease" or "impaired or abnormal function" (or whatever the appropriate term) is significantly related to the reason for making that identification. When it comes to kidney function, there are at least two reasons: (1) to take kidney function that is less than normal into account where it is relevant to determining proper dosages of drugs, the metabolites of which are excreted by the kidneys, in order to preclude inadvertent overdosing, and (2) to determine when treatment is needed to address the adverse effects of insufficient kidney function.

Thus, identifying the decrement in "normal" kidney function for which medical intervention is indicated depends notably on the balance of potential harms and benefits posed by available treatments. That is, if treatment is difficult, complex, painful, and expensive, it stands to reason that treatment should be postponed as long as reasonably possible. Rigorous treatment should be started only when it is no longer possible to avoid severe or irreversible damage without it.

The standard treatments for kidney disease certainly meet this standard. Nobody would undergo dialysis or transplantation unless he or she really needed it. Thus, the definition of need is clearly and necessarily affected by what is needed. At the same time, if a treatment is only partially effective, what it means to "need" a treatment could be altered according to its effectiveness. For example, suppose that kidney dialysis used to be less efficient than it is now, as a result of improved technology—suppose that it once could remove only 50 percent of the toxic unexcreted waste products from blood, but now it can remove 90 percent. If 60 percent effectiveness in cleansing the blood of waste products is needed to avoid illness or permanent damage, then dialysis would be indicated much sooner for a given individual in the early days of the technology than it would be for the same individual now. This is because removing half of the waste products from the blood would be sufficient to prevent illness or damage only if the half that remained in the blood was still low enough to reach the 60 percent effectiveness level. One would have to have better kidney function to get there with less efficient dialysis. Thus, what it means to "need" treatment depends on contextual factors like the state of treatment technology as much as it does on scientific tests and measures.

What is the probable effect, then, of the introduction of new regenerative medicine technologies, such as cell-based interventions, in situ regeneration, and cartridge or wafer insertion, on how we understand kidney disease? Unlike dialysis (which is a repeated procedure that also necessitates close medical monitoring and correction of adverse effects such as anemia) and transplantation (which is a major operation, requires ongoing immunosuppression and close monitoring, and may need to be repeated because transplanted organs often have relatively short productive life spans), these regenerative medicine technologies would ideally require only a single intervention at one time point: an injection, or a simple surgical insertion of a small tissue capsule. Some regenerative medicine interventions may require repeated treatments, but it is very unlikely that the frequency would approach that of renal dialysis or the medication regimen required after conventional renal transplantation. These interventions may take more time than dialysis or transplantation to become effective, but all are hoped to be significantly less invasive, with fewer risks of harm and adverse effects than either conventional treatment.

Both of these factors would probably lead to earlier intervention with regenerative medicine technologies than with conventional treatments. Over time, the definition of "normal" kidney function—the level of function at which treatment would be recommended, which, as earlier noted, will always be higher than the level that would cause illness or irreversible damage—would probably then change, such that the lower end of normal might be increased, in large part because the balance of harms and benefits might change as the potential harms of treatment are lessened. That is, if treatment is unproblematic, then the condition or conditions in need of treatment may expand.

This is one aspect of a very familiar phenomenon in health care. It is well known that the indications for new treatments tend to expand as they are perfected and better understood. For example, conventional treatments for kidney disease were once rarely offered to patients older than sixty-five, but much older patients are now routinely treated and generally tolerate these difficult interventions no less well than younger patients. Similarly, some novel technologies are likely to be applied earlier as confidence in them grows—for instance, to younger patients and/or to those who have suffered less damage from their disease. Some gene transfer interventions—notably, investigational treatments for severe combined immunodeficiency and for cystic fibrosis—have demonstrated far more success in younger patient-subjects than in older persons.[76] An even more common type of example is found in the broadening of indications for novel interventions, from serious conditions to a wide range of minor indications. This path has been followed with human growth hormone injections for idiopathic short stature, botulinum toxin (Botox) injections for minor medical and primarily cosmetic conditions, and testosterone injections for older men, to name just a few interventions with expanding indications.[77] Even current controversies about the use of opioids for chronic nonmalignant pain reflect increasing confidence in the use of powerful analgesics, formerly employed only as a last resort, and thus the expansion of medical need for this category of drugs for less serious indications.

Thus, the change in how we think about concepts such as "normal" and "need" that is heralded by some novel regenerative medicine interventions is by no means unprecedented. The contested terrain of concepts of health and disease has never been truly fixed, nor truly fluid. Nonetheless, the potential for permanent alteration in function that so attracts us to these novel biotechnologies is somewhat novel in itself. And when this change is examined alongside another potential line-shifting characteristic of these regenerative medicine interventions, something new may indeed emerge.

The change in the harm-benefit balance that we have identified when regenerative medicine technologies are employed might also lead to a change in a different form of line drawing. Instead of or in addition to moving the line between normal and diseased, these four regenerative medicine technologies might instead change the relationship between prevention and treatment. Moving the "normal" line means recategorizing people who were formerly viewed as having normal kidney function to now having abnormal function, in large part because treatment has improved. But we might alternatively consider earlier intervention as a way of maintaining normal function—and thus categorize the intervention not as *treatment*, but as *prevention*.

The relationship between prevention and treatment is, not surprisingly, another distinction that seems sharp and clear but upon examination turns out to be quite nuanced.[78] So-called primary prevention is usually defined as maintaining health and preventing disease, and is thus clearly distinguishable from treatment. However, secondary prevention is usually defined as early diagnosis and treatment of a disease to minimize its adverse effects. Thus, the advent of successful regenerative medicine interventions of the types we have been considering might change the definition of kidney disease so that disease is diagnosed earlier, in which case treatment and prevention would converge. Alternatively, what is considered normal kidney function might not change, such that use of a regenerative medicine intervention would be categorized as "prevention" or "treatment" depending solely on the measured kidney function that serves as the basis for the intervention. And here some additional nonmedical factors are likely to come into play. Because health insurance reimbursement is provided only for medically indicated treatment and a small select category of preventive interventions, such as immunizations (primary prevention) and some diagnostic screening and testing (secondary prevention), unless the category of reimbursable preventive interventions expands considerably, patients and their doctors will prefer to change the point at which kidney disease is diagnosed in order to be assured that health insurers will provide them with financial access to earlier "treatment"—which then is not readily distinguishable from secondary prevention.

Finally, although it is still a far-future scenario, there could well be a cumulative effect arising from changes like these in the conceptualization of health and disease and in the practice of medicine—changes that are likely to arise from the many envisioned applications of regenerative medicine interventions. The result could, over time, be a significant change in our understanding of healthy aging, including changes in what we consider normal functioning as we age and ultimately a lengthening of the projected life span. Both changes are characteristic of what has been called human enhancement and even "transhumanism."[79] Again, this point is raised to highlight how regenerative medicine is anticipated to play a signally important role in medical progress—and the expected concomitants of medical progress are corresponding changes in how we think and how we live. It is part of the responsibility of both science and ethics to anticipate potential changes and help direct examination of them and discussion about them.

Following Up

Some other characteristics of regenerative medicine interventions—best exemplified by the need for long-term follow-up—can potentially complicate what might otherwise seem like simple determinations. Once again, regenerative medicine is not unique in this regard; it is, instead, uniquely illuminative of a more pervasive challenge in translational research. Long-term follow-up in regenerative medicine research may be necessary over many years simply in order to determine whether an experimental intervention is a "success" or a "failure." Cell-based interventions may need long-term follow-up so that investigators can learn about patterns of bioaccumulation and their potential effects, such as insertional mutagenesis, as has been seen in some gene transfer research, or other tumorigenic effects, as may be seen when some types of stem cells are used. Intensive long-term follow-up may be necessary in order to learn how best to promote rapid regeneration without adverse effects (e.g., oncogenesis).

Long-term follow-up is also likely to be extensive in any study involving the implantation of organs or tissues regenerated ex vivo, to ensure that success or failure can be determined in functional terms. Only long-term follow-up may be able to determine whether the experimental intervention is "working" when it is difficult to know when success or failure should be declared. For example, when, if ever, can a partial regeneration can be deemed successful?

The first patient-subjects in early-stage regenerative medicine research will have important roles in defining and refining functionality, and thus helping to define both failure and success. They are likely to be asked to make a considerable commitment to the research path, without changing paths to pursue standard treatments if they get tired of waiting for functional regeneration. It is always true that research subjects may cease participation at any time, and it is also true that many research subjects are lost to follow-up. Yet the importance of what can be learned from long-term follow-up is such that researchers would do well to emphasize the nature of the research partnership from its very beginnings, and in addition to anticipate the administrative and financial demands that good long-term follow-up places on both researchers and subjects.[80] Indeed, the best examples to date of the importance of such considerations are the bladder augmentation study previously discussed and a urethral replacement study, in which patient-subjects were followed for a very long time before study results were deemed robust enough to assess the success of the intervention.[81]

The Fuzzy Research–Treatment Distinction and the Therapeutic Misconception

As hinted by the previous discussion, regenerative medicine research may, generally speaking, be especially vulnerable to the therapeutic misconception. The therapeutic misconception is the conflation of research and treatment, a hopeful error made not only by patient-subjects but also by researchers, the media, and even research review boards;[82] it is also the significant overestimation of potential direct benefit and/or the underestimation of risks of harm.[83] The therapeutic misconception can arise in regenerative medicine research for several reasons. First, there is considerable public confusion about the many different types of stem cells used in treatment and research.[84] This confusion could easily make it difficult to distinguish the numerous therapeutic uses for determined stem cells, both autologous and allogeneic, from research uses of multipotent and pluripotent stem cells. As noted earlier, the very term *cell therapy* invites such confusion when it is applied to research interventions. The burgeoning market for stem cell tourism, both domestic and global, adds another layer of confusion and blurring of boundaries. Stem cell clinics use various types of stem cells in unproven (and generally ineffective) "therapies" that are offered without having first been tested in research.[85]

A second reason that the line between research and treatment is growing less distinct in regenerative medicine research is its necessary focus on patients as subjects from the earliest trials—a focus that has become characteristic of research involving most novel biotechnologies, and that has always been characteristic of surgery. Classical early-stage research designs traditionally enrolled healthy volunteers, who, by definition, cannot benefit from the intervention under study (most often a pharmacological agent). This helps to underscore the absence or very low likelihood of direct benefit for research subjects from as-yet-unproven interventions. However, early-stage research involving novel biotechnologies is highly likely to enroll patients as subjects,[86] for several reasons, most notably that there may be little value in the data gathered from subjects who do not have the disease or condition of interest, but also because many novel interventions carry risks of harm far more significant than the very small doses of new drugs usually studied in traditional first-in-human trials. Surgical research, moreover, is all but impossible to conduct on anyone other than patient-subjects because the risks of harm so far exceed the generalizable knowledge that can be derived from surgery on healthy volunteers.[87] And, as we have seen, surgery is now and will continue to be an important component of a great deal of regenerative medicine research, in both preclinical and clinical stages.

The result of this combination of factors is that research that combines novel biotechnology and surgery, as does much regenerative medicine research, is especially likely to present the possibility of direct benefit to patient-subjects, even in the earliest stages. And when direct benefit is at least somewhat likely for subjects, the line between treatment and research can be difficult to maintain. It can also be difficult to articulate—and to understand—outside the highly specific context of the informed consent process in a given clinical trial, as the following example will demonstrate.

The decision to publish the results of the bladder augmentation trial reflected a determination that follow-up had been sufficiently extensive to declare the intervention successful. Media coverage at a TED (Technology, Entertainment, Design) conference several years later demonstrated the ease with which early-stage research like that trial can be mischaracterized and misunderstood by the media and the lay public.

TED conferences, begun in 1984 and devoted to "ideas worth spreading" (www.ted.com), showcase talks by leading thinkers, scholars, public intellectuals, scientists, and others. In 2011 one of us (A.A.) gave a TED talk that briefly described preliminary work in organ regeneration. The highlights of this work include the use of bioprinting devices to build collagen scaffolds on which solid organs might be "seeded" using determined stem cells derived from individual patient-subjects—much like what had been done in the bladder augmentation study. For the TED talk, however, an example was used that reflected the recent progress of preclinical organ regeneration research: a bioprinted collagen matrix shaped like a miniature kidney. The bioprinted kidney matrix was displayed and clearly described as a nonfunctional model. In addition, one of the patient-subjects from the bladder augmentation trial, now a young adult, was brought onstage. He stated that his kidneys would have failed if he had not participated in the trial—a true statement, based on the relationship among the bladder, the ureters, and the kidneys, that could be misunderstood by laypersons who failed to note which study the young man had participated in.[88]

Having heard this, having seen the model kidney matrix, and apparently lacking much scientific knowledge, a freelance reporter at the TED conference mistakenly stated on a Web-based news site that the bioprinting process had produced a functional kidney, and implied that the patient-subject had received one. This incorrect and scientifically unverifiable account was widely picked up and re-reported by other Web-based news outlets, including several with staff writers having scientific expertise that should have been sufficient to halt the spread of incorrect information had any attempt been made to verify it. It took much concentrated effort by media staff at the Wake Forest Institute for Regenerative Medicine to correct the misconceptions, which presumably appeared plausible and which certainly represented wishful thinking.[89] The misleading reports were corrected and/or withdrawn before they reached major news outlets and print media. This demonstrates how easy it is to slip into the therapeutic misconception—and how our faith in scientific progress makes not only patient-subjects but everyone in society susceptible to it.

Faithfulness to Science and Society

How can—and should—regenerative medicine scientists, bioethics and communication scholars, and media professionals work together to increase the public's scientific literacy? Examples abound, in both print and television news, of reporting about ongoing research of all types—including laboratory and animal studies—that causes patients to flood academic medical centers with requests for enrollment. Bioethics and communication scholars like Tim Caulfield and Celeste Condit have examined scholarly and popular depictions of research, especially novel biotechnologies like genomic and stem cell research, and have come to several useful conclusions.

First, both scientists and science reporters are, in different ways, responsible for some of the exaggerations that excite our hopes for rapid scientific progress.[90] This is, to a certain extent, unsurprising. As a general matter, research involving novel biotechnologies is complex, highly interesting to the public, and often the subject of press releases authored by public relations professionals working in both academia and industry. It is not easy to strike a balance between describing the promise of such research and overpromising about its potential results, whether the audience is the readership of a newspaper or of a scientific journal. Yet many programs exist both to educate scientists in how to talk with the media and to educate journalists and public relations staffers about science. The goal of research is clear—to move science forward in order to help future patients.[91] Even when it is difficult to talk generally about distinctions that are fuzzy, such as the line between research and treatment, misconceptions can and must be corrected in the critical and ongoing partnership that is the researcher-subject relationship.[92]

Does regenerative medicine research present particular challenges in this regard? Our answer is a qualified yes, for two reasons. First, the complexity and diversity of the field means that there will always be a gap of sorts between the promise it offers and the details of any particular clinical trial. This means that researchers will often have to begin with the assumption that the therapeutic misconception is influencing not only the hopes of potential subjects but even their own expectations and those of the rest of the research team.

However, careful conversation, both in public and with potential subjects,[93] can make important progress in clarifying and extending public understanding. The second reason that regenerative medicine research may present special challenges to communication and understanding may be more difficult to overcome. As we have discussed, the field's high-profile contributions to the ever-shifting meanings of concepts such as *normal*, *disease*, *prevention*, and *treatment* highlight the suggestive role of regenerative medicine in discussion of much larger questions, including our expectations about healthy aging and even about what it means to be human. Such metaphysical arguments are not only important expressions of our faith in science, but also a sign that scientific progress is a signal occasion for the kind of reflection that once belonged solely to religion.

In light of this provocative role, how can we encourage public engagement with the ethical, social, and policy implications of research in regenerative medicine? Is the public discussion occasioned by regenerative medicine research really likely to be so sweeping? Responsible regenerative medicine researchers will say no; this broad and scientifically exciting field progresses, like all promising science, in small steps, gradually increasing our understanding of basic biological mechanisms, as the first part of this chapter has demonstrated. Nonetheless, the search for those biological keys, and the desire to manipulate them to overcome human disease, does raise those larger questions, even though they are theoretical and likely to remain so. Is faith in science too powerful, then? Is it too hard to address through public discussion?

Our answer is a qualified no, because any other answer risks underestimating the public. For one thing, scientists have an obligation to help improve public understanding of their work; science is, after all, a social practice with social goals. Regenerative medicine researchers are obligated to employ the consent form and process to support and enhance the autonomy of potential subjects deciding about participation in a particular clinical trial. Their responsibility to improve public discussion, understanding, and engagement with the progress and limits of the science is analogous, albeit on a different scale.

Moreover, despite the complexity of the science, and the acknowledged current problems in how the science is often presented by the media for public consumption, that public can demonstrate considerable capacity for sophisticated understanding. Celeste Condit's work examining laypersons' descriptions of genomic research illustrate this well.[94] Genetic determinism has been a common motif in media descriptions of the search for genes associated with an ever-widening range of conditions, from rare single-gene disorders, to common chronic conditions with many genetic associations, to behavioral genetics. Yet Condit and others have shown that nonscientists have little difficulty reconciling free will and genetic determinism.[95] "Is it me or my genes?" may be an important question to explore, but it does not preclude assuming responsibility for one's actions, one's health, or one's life.

In much the same way, while the large questions potentially raised by regenerative medicine research are worth exploring, at the same time it is essential to emphasize the small steps made by regenerative medicine science in adding to our understanding of the mechanisms of health and life. Faith in science, after all, must be justified by works.

2

FROM *ARROWSMITH* TO ATWOOD

How Did We Come to Disrespect Science?

Ronald M. Green

A ragged fourteen-year-old girl who has just buried her mother drives the wagon. In the back lie her fevered father and her younger brothers and sisters. The father urges her to head to Cincinnati, where they have a relative who might take them in, but the girl replies, "Nobody ain't going to take us in. We're going on jus' long as we can. Going West! They's a whole lot of new things I aim to be seeing!" This resolute young woman is the great-grandmother of Dr. Martin Arrowsmith.

Thus begins Sinclair Lewis' 1925 Pulitzer Prize–winning novel *Arrowsmith*. Many years later, at the novel's end, Arrowsmith culminates his medical research career by using a vaccine he has invented to halt a bubonic plague epidemic on a Caribbean island. He does this in the face of opposition from a medical missionary who describes the plague as God's just punishment for sin. In this victory over plague, won at the cost of the death of his wife, Arrowsmith fulfills the heroic resolve of his great-grandmother and symbolizes the spirit of science that fights against disease.

Fast-forward to the opening decades of our own century and the highly lauded dystopian novels of Margaret Atwood. In *Oryx and Crake* (2003) and *The Year of the Flood* (2009), Atwood depicts a world nearly destroyed by human scientific and biomedical interventions. Global warming and pesticides have wiped out whole species of animals and plants. In their place, dangerous genetically engineered animals prey on surviving human populations. Amid this chaos, the only voices of sanity are those of a gentle quasi-religious community, God's Gardeners, whose teachings and orations punctuate the novels. But these gentle people, along with most of the human race, ultimately succumb to the "waterless flood," a viral epidemic resulting from gene splicing gone awry.

Between 1925 and 2009, the world turned upside down. Religion went from being a threat to scientific advance to the sole bastion of human feeling in a world of technocratic domination. Infectious diseases and epidemics, once among the greatest challenges to human well-being, became human creations, and the science that once sought to control them became their cause. The scientist-physician who was the hero became the novel's villain.

How did this happen? How did we go from *Arrowsmith* to Atwood? What are the reasons for this dramatic shift in cultural valuations and fears? Thoroughly answering this question is—and should be—the work of cultural historians and commentators. In this brief space, I cannot identify all of the causes, nor can I defend the claim that any particular factor really has played a causal role. What follows, instead, is a chronological and impressionistic tour of the factors that I believe have transformed our evaluation of science and biomedicine. My only justification for engaging in such a broad sweep of cultural interpretation is that I have lived through and personally witnessed many of the developments I describe here.

THE ATOM BOMB

The dropping of the atomic bombs on Hiroshima and Nagasaki was a watershed event in the trajectory from *Arrowsmith* to Atwood. In some ways atomic energy represented the fulfillment of more than a century of scientific and technological ambitions, but it also marked the moment when fear of science's dangers began to eclipse wonder at its benefits. Although tens of thousands of people died in the bombings, use of the bombs abruptly ended a cruel war and may have saved hundreds of thousands of American and Japanese lives that might have been lost had the war continued. Many people, including some of the scientists who worked to develop the new weapon, also believed that by rendering war "unthinkable," the bomb would put an end to the horrendous mass conflicts that had marked the century. But from the first, even the atomic scientists recognized that a door had been opened to terrible new possibilities. J. Robert Oppenheimer's quote from the Bhagavad Gita on witnessing the first test detonation in the New Mexico desert rings down from that moment: "Now I am become death, the destroyer of worlds." So, too, does the blunter remark made to him by his colleague, test director Kenneth Bainbridge: "Now we're all sons-of-bitches."[1]

Yet, like a rocket that continues to soar upward following the shutdown of its motor, the prestige of science continued to grow in the aftermath of the Second World War. Perhaps the apogee was the development and introduction from 1952 onward of the Salk and Sabine polio vaccines. As a child in grade school, I remember the fear that stalked communities each summer when we heard of schoolmates stricken with this dread disease. Parents forbid us to frequent public swimming pools, where the contagion might lurk. Here before us was an epidemic, humankind's ancient foe. I remember the moment when, starting college, I trooped to a local Providence high school and stood in line to receive a sugar cube laced with the Sabine vaccine. I shared the joy at the achievements of our own generation of brilliant Arrowsmiths.

The prestige of science grew with the Russian announcement of the launch of Sputnik in 1957. More than ever, we needed our scientists to protect us from Soviet technological advances, especially the weapons of mass destruction that enemy missiles could deliver. American scientists and engineers, with their white coats and slide rules, replaced G.I. Joe on the front lines of the cold war.

Government support for science was implemented through the wartime establishment of the National Defense Research Committee and Office of Science Research and Development, forerunners of the National Science Foundation, and through initiatives like the National Defense Education Act of 1958 (which helped fund my wife's graduate education in French). Beginning in the mid-1960s, but accelerated by Richard Nixon's "War on Cancer," the National Institutes of Health (NIH) received vastly expanded federal funding.[2] But while science and scientists now had unprecedented access to support, it was in some ways a real Faustian bargain, for now scientists were becoming agents of a vast "military-industrial complex," which President Dwight Eisenhower warned about in the closing address of his presidency. "Today, the solitary inventor," Ike observed, "has been overshadowed by task forces of scientists in laboratories and testing fields. In the same fashion, the free university, historically the fountainhead of free ideas and scientific discovery, has experienced a revolution in the conduct of research. Partly because of the huge costs involved, a government contract becomes virtually a substitute for intellectual curiosity." We should respect scientific research and discovery, Ike added, but "we must also be alert to the equal and opposite danger that public policy could itself become the captive of a scientific-technological elite."[3]

Once again, it took fiction to express our feelings. In Stanley Kubrick's 1964 film *Dr. Strangelove*, science, and scientists, have become insane. Strangelove, a turncoat Nazi who can barely suppress his Hitler salute, dreams of a troglodyte post-nuclear-war world, where a surviving remnant of scientific and political leaders will need the help of the most beautiful females to repopulate a globe laid waste by the "Doomsday Bomb."

THE ENVIRONMENTAL MOVEMENT

The 1960s also saw a broad reaction against one of our "wonder weapons" in the fight against parasite-born diseases: DDT. By depicting the harmful consequences of this and many other pesticides, Rachel Carson's 1962 book *Silent Spring* had a permanent impact on national thinking and stimulated the emergence of the environmental movement. That movement received new impetus from the war in Vietnam. The war itself, in which the technologically backward Vietnamese showed themselves capable of defeating our most advanced weaponry, contributed to the growing mistrust of science and technology, but one feature of the war especially highlighted our counterproductive and dangerous obsession with science: the use of Agent Orange to defoliate vast tracts of Southeast Asia's forests. Not only did this program prove largely unsuccessful in stopping the Vietnamese insurgency, it left a legacy of dioxin-induced illness among thousands of Vietnamese civilians and our own soldiers. In the social conflicts occasioned by pesticide use and defoliants, U.S. industrial corporations also came under attack. For many among the large generation of baby boomers, science and the military-industrial complex were becoming one and the same thing. Tellingly, in 1971 Dr. Seuss published *The Lorax*, a child-level indictment of greed and environmental irresponsibility. In a 1970 commencement address at Bennington College, novelist Kurt Vonnegut, a guru of the antiwar and environmental movements, focused his attack on science itself, cautioning baby boomers that "we would be a lot safer if the Government would take its money out of science and put it into astrology and the reading of palms."[4]

It was through the environmental movement that the political and cultural left made its most pronounced attacks on scientific and technological developments, but there were other, more subtle intellectual influences that led some progressives to be ranked among critics of science. These included the rise of feminist, postmodernist, deconstructionist, and multicultural thinking. In different ways, each of these cultural and social movements asserted that truth is subjective and rooted in the linguistic and personal perspective of the observer.[5] Suddenly, science was no longer perceived as the search for objective truth but the expression of the points of view and interests of well-to-do, corporately or governmentally financed male scientists. In the world of ideas, this relativist idea was powerfully reinforced by Thomas Kuhn's influential book *The Structure of Scientific Revolutions*,[6] which argued that the history of science was less an unfolding of truths about nature, than a series of abrupt "paradigm shifts" that occurred when one dominant scientific faction was replaced by another.

Nevertheless, while attacks on science from the left may have taken their toll on educated people's confidence in and respect for the scientific enterprise, attacks from the political and cultural right have most contributed to our current malaise.

THE REAGAN YEARS AND THE RISE OF CONSERVATIVE RELIGIOUS POLITICS

To this growing apprehension about science, the 1980s added a new and politically opposite impetus. Ronald Reagan owed his 1980 election in part to the "Southern strategy," developed a decade earlier by Richard Nixon. Driven in part by racial tensions, it united a new coalition of Republican economic conservatives, postindustrial blue-collar workers, and disaffected Southern Democrats. The latter brought with them a commitment to traditional religious values, including the fundamentalist opposition to evolution that had festered in the South since the Scopes trial in the 1920s. Although ridiculed as merely a "theory," evolution, of course, lies at the foundation of all modern biomedical science, from the study of infectious diseases and cancer to molecular genetics. To challenge evolution, therefore, is to question science itself. Although Reagan, and his Republican successor George H. W. Bush, trod carefully in this area, those opposed to evolution recognized that they now had friends in the highest reaches of American government. From this beginning, and through its subsequent avatars as "creation science" and "intelligent design," antievolution and antiscience would become major themes of the political and religious right.

The Reagan/G. H. W. Bush years contributed several other components to the modern opposition to science. One is the politicization of disease. It was during these years that the HIV epidemic broke out, an occurrence, one might think, that would lead to a reaffirmation of the value of a scientifically based fight against disease. But from the start, conservatives perceived AIDS as an illness contracted by, and confined to, gays and drug abusers.

This view of AIDS as a just punishment for immoral behavior was only slowly reversed, partly as a result of the impassioned efforts of AIDS activists, but it contributed to delays in responding to the disease. The fight against AIDS was relegated to members of despised communities and to scientists and physicians with whom they worked. Instead of fostering a love of science, this epidemic subtly enlarged the divide between the science community and many religious traditionalists.

With its strong probusiness stance, the Reagan and first Bush administrations also gave tacit support to the emerging corporate struggle against science. This struggle began in the 1950s as the tobacco companies fought to combat emerging scientific evidence that smoking causes cancer. As documents uncovered in subsequent litigation revealed, one powerful tool they developed was the use of science against science. By funding proprietary research or otherwise favorable investigators, however slender or threadbare their results, the industry was able to foster the pretense that the scientific evidence was not yet "in" on tobacco's dangers. This technique has been dubbed "manufacturing uncertainty." As Christopher Mooney observes, it received its best articulation in an oft-quoted passage from a circa 1969 Brown & Williamson document: "Doubt is our product, since it is the best means of competing with the 'body of fact' that exists in the mind of the general public. It is also the means of establishing a controversy."[7]

This technique could not easily succeed if the debate were confined to members of the scientific community. There, outlier positions with little evidential backing and peer-reviewed support are rarely heeded. But many of today's leading science debates also involve important matters of public policy and legislation, and thus become active topics of discussion in the news media. In this sphere other changes wrought by these conservative administrations also played a key role. Principal among them was an August 1987 action by the Federal Communications Commission (FCC) abolishing what was called the "fairness doctrine," which required radio and television networks using public airways to strive toward objective reporting of the news. In one stroke, the era of Edward R. Murrow, Walter Cronkite, Eric Sevareid, Ed Bradley, and Daniel Schorr came to an end, replaced by a new competitive marketplace. Instead of intensifying the quest for understanding, these changes forced news programs into financial competition with entertainment, offering a new forum for extreme, outlier, and controversial opinions. As Shawn Lawrence Otto notes, "Without enforced standards or peer review, news was cut loose from knowledge and the emotions of outrage and comedy were increasingly relied upon to sell the news."[8]

Antievolution groups would later develop these tactics into a broad strategy for bringing their challenge to evolution into the school curriculum. Having created a controversy about the validity of evolution through the vigorous deployment of unfounded outlier opinions and arguments, they would then insist it was the responsibility of educators to "teach the controversy." Thus, House Speaker John Boehner (R-Ohio) wrote to the Ohio Board of Education urging that the state's science curriculum content standards require teaching creationism. "It's important," said Boehner, "that the implementation of these science standards not be used to censor debate on controversial issues in science, including Darwin's theory of evolution." He added, "Students should be allowed to hear the scientific arguments on more than one side of a controversial topic. Censorship of opposing points of view retards true scholarship and prevents students from developing their critical thinking skills." But as Otto observes, this is nothing more than antiscience doublespeak. The controversy that Boehner and other antievolutionists would have us teach is entirely of their own making.

Sexual Politics

Although the 1980s laid much of the groundwork for vigorous attacks on science, the 1990s represented something of a calm before the storm. It is true that in 1995 the Republican-controlled Newt Gingrich "Contract with America" Congress abolished the congressional Office of Technology Assessment, which, with its well-researched reports that often undercut lobbyists' claims, had become a target of corporate and conservative opposition. But in other areas, the Clinton administration showed itself to be highly supportive of scientific research generally, and biomedical research in particular.

In 1993 the still Democratic-controlled Congress, responding to developments in genetics and assisted reproductive technologies, ended a Reagan-era law that prohibited federal support for human embryo research.[9] In response, the NIH formed a multidisciplinary body, the Human Embryo Research Panel, on which I served, to provide guidance for NIH-supported research in this area. The panel not only recommended federal funding for research on in vitro fertilization, prenatal testing, and other technologies, but also was the first body to urge federal support for embryonic stem cell research.

By this time, the antiabortion movement had made an equation between feticide and any destruction of the postconception human organism, including the early embryo. So opposition to the work of our panel, much of it from conservative religious groups, was intense and included lawsuits and threats of violence.[10] With the election of the Gingrich Congress in November 1994, our recommendations were doomed, and a new moratorium was imposed on embryo and stem cell research that would effectively last until the Obama administration in 2009.

This episode showed that abortion-related controversies were only one expression of a broad and religiously motivated movement into the arena of sexual politics. In addition to stem cells, other issues on which conservative religious organizations focused their attention included opposition to sex education in public schools, condom use for the prevention of AIDS, "abstinence only" as a response to teen pregnancy, access to Plan B and other forms of emergency contraception, and provision of the human papillomavirus vaccine. From the 1990s to the present, each of these areas has become a center of public controversy. Because science provided evidence for many of the policies that conservatives opposed or undermined those that they supported (such as abstinence-only sex education), these sexual issues were also often aligned with attacks on the credibility of scientific information and scientists themselves.

THE "W" YEARS

All these developments reached a crescendo during the eight years of the George W. Bush presidency. Chris Mooney, in his book with the same title, described this period as a "Republican war on science." It initially appeared as though the new president might adopt a progressive stance on some key issues. For example, in the summer of 2001, Bush took what seemed to be a moderate position in the stem cell debate. Pressured by conservative supporters to forbid any federal funding for embryonic stem cell research, but also facing strong advocacy of it by scientists, clinicians, and patient-care groups, Bush chose to permit NIH-funded research on what he described as the "more than sixty genetically diverse" embryonic stem cell lines in existence at the time of his statement, lines on which "the life and death decision has already been made." In fact, members of the scientific community had not established that these lines were viable, and eventually all but twenty-two proved useless. Mooney may exaggerate the willfulness of Bush's position and declaration when he describes it as "one of the most flagrant purely scientific deceptions ever perpetrated by a U.S. president on an unsuspecting public,"[11] but there is no doubt that the president's position exhibited serious neglect of the scientific realities.

The same neglect, much of it politically motivated, marked many other initiatives during the Bush years. These included the significant increase in federal support for abstinence-only programs and the enlistment of the FDA itself in efforts to limit availability of emergency contraception medications.[12] The interventions of the president and many conservative legislators in the Terri Schiavo case, despite the existence of a substantial body of medical opinion indicating that the young woman had irreversibly lost all higher cognitive function, mark another science low during this period.

But perhaps the most egregious interventions by this antiscience administration occurred in relation to the issue of global climate change. Evidence for climate change has been mounting since the mid-1950s, when models predicted that growing levels of atmospheric carbon dioxide would create a "greenhouse effect" and cause global warming. A 1995 report by the Intergovernmental Panel on Climate Change, a body established and endorsed by the UN, confirmed the significance of human influence on climate. At the start of his administration, Bush asked the National Academies to prepare a report. He received a response in 2001 in which the agency declared climate change to be real and serious. Despite this, describing the science as "too uncertain," the president refused to sign the 1997 Kyoto Protocol, which would have limited U.S. and other nations' production of greenhouse gases. This set the tone for Republican politics for the decade ahead. With strong support from corporate interests, including oil companies like Exxon-Mobil and entities controlled by oil billionaires Charles and David Koch, leading Republican politicians championed climate change denial. Tactics developed in the tobacco wars a generation earlier were redeployed. This included the exploitation of opinions from a small number of dissident scientists. As before, the aim was to use outlier positions or unsubstantiated research to sow doubt about and otherwise discredit what was an overwhelming scientific consensus.

These efforts culminated in the "Climategate" scandal of 2009, when, several weeks before the Copenhagen Summit on climate change, unknown hackers broke into a server at the Climatic Research Unit at the University of East Anglia. The hackers disseminated emails that were purported to reveal deception and misconduct by the climate researchers. Numerous scientific panels completely exonerated the researchers, but this did not prevent Republican James Inhofe, ranking member of the Senate's Environment and Public Work's Committee, from issuing a report in 2010 that named seventeen prominent climate scientists as engaging in "potentially criminal behavior" for allegedly violating federal laws and regulations.[13]

Tactics utilized by Senator Joseph McCarthy half a century earlier to attack political opponents were now turned against respected members of the scientific community. That such behavior was permitted in the U.S. Senate testifies to the extent to which many constituencies—corporate interests threatened by proposals to limit greenhouse gases, religious conservatives who believe that human beings have a biblically ordained right to dominate the natural world, and many ordinary citizens unable to sort out media reports of competing scientific claims—have fed the burgeoning antiscience movement.

The Current Generation

A final contributor to the contemporary disesteem of science is the attitudes of the current generation. Here I am at my most impressionistic and anecdotal. Having taught bioethics for decades, I lately found myself confronted by classes and lecture audiences highly prone to question the value of biomedical research, whether in the area of stem cells or genomic science. While appreciating the possibility of cures for cancer or Alzheimer's disease, many young people today question the value of efforts to reduce death and morbidity caused by disease or prolong healthy functioning. In doing so, they voice various concerns. "What about world population?" "Don't we already have too many people for the world to carry without reducing the toll of disease further?" "Why do we need assisted reproductive technologies in this already overcrowded world?" "With our economic problems, do we really want to expand the number of older people?" "Don't genetics and prenatal testing risk a new eugenics?"

Many things contribute to the growth of this biomedical skepticism. But a leading factor, I think, is our relative biomedical success. At least where young people are concerned, we have to a large extent realized Arrowsmith's dream. In the developed world, the older infectious diseases have been eliminated. New technologies permit longer lives and enhanced functioning for people stricken with serious conditions. Even cosmetic problems have been reduced, with cleft lip or clubfeet now virtually nonexistent, and, at least among the students of elite universities, bad teeth rarely seen. (I recently asked one large class of mine how many students had had orthodontia, and 60 percent of the class raised their hands.)

Thus, young people tend to take for granted the great biomedical achievements of the past. This partly explains their lack of emotional investment and relative passivity in defending and sustaining science and biomedicine, and it readies the ground for the otherwise pervasive attacks on science and scientists emerging from corporate interests, uninformed politicians, and conservative religious groups.

This passivity, of course, is deeply troubling. Although we may have conquered many of humankind's ancient infectious foes, evolutionary science tells us that neither nature nor disease stands still. In the unending combat of parasite and host, what Matthew Ridley calls the "Red Queen" phenomenon still persists: the more we try to outrace our infectious predators, the more they race to keep up.[14] As recent experience with the SARS and avian flu pandemics shows, globalization actually increases the threat from emergent pathogens, and makes it all the more important to develop the science and technology needed to combat them. Far from being obsolete, Arrowsmith's passion is more necessary than ever.

CONCLUDING QUESTION: WHAT CAN WE DO?

The picture I have painted of science denial is probably too dark. There are many signs that Americans continue to value and support science. This includes continuing high levels of funding for the NIH and National Science Foundation. Indeed, the emergence of the "creation science" and "intelligent design" movements shows that even when seeking to undermine science, opponents must often appear to appeal to the science to ground their arguments. If hypocrisy is the compliment that vice pays to virtue, then the pseudoscience movements of our day are the compliment that antiscience pays to the prestige of legitimate science. This includes catchword calls for "sound science" as a ploy used by climate change deniers and others to call into question well-established scientific conclusions.[15]

Nevertheless, there is also reason for concern. As I write, the morning news contains a report that the Republican-led North Carolina General Assembly has just passed a bill requiring state agencies to ignore the findings of a specially appointed state science panel that, drawing on climate change information and the risk of rising sea levels, recommended raising the height for permitted development of the state's coastline. The defeat, said the news report, was largely driven by lobbyists for real estate developers eager to continue their sale of shoreline properties. Here is science denial at its commercial worst.[16]

What can be done? How can we reverse a trend that could, in the short and long run, lead to local and global disasters? I want to close by briefly offering four recommendations.

First, there is a need for better information and better reporting of science. Media must get away from the debate and controversy format and provide real scientific information, as well as inspire the public with an interest in science. Public Broadcasting's excellent Nova series shows what can be done. Recently, many news outlets have actually reduced the staffing and size of their science reporting departments.[17] Will it take proliferating climate crises, nuclear power disasters, and new epidemics to reverse this? Let us hope not.

Second, we must watch our words. Conflicts over science are rife with words that are misused, misunderstood, or taken out of context. For example, antievolutionists have made much of the fact claim that evolution is "only a theory." But, of course, all scientific accounts of reality are "only theories," because they are based on inductive reasoning and subject to continual revision as new data are collected. In this sense, even the fact that the earth is round is "only a theory," but, like evolution itself, which is massively supported by data from almost all realms of science, it is as close to fact as science allows. Drawing attention to the theoretical nature of evolution is a rhetorical trick that creationists have exploited successfully because so many people do not understand the language of science.

The same can be said of the phrase "sound science," which, as we saw, has been deployed by corporate and political opponents of climate change and many other initiatives protective of the environment. This has become the "official slogan" of this oppositional movement, where, on the basis of appeal to extreme or outlier views, it is used to call into question the consensus of scientific opinion. Mooney observes that tobacco companies initially introduced the phrase to challenge mounting evidence of the link between smoking and cancer.[18] Thus, "sound science" actually means its opposite: science unsupported by evidence and contrary to the overwhelming preponderance of scientific opinion. Like other features of the antiscience movement, it draws its power from the public's latent respect for science and people's misunderstanding of the language of these debates. These misuses will only attenuate as scientist and humanist educators work to convey the proper use of language in this realm.

Language and rhetoric are also implicated in a third thing we must do: change our heroes. *Arrowsmith* celebrated the scientist as fighter and hero in a war against humankind's ancient enemies. Today our social applause is directed to the warrior, financier, or athlete. Young people, in particular, must once again be encouraged to direct their enthusiasm and dub as "awesome" scientists, engineers, and technological innovators. Inventor Dean

Kamen puts it bluntly: "We get what we celebrate. If we celebrate actors and celebrity, we get the balloon boy and stupid people acting out to get on reality shows. If we celebrate sports, we get a bunch of kids wearing jerseys, but how many of them will actually become millionaire sports heroes? What if we celebrate science and engineering with that same adoration?"[19]

Finally, let me say something as an educator. I believe we need to rethink premedical education and its place in the college curriculum. I am convinced that premedicine today is one of the leading causes of science illiteracy and disinterest among our college-educated population. This is because the premedical requirements and curriculum have harnessed science teaching at the college level to the demands and requirements of medical schools. With guaranteed premedical enrollments, departments of physics, chemistry, and biology have not had to develop courses and teaching skills that would attract the vast number of undergraduates. Indeed, rigorous science courses populated by premeds often drive these other students away. No single actor is responsible here: not the departments, the students, or the medical schools. But the whole system has functioned to drive many of our best students away from the sciences at the start of their college years.

On that note, with many things unsaid and complex issues only touched on, I will close. We may never return to the era of *Arrowsmith*, but should try.

3

THE "WARFARE" OF SCIENCE AND RELIGION AND SCIENCE'S ETHICAL PROFILE

Thomas M. Lessl

As science grows so also does its public responsibility, but some habits of communication that foster its advancement also diminish its ability to rise to this challenge—of addressing the ethical pressures that science and technology bring upon our world. My aim is to put this problem in historical perspective. I mean to argue two points: first, that scientists often manifest communication habits that promulgate ethical confusion, and, second, that these patterns are rooted in science's institutional history. By "ethical confusion" I mean something specific: a contradictory tendency to invoke something like programmatic agnosticism, now more often called "methodological naturalism," an official repudiation of the notion that scientific knowledge supports moral meanings or any other kind of meaning beyond the ken of materialistic causality, while also advancing (albeit more subtly) the opposite notion that the growth of knowledge and moral betterment are the same thing. I tie this pattern of equivocation to science's institutional history because it is a rhetorical habit that was made attractive by the specific pressures scientists confronted as they struggled to gain professional standing in the nineteenth century. With science's successful institutionalization in that period, this pattern gained an informal sanction and a momentum that has sustained it ever since.

It is not my intention to suggest that science should have no place in public life—a separation of science and state. Science could succeed only by acting in this arena, and countless matters of public interest depend upon its wise councils. But moral reason is the fabric of public life, and the manner by which science arose as a great institutional power has forced it into a contradictory posture. The pressures that came into place in this nineteenth-century period also encouraged scientists to represent their achievements as products of a dispassionate objectivity and to simultaneously represent that same knowledge as the moral leaven of modern Progress. Ever since, science has drawn much of its public prestige from its perceived objectivity, something tied up with the claim that it deals only with matters of fact, with "is" but not "ought." It is the fact that it is impossible to sustain this division where science bears upon public life that introduces the problem. So long as our scientific culture adheres to this position of ethical agnosticism while also wishing to present itself heroically (and thus as a moral actor of great import), it will sustain such equivocation.

I describe this aspect of the scientific self-conception as "heroic" because it is promulgated in a kind of narrative romance, legends of warfare between religion and science that demonstrate those special virtues of the latter that the former lacks. Superficially these stories might seem to do the opposite, to uphold an is/ought divide that illustrates science's inflexible neutrality on matters of right and wrong. They do so, typically, by relating episodes that illustrate how the "cherished beliefs" of religious people made them resistant to the strictly fact-based inquiries of science. Whereas religion's preoccupation with "ought," by such accounts, necessarily distorts its judgments, science gains its special clarity from its rigorous devotion to understanding what "is."

However, upon closer inspection we will see that the same narratives advanced in support of this is/ought distinction equivocate by also collapsing the "is" of scientific objectivity with the "ought" of a historical vision grounded in the notion of Progress. This pattern can be detected in a recent sociology text that invokes the warfare narrative in setting out two reasons why science "is a very powerful method of explaining the world." Its authors illustrate the first of these reasons, that "truth can be separated from fallacy (fiction)," in the following fashion.

> A classic example is the religious suppression of Galileo's argument that the Earth revolved around the Sun (and not the other way around, as the Catholic Church hierarchy believed). For a time this idea was successfully suppressed, but its demonstrable truth was simply too powerful to deny. Under modernity, therefore, objective truths replace subjective faiths as the primary form of explanation.[1]

By asking readers to suppose that Galileo's conflict with the church speaks to the central concerns of the debate over Copernican science, these authors fundamentally misrepresent not only this episode but also the character of science itself. For all its drama, the Catholic Church's suppression of Galileo was only a sideshow to what was, by and large, a scientific debate. It may have had something to do with the fact that Aristotelian cosmology had long been allied with Catholic theology, but this did not mean that the older geocentric view stood on religious grounds. It stood on Aristotelian grounds, and in its epistemological rudiments Aristotle's approach to science had been no less naturalistic than Galileo's.

Once having imagined that science and religion represent competing and opposite epistemologies, one firmly objective and the other spoiled by subjective biases, an *essential* subjectivity within scientific conceptualization falls out of view. Ironically, no one who has ever read the book that was at the center of this dispute, Galileo's *Dialogue Concerning the Two Chief World Systems*, could believe that this was a conflict between objective science and subjective faith. The opposing position voiced by the character Simplicio in the book is thoroughly Aristotelian, not Catholic, and his arguments, as much as those of Salviati, his Copernican counterpart, center around the familiar concerns of science: evidence, hypotheses, and the relative strength of the two competing theories they informed. What Salviati questions in the dialogue are not religious beliefs but various scientific assumptions rooted in the Aristotelian tradition that stood in the way of the new cosmology.[2] Galileo's revisiting of such premises had as much to do with the ultimate triumph of the Copernican position as any new evidence he advanced. Objective truths did not replace subjective faith. It would be more accurate to say that a stronger subjectivity triumphed over a weaker one, that the greater explanatory power of a new set of premises and theoretical formulations better accounted for the new evidence. The Newtonian physics that emerged from this was no less grounded in the inward world of conceptualization than the Aristotelian doctrines it replaced. This episode of scientific history bears witness to a fundamental feature of science, its dependency upon a kind of high-order rationalism that assumes that the testimony of the senses can be brought into faithful accord with the convictions of thought. In this regard, the rise of modern science represents not so much the abolition of subjectivity as its affirmation. It more powerfully demonstrated what Aristotelian science had always assumed, that with great effort the inward experience of consciousness can be brought into harmony with natural truth.

The fact that the previous passage obscures the real character of scientific revolutions by putting a Catholic mask on Aristotle will seem even more perplexing once we look at the second reason these authors give to account for why science "is a very powerful method of explaining the world." Having just represented the triumph of science as the triumph of objectivity, they next go on to link science to that most subjective of modernist faiths, the doctrine of "Progress,"

> the idea that, as we understand more and more about the natural world, modern society is constantly "moving forward"—from superstition to science, ignorance to knowledge and, finally, from subservience to mastery of nature. Once the natural world has been "mastered" (or at least its foundational principles understood), it's but a small step to the idea of mastery of the social world; if the inanimate world of "things" is governed by natural laws, perhaps the same is true of the animated world of people?[3]

It will not likely occur to most readers that the scientific objectivity outlined in the first passage ought to preclude any claims about Progress. This is because this premise of value arises not from philosophical reflection but from the drama of warfare itself. The warfare story loads the sins of "mere opinion," "faith," and "cherished beliefs" onto the back of a religious scapegoat which is then driven out the city gate. This cleanses the scientific conscience—but only so that a similar faith can make its way in through a back entrance.

In invoking the warfare thesis, the authors of this sociology text may have intended only to teach something about the discipline of mind that makes science possible, and in this regard it may be a useful fiction—philosophically false but pragmatically helpful. The greater mischief arises from the fact that such writers also influence how science is viewed in the more consequential world of public affairs. An ethical blindness is likely to arise whenever we allow ourselves to suppose that the mastery of nature automatically equals the mastery of our selves—the usual meaning of "Progress." Where this pattern dominates, we should also expect to find policy makers who are prone to a facile moralizing that denies the validity of subjective claims while failing to recognize the subjectivities they advance.

What I have described thus far finds its wider pattern in what Reinhold Niebuhr long ago described as the "easy conscience" of modernity.[4] The general tendency of modern thinkers to identify reason with nature has also tended to externalize the problem of evil, and in doing so they have ceased thinking about the inward complexities of heart that make evil possible. Unlike classical rationalism, which thought moral emancipation possible only through the constant striving of spirit against the baser inclinations of our biological nature, and unlike Christianity, which recognized how a complex and defiant will could overrun reason, the modern mind tends to presume a pre-established harmony between human reasoning and the natural order. For the modern thinker it is easy to be good; society can educate away evil without any special striving.

The warfare narratives simplify these moral challenges in their own way. Their overt message is that religious belief is continuously being forced into retreat by an advancing front of objective knowledge, and this seems to make religion and science opposites. But if we look more closely we will realize that they actually present them as alter egos. Their supposition that science can overturn beliefs that have moral significance will always insinuate that science is also able to answer the moral questions once raised by the religion. Where this is believed, the easy conscience of modernity becomes both more seductive and more dangerous. The stretching of science's authority to encompass questions of "ought" as well as "is" becomes especially difficult to stop once this pattern is found useful for enabling science to better compete for institutional supremacy.

I wish to emphasize the institutional motives responsible for these now ubiquitous narratives because I believe that they account for why the ethical message they promulgate is so intractable. Many who share my concerns are likely to regard this as a problem needing the illumination of philosophical discussion. I agree, of course, but a key point of this inquiry is to consider what this pattern might tell us about the challenges of bioethics once we recognize that it does not have an intellectual basis. If it is an example of what Eric Voegelin has referred to as the "prohibition of questioning," a tendency to avoid rudimentary metaphysical questions (such as those concerning ethics) by those committed to various forms of scientific naturalism, then it will not be amenable to any philosophical corrective.[5] To push back against such ways of representing ethics would first require that we understand certain institutional motive forces and the symbolic infrastructure that the warfare narrative has put in place to sustain them.

In the remainder of this chapter I wish to examine the historical circumstances that brought the warfare narrative into the foreground of scientific rhetoric. A chief impediment to the growth of science in the nineteenth century was the fact that the institutions of higher education best equipped to foster such work had not been created for this purpose. The medieval university was made in the image of the church. At its core, it was disposed to value notions of education that coincided with the moral concerns of religion, and this remained largely the case until well into the nineteenth century, despite the rising secularism that was then making inroads into the curriculum. So long as the university remained under clerical control, science could gain no significant share of its resources, and thus the warfare narrative emerged to challenge this religious hegemony. But because deeply rooted cultural traditions are much more easily co-opted than overthrown, a closer look will show that the warfare narrative imitated this more traditional vision by making science history's agent of moral advancement. Our scientific culture's commitment to this historical vision tends to trump its professions of value neutrality, and it is this rhetorical problem that accounts for the abiding patterns of ethical equivocation I have outlined already.

BIG SCIENCE'S BIG GUN

The warfare narrative has unmistakable antecedents in the writings of the French *philosophes* of the eighteenth century.[6] However, it was not until the advent of what Derek de Solla Price has called "big science" in the nineteenth century that it became a staple of science's public profile.[7] This suggests that its foregrounding had something to do with the vital rhetorical challenge I have already outlined.

We now take for granted that universities are the primary sponsors of science, but this had not been the case in the period of small science. Many who practiced science in that era had ties to higher education, but scientific research was unlikely to be part of their job description. Many others were amateur virtuosi like Robert Boyle, Joseph Priestley, Benjamin Franklin, and Charles Darwin, persons of independent means making independent contributions to science. With the exception of a few astronomers, chemists, and mathematicians, those fortunate enough to hold university positions were likely to teach subjects like theology and philosophy by day and to pursue their scientific interests only by night. By the middle of the nineteenth century the pressures created by the growing cost and complexity of scientific research had rendered this model obsolete. This demanded a larger scientific workforce with more specialized training and monetary support, and this challenge could be met only if the whole infrastructure of higher education was reformulated along scientific lines.

Along with this came growing pressure to challenge a teaching mission that traditionally had a humanistic and religious orientation. The institutional pressures created by science's exploding needs could not be addressed merely by making more space for science. Such a solution would have left higher education in the hands of ecclesiastical overseers and scientists without sufficient power to manage their own destiny. In the nineteenth century, a different sort of Copernican revolution was needed, one that would surrender to science the stable position at the center of all learning that the church had traditionally enjoyed. In the Middle Ages all subjects and even science moved in a religious orbit. Those fields of study closest to the center of this intellectual cosmos were those most relevant to faith, and for a faith so fundamentally hermeneutical as Christianity, it is not surprising that the language arts had long occupied its habitable zone. Philosophy moved within an inner orbit as well since it lent its analytical rigors to an ever-expanding set of theological problems. But science could never be much more than a dwarf planet within this theology-centered universe; only a reordering of this cosmos around a new gravitational center could give it position.

The first effort at institutional reform of this kind came in revolutionary France at the end of the eighteenth century with the creation of the École Polytechnique, the first university devoted wholly to scientific and technological pursuits.[8] But it was in Germany that this model blossomed. The autocratic leaders of the states drawn loosely together in 1815 as the German Confederation were strongly motivated and more at liberty to institute such reforms. The German aristocracy recognized that a greater investment in science and engineering might enable their emerging nation-state to gain ground on France and England, Europe's traditional superpowers, and it had a free hand to impose scientific reforms from the top down. In England, by contrast, where the central government was weaker and less motivated to see science as key to its own competitive interests, the push for such educational reforms came from the bottom up.[9] In a democracy, extraordinary institutional problems are more likely to give rise to similarly extraordinary feats of rhetorical creativity, and thus it was both here and in the United States that the warfare narrative came into play as an important rationale for change.[10]

The rise of the warfare mythology was made indispensable by the fact that science's success depended on the assumption that it was the rightful heir to a throne of learning falsely usurped by religion. By calling this myth, I do not mean that the episodes of conflict it invokes are merely unhistorical, though any comparison of such tales with scholarly histories is likely to reveal persistent errors and fabrications.[11] I mean that the warfare theme has foundational significance for the scientific culture. As tales inspired by an imagination bent on undermining a religious conception of education, they also needed to essentialize such conflicts as ones expressing a fundamental moral dialectic. These tales do this by putting science on one side of history as the great champion of Progress and religion on the other as its great antagonist, the root of all things regressive. This polarity sets up a consistent and enduring formula for decoding history in ways favorable to science's ascent.

It is notable in this regard that the British biologist Thomas Henry Huxley was at once the foremost leader of the campaign to establish science in England's universities and also that country's foremost promulgator of the warfare narrative. One of his first renderings of the narrative appeared early in 1860 in a review of *Origin of Species* penned for the radical weekly, the *Westminster Review*. That Huxley would choose a political outlet for a scientific book review is itself telling, and we begin to see why in his opening volley against the opponents of Darwin's thesis.

> Everybody has read Mr. Darwin's book, or, at least, has given an opinion upon its merits or demerits; pietists, whether lay or ecclesiastic, decry it with the mild railing which sounds so charitable; bigots denounce it with ignorant invective; old ladies of both sexes consider it a decidedly dangerous book, and even savants, who have no better mud to throw, quote antiquated writers to show that its author is no better than an ape himself; while every philosophical thinker hails it as a veritable Whitworth gun in the armoury of liberalism; and all competent naturalists and physiologists, whatever their opinions as to the ultimate fate of the doctrines put forth, acknowledge that the work in which they are embodied is a solid contribution to knowledge and inaugurates a new epoch in natural history.[12]

The historical fidelity of what Huxley depicts is now so widely assumed that we would hardly think to question it. But while there can be little doubt that *Origin* encountered much resistance, Huxley's clean breakdown simplifies beyond reason the complexity of this reception. When he puts bigots, religionists (pietists), and humanists (savants) all on one side, and on the other "every philosophical thinker" ("philosopher" being Huxley's preferred name for scientists) along with "all competent naturalists and physiologists," he imposes a neat polarity that was unimaginable at the time. Those who accepted Darwin's account, as any historian of the period would know full well, were as likely to be religionists as not, and those who attacked it were just as likely as not to be scientists.[13]

The complexity of this response is especially visible in the famous debate Huxley was drawn into later that year with Bishop Samuel Wilberforce at the annual meeting of the British Association for the Advancement of Science in Oxford—an event that was itself destined to become part of this warfare mythology. Wilberforce undoubtedly had religious motivations since his opposition to the naturalistic slant of Darwin's book paralleled his efforts to turn back a rising liberal tide among the Anglican clergy. But he did not enter this debate to refute Darwinism on religious grounds, and just as certainly not as an advocate for special creation. He spoke, in fact, on behalf of a scientific perspective, one that came from Richard Owen, who then happened to be England's leading naturalist. Owen's take on natural history, though generally theistic, was no less evolutionary than Darwin's.[14] Thus, what we find in this famed encounter, once we strip away its various legendary accretions, is a scientific debate. Wilberforce spoke on behalf of what David Livingstone describes as the "considerable scientific opposition to Darwin's proposals" that was characteristic of this period.[15]

So why the false polarity in Huxley's review? This makes sense once we recognize what he had to gain by maligning the reigning institutional culture. Clergy like Wilberforce and scientific leaders like Owen represented this establishment, and if Huxley was to have any hope of rallying a new coalition of scientific patrons from the emerging industrial class and from England's political left, he needed a compelling narrative. This was the symbolic attraction of Darwin's thesis. Because it seemed to say that the unlimited reach of scientific naturalism had been shown by Darwin's discovery, anyone who did not now subscribe to naturalism was automatically science's enemy. This meant, more or less by definition, that the current governors of the university were incapable of providing an institutional home for science. What science needed instead was an institutional framework created in its own image, and this is the clear inspiration behind Huxley's alignment of Darwin's thesis with industrialism as "a veritable Whitworth gun in the armoury of liberalism." In the technological genius of the industrialist Sir Joseph Whitworth, scientific naturalism found its worldly reflection, and industry was the natural ally of the liberalism that was everywhere loosing the bonds of traditional authority. Just as Whitworth's new twelve-pound, breech-loading artillery was preserving England's empire abroad and secular liberalism was raising it to new greatness at home, scientific naturalism was the new spiritual power destined to infuse this energy into Great Britain's universities.

The reader who first encounters the strident language of this opening passage and then goes on to read the body of Huxley's review will be surprised to discover just how tepid his support for Darwin is—coming as it does from one known to us as "Darwin's bulldog."[16] What then had he meant the previous fall when he famously assured Darwin that he was sharpening his "claws and beak in readiness" against the elder scientist's enemies?[17] The various historians who have considered this paradox seem to agree with Frank Turner's assessment that the "immediate social implications of the acceptance of evolution were more important to Huxley than agreement about the mechanism."[18] What he wanted above all from Darwin's theory was the naturalism it symbolized. Huxley was never convinced that Darwin's mechanism could do explanatory justice to the problem of evolution, but the naturalistic posture it represented gave him an inexhaustible supply of ammunition with which to shell the Anglican establishment.[19]

We might say that Huxley's depiction of a uniform religious opposition to science advances a metaphysical posture (naturalism) that was pivotal for sustaining an ideological posture (scientism) that could in turn rationalize the recreation of higher education in science's image. Once philosophical naturalism was presumed necessary for scientific advancement, it followed necessarily that social structures resistant to it, like those associated with religion, were learning's enemies.

When he returns to the science-religion question some thirty pages into this review, Huxley sustains this polarity by invoking a version of the positivist philosophy of historical Progress that Auguste Comte had recently brought into vogue among English freethinkers. In the distant past, Huxley explains, humans did not regard themselves naturalistically as members "of the same system and subject to the same laws," but "the question of their origin, their causal connexion, that is, with the other phænomena of the universe" was certain to arise. Because "positive knowledge was not to be had," this curiosity was channeled into religious myths that "embalmed for us the speculations upon the origin of living beings" of prescientific societies. Religion was merely science at an immature stage of development and was now being made obsolete by the advancement of positive knowledge.[20] Therefore those who stubbornly cling to orthodoxy, as Huxley expresses this in the next passage, also commit a sin against history.

> The myths of Paganism are as dead as Osiris or Zeus, and the man who should revive them, in opposition to the knowledge of our time, would be justly laughed to scorn; but the coeval imaginations current among the rude inhabitants of Palestine, recorded by writers whose very name and age are admitted by every scholar to be unknown, have unfortunately not yet shared their fate, but, even at this day, are regarded by nine-tenths of the civilised world as the authoritative standard of fact and the criterion of the justice of scientific conclusions, in all that relates to the origin of things, and, among them, of species. In this nineteenth century, as at the dawn of modern physical science, the cosmogony of the semi-barbarous

> Hebrew is the incubus of the philosopher and the opprobrium of the orthodox. Who shall number the patient and earnest seekers after truth, from the days of Galileo until now, whose lives have been embittered and their good name blasted by the mistaken zeal of Bibliolaters? Who shall count the host of weaker men whose sense of truth has been destroyed in the effort to harmonise impossibilities—whose life has been wasted in the attempt to force the generous new wine of Science into the old bottles of Judaism, compelled by the outcry of the same strong party?[21]

Having already represented religion as pseudoscience, Huxley has also stacked the deck against every objection to naturalistic evolution: those who might object on religious grounds are treated as false scientists, and those who might object on scientific grounds are treated as antiquated religionists. Heads you lose; tails I win.

This was vital to Huxley's campaign against clerical administrators. If every expression of religious thought represented false science, religion was an intrinsic threat to science, and all those educational institutions allied with it were therefore part of the same conspiracy to hold science back. But the reasonableness of such an argument also depended on believing that religious opposition to science had been the characteristic pattern in history. This explains why Huxley's summarization of the past relations of religion and science in his next triumphal passage, despite its subsequent immortalization in *Bartlett's Familiar Quotations*, is so impossibly unhistorical.

> It is true that if philosophers have suffered, their cause has been amply avenged. Extinguished theologians lie about the cradle of every science as the strangled snakes beside that of Hercules; and history records that whenever science and orthodoxy have been fairly opposed, the latter has been forced to retire from the lists, bleeding and crushed if not annihilated; scotched, if not slain.[22]

One could certainly accuse orthodoxy of being insufficiently attentive to science in the past and even of interfering with it on a few notable occasions, but Huxley's claim that it was bent upon the death of "every science" has no historical basis. However, this polarity makes sense once we interject an a priori positivism that presumes that the religious motive and the scientific motive are the same. In such a world religious belief, even if it did not object to scientific claims, would have a competitive meaning and a motive like Hera's jealousy against the offspring of Zeus' lovers.

The warfare narrative in this regard is a form of *petitio principii*: the positivist conclusion it seeks to demonstrate has already predetermined the meaning of the historical data it offers as evidence. Those drawn into its circular logic are unlikely to know that the Catholic Church, from the time of Augustine on down, had regarded neither scientific claims as theological nor theological ones as scientific. Nor had it insisted, in general rule, that scientific understanding needed to conform to the descriptions of nature found in scripture.[23] It is only our willingness to believe that the exceptional case of Galileo is the rule that could make a generalized state of conflict plausible. But even then we could sustain this belief only by overlooking vital historical details. The seventeenth-century church certainly did deviate from its own hermeneutical traditions when it commanded Galileo not to contradict various scriptures depicting a stationary earth, but what the warfare narratives consistently omit is the fact that the church did so with the approval of what people now like to call an "overwhelming scientific consensus." The seventeenth-century church stood with an Aristotelian natural philosophy that had been in ascendance for five hundred years, and that still represented the majority opinion. Thus what hovered above the cradle of Copernican science, as Giorgio de Santillana (a self-proclaimed "scientific rationalist") showed long ago, was not superstition but science itself. It was an Aristotelian majority that wished to murder the infant theory in its crib.[24]

THE ETHICS OF EQUIVOCATION

In our time the warfare narrative no longer has credibility for historians, but it remains as ubiquitous as ever. Its dramatic appeal undoubtedly accounts for this in part, as does the fact that scientists, who spend their college years submersed in highly specialized courses of study, gain little exposure to their own history. But while historical naïveté may enable scientists to repeat such tales without pangs of conscience, this does not account for the consistent themes that run through them. We would expect mere historical misunderstanding to produce a random variety of divergent stories, but the various themes that are voiced in these narratives seem to converge into something more like a unified mythology. Since it was an ideological motive that gave birth to this narrative, it seems likely that something similar keeps it alive, and undoubtedly this has something to do with the 1.1 trillion dollars that science needs to bring in each year to keep up its work.[25]

In a world as dependent upon science as ours, it would be imprudent to dismiss the public advocacy that keeps it afloat. My concern is that these efforts also promulgate a fundamental ethical confusion that passes uncritically into the public consciousness. The warfare narrative rests the authority of science upon the claim that it exercises a kind of disciplined rationality that bars the prejudicial influence of value from its inquiries. But in various ways it advances the inverse of this as well by suggesting that it is science's very neutrality that makes it so especially virtuous. That the narrative would turn upon such an equivocation is explained by the historical circumstances in which it arose, but the ethical confusion it sustains becomes more dangerous as science grows more powerful. It invites publics to let down their guard whenever scientific knowledge bears upon questions of the good. Political actors who have come to presume the moral neutrality of science will not be disposed to notice when it betrays this pledge. Moreover, having grown uncritical of the easy conflation of science with Progress, publics that must wrestle with the policy implications of science are likely to presume that difficult ethical challenges can be overcome merely through additional scientific discovery.

A closer look at the habits of thought sustained by the warfare narrative will show why this danger arises. Equivocation in its simplest verbal form occurs whenever the sense given to a term at one juncture of an argument shifts in some significant and especially contradictory way at another. In the case at hand, this occurs when scientific language that is used at one moment to express a value-neutral meaning is used at others in a value-laden sense. When this inconsistency is overlooked, audiences are disposed to think they are getting a value-neutral meaning simply because that is what they have been led to suppose and what they have come to expect from science. This, in fact, is an overt message of the warfare narrative. It accents the special truth-seeking power that science gains from its ethical neutrality by contrasting it with religion's ethical commitments. Religion, in this regard, plays the part of foil. However, what the reader may miss is the fact that this contrast also sustains an underlying identification. To contrast science with religion as the superior avenue to natural understanding is to insinuate that both endeavors have the same goal, and if this says that religion is a kind of failed science, it just as surely says that science is a better religion. This is the flip side of what we have seen already in the case of Huxley. When he depicts science as forever beating back the weaker assertions of faith, he is also asking his readers to assume that science and religion are competing for mastery of some common ground of knowledge, and this in turn implies that the questions of value raised by religion find their answers in science—something that Huxley openly asserted throughout his public career.[26]

In typical accounts of the persecution of Galileo, this pattern of equivocation is often recognizable in a back-and-forth shift between descriptive and evaluative meanings of the term *center*. The church's belief in earth's centrality is represented as a scientific claim derived from some combination of revelation and scholastic philosophy, and uncritically adhered to because it upheld the "central" value of human beings in God's universe. By collapsing these qualitatively distinct senses of centrality, the stories depict science as triumphing over religion, but the verbal equivocation also assigns to science an authority similar to that of faith. To illustrate this danger we might take a quick look at how this pattern manifested itself in a recent opinion piece written by a biologist for my local newspaper. The author's subject is exoplanetary research and the expectation that astronomers will one day find life on some other planet. The main point he wished to advance was that such discoveries are likely to trouble the general public because they, like the opponents of Copernicus and Galileo before them, harbor values that cannot withstand the onslaught of material fact.

> Many consider Earth to be a privileged planet, singularly unique in all the cosmos. The idea that our tiny home planet was somehow the very center of the universe took a big hit in 1543 when Nicolaus Copernicus demonstrated that Earth was just like the other planets. It, too, slowly circles our sun in an orderly and regular journey that we call a year. It would take nearly 150 years for most people to accept that the sun, and not the Earth, lay at the center of our corner of the universe. The astronomer Galileo nearly paid with his life in his defense of this truth. Since then, most of us have been content in the belief that it was our sun, and our planet, that were chosen to be the cradle of life. Yet here in the 21st century, we must now come to terms with another sobering realization. We are almost certainly not alone.[27]

The author's logical equivocation is apparent in his claim that the earth's "privileged" value suffered a devastating blow once it was "demonstrated" that the earth was not the "center" of the natural universe. A metaphorical sense of "centrality" expressing value has been conflated with the merely geometrical sense of that term—"centrality" as denoting a body's position in space.

This error will become more apparent if we look at a different example. For instance, no one would take the statement that "in the 1980s Silicon Valley became the *center* of technological innovation in America" to mean that Silicon Valley is a place round about Lebanon, Kansas—the geographical *center* of the United States. The equivocation is more obvious in this second example simply because it is not backed by a larger story that sustains the same confusion. Once we believe that the church held out against what Copernicus had already "demonstrated" for 150 years and that it added injury to insult by threatening Galileo's life, a powerful antiscientific motive is put in play that must be explained. Its supposed attribution of value to the earth's "central" position seem to offer an explanation: the church could have only acted in such a repressive fashion because it knew that the success of Copernican science would undermine its own authority to speak to such questions.

It is doubtful whether this was in fact the motive force behind the church's reaction to Galileo, but let us assume that it was.[28] If the church opposed Galileo because it supposed that the special value that revelation assigned to human nature was predicated upon the earth's central position in space, we can see why the episode might be instructive. It could effectively illustrate the dangers that arise when value assumptions intrude upon scientific thinking. But this benefit is cancelled out whenever readers are also led to suppose the inverse of this—that being attuned to scientific truth will also ensure that our moral reasoning is sound.

SOME CONCLUDING THOUGHTS

This ethical temptation is not fostered just by these warfare narratives. It also manifests, I would surmise, in the abiding patterns of public reasoning they promote and sustain. Without ever saying overtly that scientific knowledge offers a grounding for moral knowledge, these stories reiterate this premise in every telling, and consumers of such discourses, since they have no better chance than these scientific authors of recognizing the verbal slippage that sustains this, will simply fall into the uncritical habits of mind these stories model.

Of course there are many who do believe that *is* and *ought* mean the same thing, or that *ought* is just another name for *is* when it is caught up in some spell of emotion. The concentration of those who think this way is likely to be greater in the scientific community since it has so much to gain by universalizing its own naturalistic framework. Like others committed to democratic principles, I believe that people should be free to work out their own philosophical convictions. But the problem I outlined at the onset of this exploration introduces an important complication. Public debates turn upon questions of value as much as upon facts and definitions, and this means that, to be intelligently undertaken, arguments about value need to be openly aired.

What I have argued here is that many scientific actors encourage us to close off such inquiry. A scientific culture that first gained much of its modern wealth and influence by casting a positivist spell upon the world is unlikely to retreat from this rhetorical habit since it always holds forth the promise of high dividends. This also means that the enormous respect that those of us on the outside have for science will incline us to internalize this point of view. When we come to believe that the history of science has meant the progressive triumph of fact-based scientific truths over various faith-based religious ones that also happen to inform human conceptions of value, we are confronted by two choices. We can either regard science as the true source of ethical knowledge, as many of these stories insinuate, or we can regard science as the great destroyer of all value claims.

The latter option is unlikely to gain general popularity, but the former one is enticing and has set its notable imprint upon many public debates. The debate over abortion is an interesting case in point because some of its patterns suggest that even those most inclined to consciously derive their ethics from religious traditions succumb to the same temptation. Those opposed to abortion on religious grounds are likely to hold that their belief in the sanctity of human life is backed by doctrinal bases as well as by the dictates of conscience and that this value supersedes the good of personal autonomy put forward by those who might choose to terminate the life of a fetus. But they seem just as willing as others to jump ship by deferring to science in public debates. Here they are more likely to engage the related question of when a fetus becomes a human being, seemingly on the assumption that this is a question that can be answered by a scientific understanding of gestation. We might expect the religiously inclined to be the first to see that it is a dead end to argue that personhood can be established by knowing when fetuses become viable outside the womb, when they can experience pain, or can suck their thumbs. The fact that they do not see this bears witness to an extraordinary willingness to suppose that scientific knowledge can found ethical judgment.

If religionists who otherwise hold that conscience bears independent witness to the good nevertheless fall into this trap, what are we to expect from those who actively reject such traditional notions of ethical knowledge? In matters of public life that bear upon scientific knowledge, we would expect scientism to have even greater influence. This seemed to be the direction Al Gore was heading in 2007 when he summarized the message of *An Inconvenient Truth* by saying that climate change is “not a political issue; it’s a moral issue. We have everything we need to get started, with the possible exception of the will to act."[29] I take this as saying that the scientific case for anthropogenic climate change, the sole subject of his celebrated documentary, is now so compelling that there is nothing left for political debate to decide. The only choice left is a moral one, to act or not to act. Of course I agree with Gore in a narrow sense: it does seem clear that we are destroying our environment, and this does oblige us to act. But while knowing how to act rightly may begin with science, it ends with public deliberation. Only the latter can enable us to discern how our sense of the good can be reasonably and justly put into effect. Gore's utterance seems to say that climate science has already decided this and that additional deliberation is not necessary once we have heard its testimony. Such an assumption is likely to tempt us to attack environmental problems blindly without consideration of the many human problems upon which they bear. Policies predicated on Gore's dictum would seem bent on arresting carbon emissions at all costs without consideration of whether this would also exacerbate volatile international tensions, global starvation, and an already polarized distribution of wealth.

This bespeaks a pattern of scientism that has been around now for several centuries and that occasionally erupts within public life in notable ways. Perhaps the most notorious example in our own history was the eugenics movement, which, at its peak in the 1920s and 1930s, convinced several state legislatures to pass the laws that eventually led to the compulsory sterilization of an estimated sixty thousand Americans. Anyone who has ever glanced at the scientific literature that sustained this is likely to be struck by the strong moral convictions that permeate it. Harry Hamilton Laughlin, the cytologist whose book *Eugenical Sterilization in the United States* drove this legislative initiative, insisted that government regulation of reproduction was an unassailable good because it derived from an equally unassailable scientific truth. Because such judgments turned upon a "biological standard," the eugenicists were "now able to prove to the scientific world, to legislatures and to the courts of the land that by the application of certain pedigree principles to the pedigree findings in a particular case, it is possible to determine the hereditary potentialities of a given individual, and thus to demonstrate the eugenical menace of a given person."[30] The willingness of so many state legislatures to follow this leap from is to ought suggests to me a public that had been thoroughly prepared by many decades of scientistic rhetoric to take for granted that the morally true is identical with the biologically true.

Those who look back upon this episode now are likely to account for it mostly by drawing to mind the ingrained prejudices of that time. In hindsight it is much easier to recognize how the abiding racism of the era and a xenophobia fanned into flame by an influx of Southern and Eastern European immigrants intruded into scientific reasoning. What we are much less likely to notice is the naturalistic moralizing that persists now under different headings. None of us would now say that genetics can tell us who is or is not a public "menace," but we hardly bat an eye when scientists claim that the evil of "speciesism" is demonstrated by evolutionary science, when they invoke common biological ancestry as grounds for animal "rights," or claim, as one official publication of the National Academy of Sciences does, that teaching biological evolution will encourage our children to "see change as an agent of opportunity rather than a threat."[31]

4

IS THERE A HUMAN NATURE?

An Argument against Modern Excarnation

Jean Bethke Elshtain

Utopian dreams die hard, this despite the brutal debacles of the twentieth century, undertaken in the sure and certain promise that an earthly utopian order was available to us if we were dedicated and ruthless enough to do what was necessary to achieve it. The totalitarian impulse lies behind utopian visions—this impulse does not exhaust what utopian dreams are all about, but we dare not ignore that an impulse to achieve total control is a major part of the legacy of utopian dreams.

If, at one point, the utopian ideal was a total transformation of human nature, we now live in an era when we are loath to concede that we have natures at all; we do well to take stock. We have lurched over time from one determinism to another. Biological determinists insisted we were what we were because biology made it so. (The so-called nature side of the by-now-antiquated and tedious nature-nurture argument.) Social determinists insisted that economics or politics or sociology or some combination made us who and what we are. It is the latter view—the more social determinist view—that took hold in the social sciences, so much so that sociologist Dennis Wrong in the 1970s penned a piece arguing against the "oversocialized" concept of human beings in the social sciences.[1]

At present we face an odd combination of positions. We are in the throes of a form of genetic obsession that can best be called genetic fundamentalism. As the controllers in the 1997 film *Gattaca* put it, "Genes tell all." (Or "cells tell all.") At the same time, there are those who see human bodies as raw material to be manipulated every which way. We do not really have a "nature," so there is no problem with this ethically. The only frustration is a practical one: how do we get as quickly as possible to full control over what sorts of entities we wish to be?

In my most recent book, *Sovereignty: God, State, and Self*, I develop the theme of modern *excarnation*, a concern for philosopher Charles Taylor as well in his masterful work *A Secular Age*.[2] I first encountered notions of disincarnation, of disembodiment, in Albert Camus' essay *The Rebel*, in which he notes that the French revolutionaries, in the name of entirely abstract ideas, slaughtered the bodies of those who did not fit into the new order with a specific, gruesome form of death—decapitation—if only because they harbored internal doubts about the course of the revolution.[3] Because the revolutionaries saw themselves as creating a brand new world, they decided the king must be beheaded as well. In beheading the king, they aimed explicitly to sever the link between a corporal being and the incorporeal world of transcendence.

As a result of this violent act, Camus suggests we now face only an "empty sky—it is no longer 'peopled.' I note that in 'snapping the connection between the transcendent and the earthly,' two things were accomplished. First, the transcendent becomes remote, gauzy, dematerialized, a vague gnosticism . . . presentist and based on a particular manifestation of the self. Second, the immanentist strand, rather than emerging chastened from the experience of 'revolutionary virtue' and less tempted toward sovereign excess and grandiosity, goes in the other direction and sacralizes a finite set of temporal arrangements"—this in reference to the French Revolution.[4]

De-peopling us seems to be a futurist fantasy. When I note some of the bizarre scenarios, it puts me in mind of Gnosticism, an earlier flight from the messiness of human embodiment into the realm of pure spirit. St. Augustine locked horns with the Manicheans—radical dualists who fueled Gnosticism—in large part because they could not come up with a satisfactory way of thinking about evil. This was tied to their view that earthy "matter," the stuff of bodies, was polluted. Only mind, spirit, was pure. It was unfortunate, in this view, that our brains required a body in order to survive. Here it is fascinating that cryogenics—a kind of holding pattern until new means are devised—is a way many transhumanists "plan to have their bodies frozen at death until future science finds a way to revive them. Or, rather, manufacture a new body for them and then revive them—it is not common knowledge that . . . many people do not have their entire bodies frozen, but only their severed heads," writes Christopher Beiting.[5]

Evidently this form of what I will call "Cartesian decapitation" is entirely fine for transhumanist publicists, as future science will surely produce nonhuman bodies in the future. A severed head could then be added, and Steve or Joe or whoever will have a new lease on life, albeit without a human body as we know it. Why "Cartesian decapitation"? Anyone passingly familiar with Descartes' insistence that the "extended" part of the self is inessential to who and what we are, that all that matters is the brain or consciousness, understands. This is a perfect monument to latent Gnosticism.

We are enchanted as a society with the possibility of perfecting our bodies so that they gleam, bedazzle. A tiny minority, overwhelmingly male—and I will say more about that—wants to eliminate the human body as we now recognize it altogether. We will, according to posthumanist Princeton biologist Lee Silver, "change the nature of our species."[6] Humans are presented as plastic men and women, subject to manipulation and ultimate perfection, whether through the genetic route or through fusing what are now called human beings with machines, uploading our consciousness to übercomputers so that "we" or some sort of something of us lives forever. With digital uploading, cybersex, cryogenics, eliminating death, and so on in mind, philosopher Beiting comments, "At their core, these ideas represent a deep-rooted hatred of nature, and in particular a *masculine* hatred of certain aspects of nature, such as femininity, fertility, and natural reproduction."[7]

In general, I tend not to sociologically and historically situate thinkers before analyzing their thoughts, but in the case of trans- and posthumanism it is important to pay a bit of attention to gender specifically, for the phenomenon is overwhelmingly male, upper middle class, and white. Fascinating. What is this all about? Let me turn, first, to masculine rejection of the feminine, an ancient theme that pops up in a new guise in every generation. In my first book, *Public Man, Private Woman: Women in Social and Political Thought*, I speculated about men not being able to tolerate the "feminine" part of themselves and going on to try to create permanent structures, "births" of a sort, independent of the female. Thus, women could not be citizens in the *polis*. It was an all-male realm dominated by a homoerotic ethos: women were inessential. And, indeed, that is how the *oikos*, or household, was viewed. It was necessary to generate a base for the *polis*, if you will, but women, children, slaves, the entire world of the household could never be an essential part of that world.

I argued that women were silent to that public world because that which "defines them and to which they are inescapably linked—sexuality, natality, the human body (images of uncleanness and taboo, visions of dependence, helplessness, vulnerability)—was omitted from political speech. Why?

Because politics is in part an elaborate defense against the tug of the private, against the lure of the familial, against evocations of nature and transcendence beyond our ability to control utterly. The question to be put, then, is not just what politics is for but what politics has served to defend against."[8]

I worried at the time I wrote that early book that perhaps I was overstating my case. Culling a few themes from contemporary transhumanism tells me that I was not. This is modern excarnation of the most extreme sort. It is our era's version of generating a new type of human being who will not be human at all, finally. The twentieth-century totalitarians aimed to generate new races of human beings: *homo sovieticus*, the Übermensch of Nazi ideology, even some versions of hard-core secularism that had abandoned "religious superstition" in democratic Western societies flirted with such notions. We could create human beings who were narrowly and exclusively rational. It is interesting that "women" always emerge as a bit of a problem in such visions; they are too defined by embodiment, too wedded to particular ties and attachments, especially to their own children, and so on. So it is not surprising that the contemporary advocates of excarnation should be demographically male (overwhelmingly so) and relatively privileged. The privileged have also been those who could arrange their lives so that they were in less contact with "dirt," so to speak. Others cook, clean, care for children, and so on.

Christianity is also a problem for the "brand new man" idea. Historically, Christianity lifted up images of the feminine through veneration of the Holy Mother. Christianity is an exquisitely incarnational faith: God taking human form, dying a human death on a cross, raised again in recognizably human form. You do not have Christianity if you do not have that. You have a form of sentimentalism and "niceness," but not Christianity. Small wonder Ralph Waldo Emerson, who searched for a "new man" as well, said that communion would be acceptable to him if you did away with the elements—the physical embodiments of the body and blood, the bread and the wine.

Futurists see a couple of ways to proceed in order to escape what "is," including our embodied natures. There is the notion of genetic perfection with germ line interventions that permanently alter genetic structures, pushing us in the direction of perfection (allegedly). This will, of course, be done under a society's view of what is the normatively preferable sort of human being. We already have some idea of what that is. Designer genes will perfect what careful breeding now tries to accomplish. Consider an advertisement that appeared throughout the United States in college newspapers a few years back. It read as follows: "Egg Donor Needed, Large Financial

Incentive. Intelligent, Athletic. You Must Be At Least 5'10". Have a 1400+ SAT Score. Possess No Major Family Medical Issues. $50,000." As a short, slightly overweight African American woman said to me following one of my lectures on such matters, "Somehow I don't think I'll be the normative ideal of human perfection." Nor I, I should add. Too short, among other things. Myopic, too. The list goes on, but it would be an exercise in masochism for me to spell out more!

Commonweal noted at the time that these advertisements brought back eerie reminders of earlier notices that involved trade in human flesh and suggested that "we are fast returning to a world where persons carry a price tag, and where the cash value of some persons . . . is far greater than that of others."[9] The genetic perfectionist advocates simply assume this, as genetic fantasies of wholesale rejuvenation have moved about as far away as possible from the guiding spirit of medicine—Do No Harm—to the notion of genetic enhancement as the genetic equivalent of cosmetic surgery, and this, in turn, reinforces certain societal prejudices about which bodies are desirable, which are not.

At least there are still bodies. With the transhumanist ideology, the human body is distorted beyond recognition. Critics have pointed out that many in the medical and scientific communities—actual practitioners—display "a salutary caution towards the possibilities of the new biotechnology" but "not everyone behaves in a normal fashion, and there are groups out there that . . . rush forward to . . . push it to its extremes," notes Beiting.[10] The guiding motive is to overcome *all* limits of any kind. We can gain perfect control over our bodies, we can efface the distinction between man and machine, we can make everybody a genius—that means in practice, of course, that no one is. We can redesign ourselves. (Here thoughts of poor Icarus flying too close to the sun and Greek warnings of human hubris leap to mind.) Some visions are "human" only in a rather technical sense as they bear no resemblance whatsoever to what we understand as human.

What is also fascinating is just how upbeat everyone is about knocking down all barriers. Optimism reigns. No "downside" is noted, no unintended consequences acknowledged. There is a striking naïveté that runs through these visions. The warnings about purposely setting out to redesign human nature that come from the history of the twentieth century are nowhere to be found. Why? Well, for one thing, because all of these marvels will be realized under the rubric of freedom, choice, a determined libertarianism. If everything takes place in this way, what could possibly be wrong about creating more perfect bodies or human beings, we are told—and often by so-called bioethicists, who are so closely entangled with what they are supposed to be thinking ethically about that they issue rationalized permission slips for the gen-tech industry at a rapid clip. (Not all ethicists, of course, but way too many.)

In his book *Between Science and Religion*, Phillip M. Thompson writes of a bio-industrial complex—perhaps "bio-tech industrial" would be better—consisting of corporations, the academy, government, and, yes, many bioethicists, which garners huge sums of money and is largely supported by the elite media, themselves gulled into notions of no limits and perfection.[11] These projects are very difficult to get at ethically because they present themselves to us in the primary language of our culture—freedom, choice, consent, control. Choice trumps all else. As a case in point, consider the abortion debate. The proabortion advocates have succeeded in wrapping themselves in the mantle of freedom fighting against the forces of domination, control, and a determination to erode women's "right to choose." The prolife side fights an upstream battle because the language of individualism is so enormously successful that people will describe even the good, selfless things they are doing in that rhetoric: they simply do not know any other way to talk.

Transhumanists and the genetic perfectionists are not entirely of a piece because many transhumanists, or posthumanists, find the notion that we are a natural species and that there are laws of evolution to which we are subject, anathema. We are supposed to make our own evolution. This upbeat stance is also maintained by genetic fundamentalists despite the fact that every promised "cure" or therapy promised by gene therapy has thus far failed to materialize as promised and the many trials using gene therapy have been disastrous, leading to a worsening of a patient's condition and, in some cases, death. It is not as easy as it seems, apparently, but this is rarely acknowledged. For transhumanists, not only is there a flight from the body we now possess and know, there is a flight from the earth, from terra firma itself, into the realms of space. (The assumption, apparently, is that we can reengineer human beings by adding "fur or a thickened skin, redesign[ing] the lungs, and create homo martianus.")[12]

So: perfect control over body, over mind, a future of unlimited growth, blasting away all superstition, especially religion, and so on. We have heard all this before, of course, or variants of this theme. The fact that there has never been such a thing—ever—as a spontaneously self-governing society means that a new type of hyper-rationalized human being cannot be expected to be such: does it not? At any rate, what life with others would be like does not seem to be a big concern. A form of solipsism lies at the heart of these flights of fancy. There are all sorts of slogans of the sort we frequently encounter nowadays about being nice and not harming people and that sort of thing. But the heart of it, the thing that leaps out at you and is profoundly disturbing, is in Beiting's words, the "hatred of the real, of life as it is."

In trying to get a handle on transhumanism, I was put in mind of 1970s radical feminism, with some of the voices of that genre proposing to reduce the number of males in the overall population to 10 percent—just to provide sperm—as males are inherently violent. Or replacing human birth with test-tube reproduction. Or a "cybernetic revolution" that, voila, as one radical feminist put it, would be upon us—it would just be spontaneous—and all would be well. The vision of the male was unforgiving and unrelenting in its harshness with these writers. Here is one vision of man: he is an "obsolete life form. He is an anachronism in this technological context. His muscles are no longer needed. The built-in obsolescence of his physical and emotional nature is now apparent. . . . He is being phased out by technology. Sperm banks and test-tube babies can take over his last function, his only function that has positive effects for the human race." Nasty stuff. Man must give up his life-form, either voluntarily or by force, one radical feminist opined; otherwise, there would be "no moral progress on the planet."[13]

It does not take much imagination to substitute "blacks" or "Jews" or some other group, change the wording a bit, and one has a rationale for "phasing" them out. I mention this radical feminist attack on men—men as beings in the world—in part to indicate that loathing of "the other" and a complete inability to tolerate difference at the most basic level, male and female, is not an exclusive male preserve. There are some who are "with it," who are carriers of the new society, the new norms, the new ways, and others who simply stand in the way—whether women or men, Jews or racial minorities, on and on over the course of human history. No more than the transhumanists did the radical feminists know "evil"—appreciate that no one is exempt from the sins of pride, of resentment, of idolatry, by which I mean making an idol of an idealized version of the self, including the self-to-be that will be "me." It is always the others "out there" who stand in the way. One of the first moves made by radical feminist thinkers was to disparage ordinary human bodies, of men and women alike, to express loathing of human sexuality and birth, to think of a world in which bodies really need not touch one another, not if they are male and female respectively.

I see a good bit of this sort of attitude at work in the unrealistic fantasizing of transhumanism. Problems of equality, justice, order, freedom just disappear. Problems of scarcity and distribution disappear. All the basic themes of Western political thought are, frankly, ignored, save the strain of utopianism that also runs through Western history—utopianism of a premillennialist sort: the perfect kingdom will be realized here and now. I am reminded of Hannah Arendt's frustrated reaction to many of the scenarios she encountered in the 1960s about how the United States could "win" a nuclear war. One problem, she opined, was that she could never figure out what such a war would be about. All the usual reasons nations go to war were never present. The scenarios themselves seemed to be "the thing" itself: they existed in an abstract world made by those who constructed the scenarios in the first place.

Let me bring these musings to a conclusion in two ways, first by bringing to bear the thoughts of theologian Dietrich Bonhoeffer, the anti-Nazi German theologian who was hanged by the Gestapo in the waning days of World War II for his participation in the July 20 plot to kill Hitler. Bonhoeffer confronted a twentieth-century attempt to remake human nature under the aegis of a bio-politics, biological science enforced by the coercive power of the state. (The Nazis understood their regime as a "bio-political one," and Hitler proclaimed that "reforming the human lifestyle" was his "most important goal.") Second, I draw on Hannah Arendt and her views of human fantasies about escaping the earth, the only fit habitat known to man.

Reflecting on the National Socialist regime's murdering of persons with disabilities and conditions—from cerebral palsy to epilepsy, from the spastic to the child with the cleft palate—Bonhoeffer penned thoughts on "The Natural" in his *Ethics*, left unfinished at his death. Bonhoeffer insists that we enjoy and can enjoy only a "relative freedom" in natural life, but there are "true and . . . mistaken uses of this freedom," and these mark the difference between the "natural and the unnatural." He throws down the gauntlet: "Destruction of the natural means destruction of life." There are various tendencies in the modern world that invite "despair towards natural life" and "a certain hostility to life, tiredness of life and incapacity for life." Our right to bodily life is a natural, not an invented, right, and the basis of all other rights. Harming the body harms the self at its core. "Bodiliness and human life belong inseparably together." For "our bodies are ends in themselves," and this has "very far-reaching consequences for the Christian appraisal of all the problems that have to do with the life of the body, housing, food, clothing, recreation, play and sex."[14] We can use our bodies and those of others well or ill. All lives are worth living before God. For man to determine which lives are worth living and which are not is a sin and a horror—and that was the horror through which Bonhoeffer was then living.

Human freedom is real, yes, but it is limited. For actual freedom is always situated: it is not an abstract position located nowhere in particular. Freedom is concrete, not free-floating. Freedom is, in theologian Robin Lovin's words, "a basic human good. Life without freedom is not something we would choose, no matter how comfortable the material circumstances might be." So freedom involves both avoiding "excessive identification with the surrounding culture" and flights into bizarre unrealities entirely unsuited to finite limited creatures "whose capacities for change are also limited, and who can only bring about new situations that are also themselves particular, local, and contingent."[15] Transhumanism is, above all, a denial of finitude and a flight into a world of self-sovereignty, of mastery. When a bioethicist, Arthur Caplan in this case, opines that so long as there is no coercion and individual choice holds sway, there is nothing wrong with creating more perfect bodies, one marvels at the naïveté. Choice takes place within surroundings that exercise pressure one way or another. The notion of "perfect" is culturally determined, as I noted earlier with the short African American woman—and myself—by contrast to the Barbie dolls which Ph.D.s fantasized about as suitable providers of eggs. To treat "choice" and "perfect" as if these are operative terms and absolutely clear-cut is astonishing at this late date: it is as if we have learned absolutely nothing from our own history.

Finally, to Hannah Arendt in her 1958 Gifford Lectures, published as *The Human Condition*. Perhaps the best thing to do is simply to quote her and leave her words lingering as I bring these reflections to a close. She begins by referring to the first earth-born object to circle the earth—this in 1957. She goes on to note,

> The immediate reaction, expressed on the spur of the moment, was relief about the "first step toward escape from men's imprisonment to the earth.". . . Such feelings have been commonplace for some time. The banality of the statement should not make us overlook how extraordinary in fact it was. . . . Should the emancipation and secularization of the modern age, which began with a turning-away, not necessarily from God, but from a god who was the Father of men in heaven, end with an even more fateful repudiation of an Earth who was the Mother of all living creatures under the sky?

> The earth is the very quintessence of the human condition, and earthly nature, for all we know, may be unique in the universe in providing human beings with a habitat in which they can move and breathe without effort and without artifice. . . . For some time now, a great many scientific endeavors have been directed toward making life also "artificial," toward cutting the last tie through which even man belongs among the children of nature. It is the same desire to escape from imprisonment to the earth that is manifest in the attempt to create life in a test tube, in the desire to mix "frozen germ plasm from people of demonstrated ability under the microscope to produce superior human beings" and "to alter [their] size, shape and function"; and the wish to escape the human condition, I suspect, also underlies the hope to extend man's life-span far beyond the hundred-year limit. This future man, whom the scientists tell us they will produce in no more than a hundred years, seems to be possessed by a rebellion against human existence as it has been given, a free gift from nowhere (secularly speaking), which he wishes to exchange, as it were, for something he has made himself.[16]

She goes on to say that this extraordinary desire, and question, is a "political question of the first order and therefore can hardly be left to the decision of professional scientists or professional politicians."

Who, then, decides? Before one turns to this question, one must acknowledge that politics is at issue in the first place. And this seems not to happen with an alarming degree of regularity.

5

CROSSING FRONTIERS OF SCIENCE

Trespassing into a Godless Space or Fulfilling Our Manifest Destiny?

Leah Ceccarelli

In their introductory essay, the editors of this volume turn our attention to the way President George W. Bush's Council on Bioethics characterized a conflict between science and religion, with the pioneers of biotechnology pushing limits to cross thresholds, while a religiously oriented ethics constrains the Promethean project by asking us to appreciate the giftedness of life as we accept and even celebrate natural limitations. This antithesis between an adventurous science and a restraining religion is a commonplace of contemporary American thought. As Nobel Prize–winning physicist and public intellectual Richard Feynman put it, Western civilization "stands by two great heritages. One is the scientific spirit of adventure—the adventure into the unknown. . . . The other great heritage is Christian ethics—the basis of action on love." In Feynman's opinion, it is unfortunate that we have maintained "one or the other of these consistent heritages in a way which attacks the values of the other," but he knows of no way to avoid the conflict.[1]

In this essay, I analyze the rhetorical contours of this conflict as it takes place around the figure of the "frontier," that ubiquitous metaphor for the limits of knowledge. First, I examine the public discourse of President Bush on stem cell research to illustrate how science and religion are characterized as being in opposition regarding the proper limits of research on the frontiers of science. Then I show that another perspective is available to scientists like Feynman who want to integrate science and religion but who find it difficult to imagine a way of doing so. This alternative perspective is found in the public discourse of genome scientist and National Institutes of

Health director Francis Collins. Recognizing how the relationship between religious tradition and the "frontier of science" is depicted differently in the public discourse of Bush and Collins, we get a better sense for the inventional possibilities available to rhetors today as they speak the language of our biotechnological future. Before undertaking this comparison, though, a short review of the history of the frontier of science metaphor is in order.

THE FRONTIER OF SCIENCE

The English word *frontier*, originating in a European context, has long signified the boundary between one nation and another. In an American context, though, the term has come to take on another meaning, namely "that part of a settled, civilized country which lies next to an unexplored or undeveloped region" or "the developing, often uncivilized or lawless, region of a country."[2] It was from this Americanism that a new metaphoric meaning of the term arose in the twentieth century, allowing us to talk about a "frontier" as an undeveloped intellectual rather than literal space, a not-yet-fully-explored region of knowledge that scientists might enter to make new discoveries.[3]

The entailments of this culturetypal metaphor made it an especially effective rhetorical tool for Americans wanting to justify government funding for scientific research. As early as 1910, Frederick Jackson Turner, the historian whose "frontier thesis" had persuaded Americans that their character had been uniquely shaped by a pioneering spirit, argued that universities and research laboratories would be the new testing ground for that spirit. To "conserve what was best in pioneer ideals" at a time when geographical frontiers no longer existed in the continental United States, "scientific experiment and construction by chemist, physicist, biologist and engineer must be applied to all of nature's forces in our complex modern society. The test tube and the microscope are needed rather than the ax and rifle in this new ideal of conquest."[4] By 1945 Vannevar Bush, director of the wartime Office of Scientific Research and Development, would use the metaphor to portray scientists as new frontiersmen, who if properly funded by the government would open a flow of new resources to the nation. "It has been basic United States policy that Government should foster the opening of new frontiers. It opened the seas to clipper ships and furnished land for pioneers. Although these frontiers have more or less disappeared, the frontier of science remains. It is in keeping with the American tradition—one which has made the United States great—that new frontiers shall be made accessible for development by all American citizens."[5] This vision of a federally funded scientific research enterprise would inspire the formation of the National Science Foundation and create an ongoing expectation for public support of basic science in the United States.

An argument framing scientists as bold explorers on a scientific frontier identifies progress in research as essential to national character. But it also hints at an ongoing conflict between adventurous scientists and the American public who fund their expeditions, a tension that can be summed up in the difference between frontiersmen and settlers. John Dewey spoke of the roots of this conflict in 1922 when he wrote about the antievolution "campaign of William Jennings Bryan against science and in favor of obscurantism and intolerance."[6] To explain why "antagonism to free scientific research" was finding such a friendly audience among "the middle classes [who] are for the most part the church-going classes, those who have come under the influence of evangelical Christianity," Dewey pointed to a uniquely American tension between religion and science. During American frontier expansion, the "churches performed an inestimable social function" in safeguarding "the moral and the more elevated social interests of the community" against the dangers that lay beyond the safe boundaries of the settled towns. This inherent opposition between the morality of the church and the lawlessness of the frontier remained long after the literal frontier had closed, transferring to the general public a fear of those new frontiers of scientific research. "As the frontier ceased to be a menace to orderly life, it persisted as a limit beyond which it was dangerous and unrespectable for thought to travel." The success of Bryan "in his efforts to hold back biological inquiry" could be attributed to his ability to appeal to an evangelical audience, "in fairly prosperous villages and small towns that have inherited the fear of whatever threatens the security and order of a precariously attained civilization." According to Dewey, Americans are "evangelical because of our fear of ourselves and our latent frontier disorderliness." This attitude separates the general public from scientific explorers who would define themselves against such staid townsfolk and their "frontier fear."[7]

A conflict thus arises between religious conservatives who envision the territory across the frontier as a place of savagery and who fear that the scientist's grasp for new knowledge will lead to a fall from grace, and scientists who envision the territory across the frontier as a place of opportunity, rich with natural resources to be mined by those with the courage and fortitude to explore and develop it. It is this conflict that George W. Bush described when he spoke to the public about stem cell research at the beginning of the twenty-first century.

DRAWING A FUNDAMENTAL MORAL LINE: GEORGE W. BUSH'S STEM CELL RHETORIC

In the first year of his presidency, George W. Bush announced his decision to restrict federal funding of human embryonic stem cell research. Scientists engaged in this promising new area of work would receive support, but only if they used cell lines already existing on August 9, 2001, the date that the president announced his new policy; cell lines developed by researchers after that date could not be used in laboratories that receive federal funding.[8] In a nationally televised address to the nation explaining this decision, the president was careful to describe what he said were the two sides on this issue.[9] The way Bush framed this debate served to rhetorically recast bioethical arguments for and against the use of human embryonic stem cells as competing scientific and religious claims, what rhetorical critic John Lynch calls a "Manichean idiom" that created an insurmountable conceptual chasm between supporters and opponents of the research.[10]

My own analysis of Bush's speech concurs with Lynch's reading; the speech was stylistically designed to juxtapose science and religion: the adventurous "researcher" was set against the religiously oriented "ethicist" (¶10); the former was said to be motivated by "the ends of science," while the latter showed concern for "the beginning of life" (¶12); the former was said to be focused on "improving life," while the latter wanted to "protect life" (¶12).[11] That some ethicists, both religious and secular, supported federal funding of human embryonic stem cell research was not imaginable within the framework of this speech.[12] Instead of recognizing the debate as a bioethical one pitting one set of ethicists against another, or one set of religion denominations against others, the speech described the conflict as taking place between religion and science. There was a "great peril" recognized by religiously oriented ethicists, weighed against the "great promise" envisioned by ethically myopic scientists, that led to Bush's decision to proceed with "great care" (¶18), "to explore the promise and potential of stem cell research without crossing a fundamental moral line" (¶20).

Bush's conclusion that his policy would keep scientists from crossing a line is just one of several spatial metaphors that help reveal this speech's rhetorical vision of an adventurous science trying to push past a frontier, and a restraining religion holding it back from doing so. Throughout the speech, the language used to talk about research conveyed scientists' commitment to forward movement. According to Bush, scientists "believe that *rapid progress* in this research will come only with Federal funds" (¶6); American scientists have "a long and proud record of *leading the world toward advances*" (¶7), and "the genius of science *extends the horizons* of what we can do" (¶13).[13]

But in a speech pitting science against a religiously oriented ethics, the advisability of that forward movement is called into question. The audience is placed at "a difficult moral *intersection*" (¶12) in which they are asked to "pay attention to the moral concerns raised by the new *frontier* of human embryo research" (¶15). What lies beyond that frontier is forbidden territory, a godless no-man's-land that we must not enter. "Embryonic stem cell research is at the *leading edge* of a series of moral hazards," according to Bush (¶14). Those hazards are envisioned as deadly explosives, "vast ethical minefields" awaiting those who advance past certain boundaries (¶13). These metaphors suggest that if we follow scientists on this journey to the future, we will enter a deadly place. Rather than imagine the territory across this new frontier as a verdant New World open for exploration, Bush portrays it as a frightening dystopian landscape. "We have arrived at that brave new world that seemed so distant in 1932, when Aldous Huxley wrote about human beings created in test tubes in what he called a 'hatchery' " (¶13). To follow scientists along such a path would be unacceptable.

In a speech where the imagined destination is so bleak, scientists are described as lacking an ethical sense that would restrain their impulse for forward movement. According to Bush, we recently "learned that scientists have created human embryos in test tubes solely to experiment on them," a development that is "deeply troubling and a warning sign" (¶13). The tendency of these scientists to charge ahead is contrasted with the implied audience's good sense to withdraw. "Scientists have already cloned a sheep. Researchers are telling us the *next step* could be to clone human beings" (¶14), a course from which Bush says most Americans "*recoil*" (¶15). To restrain these adventurous scientists, Bush's policy draws a "fundamental moral *line*" that they will be kept from "*crossing*" (¶20). This limiting boundary will keep the nation from "providing taxpayer funding that would sanction or encourage further destruction of human embryos that have at least the potential for life" (¶20). It is a restraint demanded by religiously oriented ethicists who, like Bush, recognize that such "human life is a sacred gift from our Creator" (¶17). After invoking the deity, Bush insists that scientists must be held back from crossing such a boundary line on this perilous frontier of science.

In other remarks Bush made over the years about his stem cell policy, he repeated the same spatial analogy for the role of a religiously oriented ethics in properly limiting an overly adventurous science. According to Bush administration policy expert Jay Lefkowitz, in private conversations prior to his decision, Bush was quick to offer a spatial explanation of how Huxley's dystopic novel related to contemporary stem cell research. " 'We're tinkering with the boundaries of life here,' Bush said. . . . 'We're on the edge of a cliff. And if we take a step off the cliff, there's no going back. Perhaps we should only take one step at a time.' "[14] The boundary between us and the biotechnological future that scientists would have us enter is here imagined as a precipice, with steps forward ensuring only a perilous fall.

When Congress defied Bush and passed the bipartisan Stem Cell Research Enhancement Act in 2006, to allow federal funding of research conducted on stem cell lines produced after Bush's limiting date of August 9, 2001, Bush issued the first presidential veto of his administration. He gave a speech on the occasion that invoked the boundary line metaphor multiple times.[15] According to Bush, this legislation "crosses a moral boundary that our decent society needs to respect" (¶3). The president aligned himself with decent society to keep scientific frontiersmen from crossing that "important ethical line," that "fundamental ethical line" (¶11). "I will not allow our nation to cross this moral line. I felt like crossing this line would be a mistake, and once crossed, we would find it almost impossible to turn back. Crossing the line would needlessly encourage a conflict between science and ethics that can only do damage to both and to our nation as a whole" (¶17). Once again, the notion that there might be ethicists in favor of the legislation was unimaginable in the narrative set out by the president, where religiously oriented ethicists are imagined to be restraining scientists who would have us cross ethical boundaries into an indecent space.

Bush recognized that his policy would be seen by scientists as restrictive, making their work more difficult. But he believed that religious morality demanded the policy he set. As long as "America pursues medical advances" and "great breakthroughs," said Bush, we must do so "with reverence for the gift of life," a religious morality that restrains us from crossing this perilous boundary line (¶19). The constraining hand of a religiously oriented ethics might be seen as an onerous limit by scientists, but Bush was confident that "America's scientists have the ingenuity and skill to meet this challenge" and do good work despite the restraint (¶19).

The Stem Cell Research Enhancement Act passed by Congress would have allowed federal funding of research on stem cell lines that had been produced with private funds from leftover frozen embryos slated to be discarded by fertility clinics. So when signing his first stem cell research veto against this legislation, Bush surrounded himself with children who were each "adopted while still an embryo," left over from fertility clinic treatments, and then implanted in women, born and "blessed with the chance to grow up in a loving family" (¶5). With the image of these adorable children emphasizing his point, Bush reminded Americans that an adventurous science must be restrained by the steady hand of religious morality: "in our zeal for new treatments and cures, America must never abandon our fundamental morals" (¶6). In making this case, he reminded the churchgoing American public of its obligation to preserve the security and order of family life against the dangers that lay beyond that forbidding frontier.

The next year, Bush's address justifying his second veto of legislation that would expand federal funding of stem cell research echoed the same themes.[16] Starting his 2007 stem cell speech with the acknowledgment that America "leads the world in science and technology" and has an "innovative spirit [that] is making possible incredible advances," he reminded his audience that "America is also a nation founded on the principle that all human life is sacred," a religious tenet that calls for restraint on that forward movement (¶1). Once again siding with a restraining religion over an adventurous science, he concluded, "I will not allow our nation to cross this moral line" (¶8). The possibility that some people applying a religiously oriented ethics might support the legislation, or that an ethics not motivated by religious principles might even exist to either support or oppose the legislation, was never entertained. The conflict was framed instead as one between science and religion, with the latter serving as a check on the forward movement of the former.

This framing of the debate over stem cell research as a conflict between an unethical science and a restraining religion is not the only way of characterizing the stem cell debate. One need only review the conflicting reports of two presidential bioethics committees under different administrations to recognize that the debate is a complicated one between different camps of ethicists.[17] More important for the purposes of this chapter, Bush's framing of the debate over stem cell research as a conflict between an unethical science and a restraining religion is not the only way of characterizing the relationship *between science and religion*. It fits a common understanding in contemporary America that science and religion must be at loggerheads, the former pulling us toward an ungodly future, the latter holding us back with a morality rooted in deep tradition. But another way of thinking about the relationship between science and religion is also available to rhetors.

For example, faith traditions that support federal funding of embryonic stem cell research present their own affirmative moral arguments for moving forward across "this frontier that offers enormous hope and challenge"; they believe that undertaking research in this area is heeding a call to people of faith "to be partners with God in healing and in the alleviation of human pain and suffering."[18] Where one faith community sees a frontier boundary as a line that "thou shalt not" cross, another sees an invitation to enter a wilderness territory to undertake a journey to the promised land.

This alternative narrative of what Americans are being called to do when they encounter a new scientific frontier might not be as commonly heard as the one that opposes science and religion, but it too has a long history. Around the same time that Dewey argued that the frontier fear of churchgoing Americans explains their opposition to the new ideas of science, an argument was being made in the scientific community that exploration across scientific frontiers was a moral imperative for Americans, a manifest destiny that they were being called to fulfill. In 1930 biologist J. Arthur Harris reminded readers of *Scientific Monthly*, a publication of the American Association for the Advancement of Science, that American frontiersmen were the heart of our nation. They were "those hardy, fearless and independent men who . . . by their daring made possible the development of a west and the regeneration of an east that was approaching decadence." Today, it is across "the frontiers of science" that we find the "moral equivalent for the old frontier in our new social, intellectual and spiritual life." Like "the prophet," Harris explained, the frontiersman disregards warnings to stop at the "edge of cultivation" and heeds the call to "go beyond the ranges." As a result, frontiersmen are often misunderstood in their time. But Harris urged "real frontiersmen of science" to persevere in their commitment to the strenuous life over the life of ignoble ease, since it is these scientific "frontiers on the exploration of which our future economic, intellectual and social development depends." In a nation where the "western frontier has passed into history," it is to "the manifold frontiers of science" that we must look for "the means of meeting the moral needs of our time."[19]

If Americans are called to enter an unknown wilderness because it is only through their struggles past the boundaries of safe civilization that they can develop the character to regenerate a society approaching decadence, then exploring these frontiers of science becomes a moral duty. When tied to religion, this perspective toward the frontier of science can invest research with a natural theological mission, in which the adventurous discoveries of scientific frontiersmen lead to a fuller realization (i.e., recognition and fulfillment) of the glory of God's creation. Such a perspective toward the relationship between science and religion was presented in another highly publicized presidential speech event just a year prior to Bush's nationally televised address on stem cell research, this one on the Human Genome Project.

EXPLORING THE BOOK OF LIFE: THE NATURAL THEOLOGY OF FRANCIS COLLINS

Like President George W. Bush would do a year later, President Bill Clinton, in June 2000, addressed Americans with a speech that portrayed an adventurous science and that spoke of religious belief. But unlike Bush's speech, science and religion were not opposed in Clinton's speech. Instead, science was envisioned in two parallel ways, first as a patriotic frontier-crossing expedition, then as a sacred religious mission. We can see those parallel visions in the metaphors selected to characterize the main subject of the speech, the human genome. Clinton's speech at the White House ceremony announcing the completion of the "first survey" (¶5), or first "draft" (¶13), of the human genome was dominated by two notable metaphors: one compared the human genome to American frontier territory, the other compared it to divine text.[20]

The two metaphors for the human genome were introduced in Clinton's speech through historical analogies; in each case, a reference to something from the past was followed by a statement that began with "Today, . . ." to make the analogical link explicit.[21] To introduce the first metaphor, Clinton recalled a moment two centuries prior when another president, Thomas Jefferson, had a "magnificent map" spread before him in that very same room by the leader of the Lewis and Clark expedition, "a map that defined the contours and forever expanded the frontiers of our continent and our imagination" (¶4). Clinton then made an analogical link to the present moment. "Today, the world is joining us here in the East Room to behold a map of even greater significance. We are here to celebrate the completion of the first survey of the entire human genome" (¶5). This comparison of the human genome to American territory being mapped for the first time was reinforced with similar metaphors that appeared throughout the speech, as when Clinton said that genomic scientists were considering "how we can most judiciously proceed toward the next majestic horizons" (¶12), or when he insisted that "we must not shrink from exploring that far frontier of science" (¶15), that we must continue our "triumphant expedition inside the human genome" (¶17) "as we continue to march forth in this, the greatest age of discovery ever known" (¶18). Through this metaphorical language, the genome is conceived as uncharted land that scientific frontiersmen enter to prepare the way for profitable resource extraction and development that will benefit the nation as a whole.[22]

To introduce the second metaphor for the genome in this speech, Clinton turned to another historical reference. He recalled that "when Galileo discovered he could use the tools of mathematics and mechanics to understand the motion of celestial bodies, he felt, in the words of one eminent researcher, 'that he had learned the language in which God created the universe' " (¶8). Once again, the president shifted to the present to clarify the analogy for his auditors. "Today, we are learning the language in which God created life. We are gaining ever more awe for the complexity, the beauty, the wonder of God's most divine and sacred gift. With this profound new knowledge, humankind is on the verge of gaining immense, new power to heal" (¶9). The genome is thus conceived as a divine and sacred gift written in God's language, a text that, when correctly interpreted, will give scientists miraculous healing powers.

The leader of the Human Genome Project, Francis Collins, would later admit that he "had worked closely with the president's speechwriter in the frantic days just prior to this announcement, and had strongly endorsed the inclusion of this paragraph."[23] The speech that Collins gave at the White House ceremony that day deliberately "echoed" this passage from Clinton's speech.[24] It also echoed the other metaphor that Clinton had introduced at the White House ceremony, of the genome as frontier territory. In fact, Collins would later recall that he had used the Lewis and Clark analogy in a speech given a month prior to the White House ceremony, thus suggesting that he might have influenced Clinton's speechwriters regarding that rhetorical choice as well.[25]

In the speech that Collins gave at the White House ceremony, he began with some obligatory words of thanks and praise directed to the president, then he set out an eloquent unification of the two metaphors that Clinton had introduced for genomic science. First, Collins embraced the notion of genomic science as adventure beyond the new frontier. "Science is a voyage of exploration into the unknown," he proclaimed. "We are here today to celebrate a milestone along a truly unprecedented voyage, this one into ourselves" (¶47). Using the same signal that Clinton had used to mark the completion of an analogical link, the word *today*, Collins made the terms of the frontier analogy even more explicit than Clinton had, reminding his auditors that the territory that scientists are exploring is the human body. In his next sentence, body as territory to explore would become body as divine text as his auditors are moved back in time again to hear from another historical figure. "Alexander Pope wrote, 'Know then thyself. Presume not God to scan. The proper study of mankind is man.' What more powerful form of study of mankind could there be than to read our own instruction book?" (¶47). Offering this metaphor of the genome as God's manual for the creation and operation of human beings, Collins used that same transition to the present to underline his meaning. "Today, we celebrate the revelation of the first draft of the human book of life" (¶48).

In this passage, Collins was mixing both frontier territory and divine text metaphors, suggesting that the territory of the human genome that scientists explore and map *is* "the human book of life," a metaphorical book of nature that biologists must explore in order to read, and must read in order to gain divine knowledge ("revelation"). This appeal was drawn straight from natural theology, specifically, Francis Bacon's "two books" concept, which says we can achieve truth not just through exegesis of the Bible (the book of God) but also by discovering signs of his magnificence in the natural world (the book of nature). The scientific mapping of genomic territory was being set out as just this sort of religious mission, a devotional reading of the genomic book of nature to celebrate and glorify God. As Collins said later in his speech, the scientist aspires to "help unravel the mysteries of human biology" (¶53) by learning "how to speak the language of the genome fluently" (¶56). "It is humbling for me and awe-inspiring to realize that we have caught the first glimpse of our own instruction book, previously known only to God" (¶57).

The link Collins made in his speech between the frontier-crossing exploration of genomic territory and a reading of the "human book of life" is significant because it shows us how he portrays the adventurous impulse of science as fully compatible with religion. Frontier-crossing scientists are not set in opposition to the restraining force of a religiously derived morality, but instead made the instruments of divine revelation; in exploring new scientific territory, they catch the first glimpse of God's instruction book for man.

This link between scientific exploration and religious revelation can be found in the subsequent public address of Collins as well. For example, consider the merger of the two metaphors when Collins later reflected on his initial decision to accept leadership of the Human Genome Project. "Here was a chance to read the language of God, to determine the intimate details of how humans had come to be. Could I walk away? I have always been suspicious of those who claim to perceive God's will in moments such as this, but the awesome significance of this adventure, and the potential consequences for humankind's relationship with the Creator, could hardly be ignored."[26] In this account, Collins described the opportunity to lead an international scientific project not as a job offer that promised great career advancement, but as both a chance to read a divine text and an "adventure."

A few pages later in that same autobiographical account, Collins described his feelings about the success of the Human Genome Project after the mission was completed. "For me, as a believer, the uncovering of the human genome sequence held additional significance. This book was written in the DNA language by which God spoke life into being. I felt an overwhelming sense of awe in surveying this most significant of all biological texts. Yes, it is written in a language we understand very poorly, and it will take decades, if not centuries, to understand its instructions, but we had crossed a one-way bridge into profound new territory."[27] In this reminiscence, we find terms such as "surveying" and crossing into "new territory" appearing alongside terms such as "biological texts" and "book" written in God's "language." The tenor is the same (the genome), but the vehicles of frontier territory and divine text are used interchangeably in the same sentences, creating a hopelessly mixed metaphor.

Six years later, Collins described the success of the Human Genome Project again with an amalgamation of divine book and frontier territory metaphors. "With the sequencing of the entire genome, scientists could launch into a dizzying array of groundbreaking research projects to unlock the greatest secret of the human body. How does our DNA, life's instruction manual, actually work? We had climbed to the top of one big mountain, and were about to start rushing down the other side, into a valley full of potential discoveries."[28] For Collins, unlocking the secret of life's instruction manual and scaling a mountain to draw resources from the fertile valley beyond were activities to be undertaken simultaneously.

I have argued elsewhere that the mixing of metaphors in a particular case has a tendency to resolve otherwise nonintersecting or competing vehicles for a single tenor into a unified metaphorical conception.[29] In this case, territory across the frontier and divine text are united in the natural theological mission of exploring nature to discover and experience awe at God's revelatory message to humankind.

Elsewhere in his public discourse, Collins has offered additional hints that he favors a natural theological perspective toward science. "The elegance behind life's complexity is indeed reason for awe," Collins wrote in his book *The Language of God*, "and for belief in God—but not in the simple, straightforward way that many found so compelling before Darwin came along." According to Collins, that too simple way was exemplified by the fallacious arguments of "William Paley in 1802 in a highly influential book, *Natural Theology, or Evidences of the Existence and Attributes of the Deity Collected from the Appearances of Nature*." In Collins' new, less "simple, straightforward" version of natural theology, "we must dig deep into the fascinating revelations about the nature of living things wrought by the current revolution in paleontology, molecular biology, and genomics."[30] Work across these modern scientific frontiers can disclose the true glory of God's mystery. "How marvelous and intricate life turns out to be! How deeply satisfying is the digital elegance of DNA! How aesthetically appealing and artistically sublime are the components of living things, from the ribosome that translates RNA into protein, to the metamorphosis of the caterpillar into the butterfly, to the fabulous plumage of the peacock attracting his mate! . . . For those who believe in God, there are reasons now to be more in awe, not less."[31]

Throughout *The Language of God*, Collins shared his awe at scientific findings that serve as "signposts to some greater intelligence."[32] These signposts include the "unreasonable effectiveness of mathematics," the beginnings of the universe in a big bang that "only a supernatural force that is outside of space and time could have done," and the "remarkable series of 'coincidences' that allow the laws of nature to support life" and thus "point toward an intelligent mind" behind them.[33] Collins testified that in studying genomics, he found the "elegant evidence of the relatedness of all living things an occasion of awe, and came to see this as the master plan of the same Almighty who caused the universe to come into being and set its physical parameters just precisely right to allow the creation of stars, planets, heavy elements, and life itself."[34]

Although Collins explicitly rejected Paley and devoted a whole chapter to arguing against contemporary "intelligent design" theory, the natural theological purpose of his 2004 book was stamped in its subtitle: *A Scientist Presents Evidence for Belief*. As philosopher of science Hub Zwart puts it, "Collins tends to be somewhat vague," so that the way his approach "really differs from an Intelligent Design perspective" remains murky.[35] In fact, contemporary intelligent design advocates have embraced certain parts of Collins' 2004 book, praising him for making "a scientific case for intelligent design" through his argument "that intelligence is the *best* explanation currently available" for certain discoveries in fields such as physics and cosmology.[36] Other reviewers who recommended the book to audiences of faith were drawn to these aspects of Collins' argument as well.[37] As one theologian put it, in Collins' "estimation, the more one really understands science, the more certainty one has about the existence of God."[38]

Collins attempts to have his personal God and evolutionary science too by pushing the creative act back further in time (to the big bang), while leaving the existence of a divine plan intact through the acknowledgment that God is outside of time.[39] The philosophical adequacy of this solution to the contradiction of simultaneously embracing an active creator God and a theory of undirected evolution through natural selection of random mutations remains under dispute.[40] But the rhetorical force of Collins' argument is clear. By characterizing the proper vocation of the scientist as a search for evidence of the existence and attributes of the deity in the exploration of our natural world, Collins merged an American frontiersman ethos with an American evangelical mission. He summed up this appeal in an eloquent passage toward the end of this book. "The God of the Bible is also the God of the genome. He can be worshiped in the cathedral or in the laboratory. His creation is majestic, awesome, intricate and beautiful."[41]

In short, the natural theology of Collins works rhetorically as a link between metaphors that portray the genome as frontier territory and sacred text. The book of nature merges these two otherwise distinct metaphors into a single appeal, an exhortation to explore the territory of the life sciences to read God's mysteries there. With this mixed metaphor, ever pushing the boundaries of science forward becomes a spiritual imperative. This natural theological perspective allowed Collins to align himself with ancient authorities such as Galileo, who argued "that scientific exploration was not only an acceptable but a noble course of action for a believer," and Copernicus, who used science to celebrate "the grandeur of God," and saw in the exploration of his laws "a pleasing and acceptable mode of worship to the Most High."[42] Scientific research that crosses frontiers could be thus sanctified by Collins, made not only compatible with the aims of religion, but reshaped into an indispensible instrument of them.

Thomas Lessl points out that the "two books" metaphor was originally used by Bacon to borrow the social authority that religion held in his time and bestow it on scientists, whose "faithful reading of God's revelation" in the natural world would make science "a new hermeneutical magisterium . . . imbued with a spiritual authority nearly equal to that of Protestant divines."[43] In America today, where science already holds social authority, the need for such a linkage is different.[44] Rather than seeking to raise science to the level of religious authority, Collins was seeking to overcome a perceived conflict between the two, the same conflict identified by Feynman, set out by Bush's Council on Bioethics, and saturating Bush's stem cell speeches.

To illustrate this alternative reading of the relationship between science and religion in the genomic discourse of Collins is not to endorse it, any more than an illustration of the antagonistic relationship set out between science and religion in the stem cell discourse of Bush is meant to endorse that vision. Rather, the purpose of these illustrations is to raise both inventional possibilities to our awareness, giving rhetors more control over how they characterize the relationship between science and religion. The figure of the frontier, that border between what is and what might be, is a rhetorical tool that can satisfy multiple purposes. In one person's hands, it is a line drawn by religious morality, a border across which decent society must not pass, a limit that scientists must be restrained from breaching. In another person's hands, the frontier calls adventurous souls to awaken their pioneering spirit and carry out an evangelical mission, exploring the unknown to better appreciate and rejoice in God's glorious creation and do the good deeds demanded of us there, like healing the sick. What this analysis suggests is that to recognize only one of these rhetorical visions, at the expense of the other, is to diminish the language of our biotechnological future.

6

The Angels and Devils of Representing Prozac

Tod Chambers

> What does it mean, for instance, that my burgeoning contemplative bent does not come directly from God but from Prozac? Might this mean that Prozac is equal to God? This is an awful, awful thought.
>
> Lauren Slater, *Prozac Diary*

Flying without Fear

For a period of three years my wife and I had what is usually referred to as a "long-distance relationship." My wife began a neurology residency at the University of California, San Diego, just as I began a tenure-track position at Northwestern University in Chicago. Those familiar with the life of a resident will understand that the burden of travel for those three years fell largely on me, and every two or three weeks I would lock up my Chicago home and take a four-hour flight to my San Diego home. I learned after a period of time what business frequent flyers know well. If you fly often enough on a single airline carrier, one experiences travel in a radically different way: one no longer interacts with overworked and exhausted personnel, but instead one enters an alternative travel world of attractive, eager, and patient assistants, who seem longing to take care of your every need. But, for me, the most unanticipated effect that this increase in travel had was an increasing dread about each upcoming flight. I had become for the first time in my life fearful of flying. Actually it is perhaps more accurate to say that I had a fear of crashing and dying; the plane was simply the means toward this end. I should say that I have been on planes since I was very young. My parents were obsessed about traveling around the world, and so, when travel was far more expensive and much more of an ordeal, I cannot remember a time when we were not flying to some place in the world to increase our symbolic capital among the upper class of New England. But now, as the months passed, my anxiety increased with each trip.

At the same time, some obsessive-compulsive tendencies began to be less of an amusing eccentricity and instead began to interfere with my daily life. On one occasion I drove from my home to my office four times in twenty-four hours to check and recheck if I had made the same grammatical mistake on a paper that had just been published. I also began to have some classic features of OCD; I remember walking four times between my car and the front door just to make sure that I had not been mistaken the last time I had gone to the door to see if it was locked. One of the few advantages of working in a medical school is that one has a remarkable network of people who can tell you who you would want treating your mother and who you should be scared to find looking down on you in the ER. So I found a great psychiatrist, and he soon had me on a number of drugs, including Paxil. Paxil is one of the antidepressant drugs that influence the levels of serotonin, which is a neurotransmitter that is believed to have an influence on a person's sense of well-being. The granddaddy of these drugs is Prozac (generic name fluoxetine), manufactured by Eli Lilly and released for general treatment in the late 1980s; the name Prozac has come to represent this entire generation of drugs, which includes Paxil, Zoloft, Effexor, and Luvox. The pharmaceutical company that makes Paxil, SmithKline Beecham, coined the term *selective serotonin reuptake inhibitors* (SSRIs). After approximately a month, my OCD simply vanished, but there was a side effect that I had not anticipated. I was no longer afraid of flying. Actually, it was not simply that I was no longer afraid of the possibility of the plane crashing: I was no longer afraid of death. Prior to this I was not—nor was I ever—particularly concerned about my death, but now the very idea of death seemed distant and something that should not concern me. Although I would not welcome a crash, I seemed unconcerned that if the plane were to crash, I would not survive the event.

FROM PHILOSOPHY TO SOCIOLOGY

This seems to confirm the greatest fear that some in the bioethics community have had about the extraordinary prevalence of SSRIs in the American population. In *Better Than Well*, Carl Elliott describes a side effect of SSRIs that is rarely cited in the medical literature but is well known to patients and their prescribers: emotional blunting. The slang term that has arisen to describe this phenomenon is "Prozac zombie." Individuals report that they feel numb during times that they intellectually identify as expecting a strong emotional reaction. Some patients have reported deaths in their families that they identify as normally producing strong emotional responses in people, but they were detached. It seems as if SSRIs have the power to transform some patients' lives into the odd indifferent narrator of Camus' *The Stranger*, who opens his tale with the striking, detached response to his mother's death: "Maman died today. Or yesterday maybe, I don't know. I got a telegram from the home: 'Mother deceased. Funeral tomorrow. Faithfully yours.' That doesn't mean anything. Maybe it was yesterday."[1] One psychotherapist notes that she no longer worried about anything "because nothing mattered."[2] In his essay "Prozac Zombie," Ian Penman reports spending days simply sitting in front of a window and "just being this nice new neutered, frozen, prone, Prozac me."[3] And perhaps the greatest horror story for an academic is that of the graduate student who upon being on an SSRI loses the desire to finish her dissertation and instead simply wants to spend the day baking.[4]

This seems to be an actual manifestation of the very thing that many of us have been taught to fear. It is a future in which humans are unfeeling drones simply moving through life as if it were a dream, and it is not the explicit totalitarian forcing of emotionlessness of, say, Orwell's *Nineteen Eighty-Four* but instead akin to the work portrayed in such novels as Huxley's *Brave New World* and Philip K. Dick's novel *Do Androids Dream of Electric Sheep?* or films such as *Equilibrium* and *THX 1138*. Dick's novel begins with a husband and wife discussing what mood the wife has planned in their "Penfeld Mood Organ." They begin to fight. The man walks over to his mood organ and hesitates in deciding whether to dial for a setting that would dissolve his anger or a stimulant that would increase his anger to the degree that he would win the fight. The wife warns him if he dials "greater venom" she will dial for an emotional rage that will outweigh every fight they have ever had. In order to calm his wife, the husband suggests that they avoid the issue altogether if she agrees to dial their mood schedule for that day. She reveals that she scheduled "a six-hour self-accusatory depression." She explains that she thought about how empty the apartment building is that they live in and

> when I had the TV sound off, I was in a 382 mood; I had just dialed it. So although I heard the emptiness intellectually, I didn't feel it. My first

> reaction consisted of being grateful that we could afford a Penfield mood organ. But then I realized how unhealthy it was, sensing the absence of life, not just in this building but everywhere, and not reacting—do you see? I guess you don't. But that used to be considered a sign of mental illness; they called it "absence of appropriate affect."[5]

After the depression, she had programmed a 481, which is the "awareness of the manifold possibilities open" to someone in the future. He suggests instead that they dial a 104 together, and she watches some TV, but she tells him that she hates to watch TV before breakfast.

> "Dial 888," Rick said as the set warmed. "The desire to watch TV, no matter what's on it."
>
> "I don't feel like dialing anything at all now," Iran said.
>
> "Then dial 3," he said.
>
> "I can't dial a setting that stimulates my cerebral cortex into wanting to dial! If I don't want to dial, I don't want to dial that most of all, because then I will want to dial and wanting to dial is right now the most alien drive I can imagine; I just want to sit here on the bed and stare at the floor."[6]

Rick finally dials for both of them 594, "pleased acknowledgment of husband's superior wisdom in all matters."

This odd alienation from one's own feelings and desires is in many ways what those in bioethics have been most concerned about. Peter Kramer's book *Listening to Prozac* made many aware of the power that SSRIs seem to have over certain individuals' personality. Many of the changes that occurred in people were not only the relief of OCD or depression but also radical shifts in their character traits, and for some people these were perceived as considerably positive shifts, a bit like being given a Penfield Mood Organ. In many ways it has been Kramer's cases of such instances that have caught the attention of those interested in bioethics and the philosophy of medicine. One of the most discussed cases concerns Kramer's first patient for whom he prescribed Prozac. In the first chapter of *Listening to Prozac*, titled "Makeover," Kramer recounts his treatment of Tess, who had grown up in a one of the poorest public-housing projects in the city and had been raised by an alcoholic and abusive father and a clinically depressed mother. But following her father's death, Tess took charge of the family, and, although she had gone through a series of degrading relationships, she was able to achieve a remarkable degree of success in her adult life. Her ongoing tendency, however, to have affairs with abusive married men inevitably led to serious depression when the relationship ended. While earlier antidepressants seemed to have had some degree of success for Tess, Kramer eventually put her on Prozac, which had just been approved by the FDA. Kramer reports that the results of the treatment were remarkable. After two weeks, he found that her depression had disappeared and instead she felt an increase in energy and vitality. Her social life had been transformed as well. She began successfully dating a number of men and had dropped a number of her old friends. She explains this change in her relationships to Kramer by saying, "Have you ever been to a party where other people are drunk or high and you are stone-sober? Their behavior annoys you, you can't understand it. It seems juvenile and self-centered. That's how I feel around some of my old friends. It is as if they are under the influence of a harmful chemical and I am all right—as if I had been in a drugged state all those years and now I am clearheaded."[7] The statement is quite fascinating, Tess reporting that on the drug she feels as if she is the only one not on a drug. After nine months, Kramer took Tess off Prozac, and there were no signs of a return to the depressive state that was the initial reason for her seeking medical treatment. But eight months later, Tess returned and asked to be put back on the Prozac. It was not that her depression had returned, for it had not, but she reported that when she was not on Prozac, "I'm not myself." This single sentence and Kramer's reporting that this was not an unusual pattern have led bioethicists to wonder, as Kramer did himself, what exactly is being "treated." In many ways it seems that medicine can shift from treating patients for their illness to altering patients to a more pleasurable way of being. It is for this shift into the arena of medical enhancement that Kramer coined the term "cosmetic pharmacology."

Erik Parens notes that in Kramer's discussion of this notion of remaking the self, Kramer's concept of the self alters. At first, it seems that for Kramer Prozac helps us discover a hidden authentic self, so the drug works as a key that frees us from our entrapment. But Parens points out that Kramer also refers to Prozac as something that "facilitates an authentic process of self creation."[8] The slipperiness of Kramer's notion of the self permits him both to see Prozac as simply revealing an authentic self and at the same time to speak about it as an empowering tool for individuals to create any self they want.

Similarly, in his discussion of the Tess case, Carl Elliott queries whether "the appropriate language to use is a transformation to a new self, or a restoration to a *true* self? Or something else? Kramer, in his most enthusiastic passages, seems to hint that at least in some cases Prozac restores a true or authentic self, a self that has been masked by pathology."[9] Elliott observes that there are also cases in Kramer's book that lead one in the opposite direction. James Edwards begins a discussion of Tess's case in relation to reactions that his students have when Tess requests to be put back on Prozac. Edwards argues that the distress these students feel at this shift toward enhancement should be more clearly delineated as either *metaphysical worry* or *ethical worry*. The first is the concern that Parens has about Prozac's effect. What does it mean to think of ourselves as essentially chemical entities that could be easily switched with a slight change in our medication? Are we thus "just interesting pieces of meat, nothing more and nothing less"?[10] This concern, for Edwards, is of a metaphysical nature. The second concern of his students is about the moral status of why Tess wishes to take the drug. The moment in the story when Tess is no longer clinically depressed but expresses the desire to nevertheless be put back on Prozac invokes in the students a moral judgment. Edwards summarizes it in the following way: "At that point their ethical worry takes the form of two prejudices they are quick to voice (and slow to defend): when it comes to changing one's life (1) the natural way is better than the artificial, and (2) the hard way is better than the easy. . . . My students claim to have no objections to Tess's self-transformation if it were done through some sort of 'talking cure,' whether psychological, philosophical, or religious. . . . Good puritans that my students are, they know that life is deep and serious and costly; nothing good comes to one without its required agony."[11] In order to counter any criticism about potential reductionism of his class's worldview, Edwards adds the following parenthetical note: "Even if they are not Christians, the cross is never far from their minds. I live and teach in the South, remember."[12]

This move from looking at the students' personal views on enhancement to an examination of how it fits within the larger culture is a turn often adopted in the discussion of SSRIs by philosophers. After discussing Tess's loss of "seriousness," Parens presents a case of another of Kramer's patients, a woman who seems to lose concern for those around her. Gail was a woman who treated her depressed moods by "shopping for clothes and a variety of drugs"; after taking a course of Prozac, her sense of well-being increased dramatically, including her feelings about shopping. It is here that Parens contextualizes Gail within a capitalist society that encourages consumption. He writes, "Guiltless spending is a side effect, not the intended effect of Prozac. But it is a side effect that meshes seamlessly with what can be one of the drug's primary uses: to facilitate better performance in an often cruelly competitive, 'capitalist' culture."[13] Elliott, in his discussion of the notion of authenticity and Prozac, places the debate within the context of American culture and Max Weber's notion of the "Protestant ethic." For many philosophers the problem becomes reframed from one of defining the "true" self to the very nature of the capitalist drive within contemporary America. Philosophy, which has long prided itself for striving to find "universal" values, becomes transformed into sociology or American studies.

One way of describing this shift is through the grammar developed by the rhetorician Kenneth Burke. Burke argues that in the description or definition of any action ("What is involved, when we say what people are doing and why they are doing it?"), there are five essential elements: *act*, *agent*, *agency*, *scene*, and *purpose* (in later versions Burke suggested that one might also wish to add *attitude*). We must describe what happened (act), who performed the act (agent), how the act was accomplished (agency), what was the context of the act (scene), and why the act was carried out (purpose).

There are a number of "misreadings" of Burke's pentadic method that hold that in simply naming these five elements in a description, one has applied the method. As the sociologist Joseph Gusfield observes, "Taken by themselves, the Pentad might seem commonplace, a little like a high school journalism instructor's admonition about what should go in the headline and lead paragraph of a news story."[14] For Burke, an author will feature a particular one of the five terms and "in developing a vocabulary designed to allow this one term full expression (as regards its resources and its temptations) with the other terms being comparatively slighted or being placed in the perspective of the featured term."[15] The key to this analytic method is to reveal that certain terms of the pentad will have greater explanatory gravity, and this privileged or controlling term reveals the author's motive. The word *motive*, Gusfield explains, does not for Burke entail the way the word is used by clinical psychologists as the stimulus for action, "a source of behavior"; instead, motive signifies "a concept used by people to make actions understandable to them and to others."[16] For Burke, motives are "linguistic products" and thus "are not *realities*, they are *interpretations* of reality—hence different frameworks of interpretation will lead to different conclusions as to what reality is."[17]

Gusfield's own sociological study of auto deaths provides a powerful example of how a shift in motives can have profound consequences for the social response to a problem. If the problem is described as *drinking-drivers*, it will lead one to be concerned primarily with the person behind the wheel of the car: if the problem is described as *drinking-driving*, one focuses on the context of the act.[18] It is by looking at what Burke terms "ratios" that one can discern the rhetoric of the description. The end result of this form of analysis is for Burke a way to uncover worldviews expressed in the language. "Men have talked about things in many ways, but the pentad offers a synoptic way to talk about their talk-about."[19] By systematically looking at the various ratios, for example, scene-act, agency-purpose, agent-act, one can discern that the author of the description has ascribed the motive of the event to a particular aspect of the pentad. Anyone who has done multidisciplinary work becomes acutely aware that one of the advantages of such an approach is that with additional disciplines come redescriptions, descriptions that differ primarily by the weight given to particular terms.

For Burke, behind each dominant term stands a philosophical worldview, which in a manner drives the emphasis of a particular term.

- For the featuring of *scene*, the corresponding philosophical terminology is *materialism*.
- For the featuring of *agent*, the corresponding terminology is *idealism*.
- For the featuring of *agency*, the corresponding terminology is *pragmatism*.
- For the featuring of *purpose*, the corresponding terminology is *mysticism*.
- For the featuring of *act*, the corresponding terminology is *realism*.[20]

In describing this element of Burke's method, Sonja Foss gives the following example:

> In a speech by Ronald Reagan on U.S. Relations with the Soviet Union . . . agent or character may emerge as the dominant term—the agent of evil Russians may seem to have a major impact on the other terms in the pentad. If Reagan's motive for the speech is situated in character, the corresponding philosophy is idealism, the system that views the mind or spirit as each person experiences it as fundamentally real. The speech and actions Reagan takes as a result of it, then, are likely to be motivated by Reagan's view that his perception of the world . . . is the real, correct one. He sees the world in black-and-white terms. The Russians are evil; the Americans good. Russian acts are bad; American acts are good. There is no alternative to this perception; it is the correct one. Because of the way Russians are—a nature that is immutable, inherently evil, and very real—the United States never can cooperate with them, see them as potential friends, or view good qualities in them.[21]

Controlling views by shifting the dominant term in a description has extraordinary power to frame the problem and with it its apparently "natural" or "inevitable" solution. Donald Schön and Martin Rein have observed the way in which policy controversies have been framed in particular ways. Framing becomes a form of problem setting. As they note, "Through the processes of naming and framing, the stories make the 'normative leap' from data to recommendations, from fact to values, from 'is' to 'ought.' "[22] Description and prescription are always profoundly intertwined. David Ling stresses that for Burke a person's description of a situation will in turn display the "appropriate response to various human situations."[23] Ling offers the following example:

> The speaker who views the agent as the cause of a problem will reflect by his language not only what Burke would call an idealist philosophy, but he will be limited to proposing solutions that attempt to limit the actions of the agent or to remove the agent completely. The speaker who finds the agent to be the victim of the scene not only reflects a materialist philosophy but will propose solutions that attempt to limit the actions of the agent or to remove the agent completely. The speaker who finds the agent to be the victim of the scene not only reflects a materialist philosophy but will propose solutions that would change the scene. Thus, an individual who describes the problem of slums as largely a matter of man's unwillingness to change his environment will propose self-help as the answer to the problem. The person who, looking at the same situation, describes man as a victim of his environment will propose that the slums be razed and its inhabitants be relocated into a more conducive environment.[24]

In his pentadic analysis of Edward Kennedy's formal explanation after the death of Mary Jo Kopechne, Ling notes that Kennedy's account of the events emphasizes scene over and against agent.[25] Kennedy becomes a victim of the setting. Any elements of personal misconduct become themselves merely a matter of the result of acting in response to unusual circumstances. Since the accident as well as his actions following the accident were caused by the circumstances, the response of the voters of Massachusetts should be to see Kennedy as innocent and thus to allow him to stay in office.

As I mentioned above, one can often find a similar shift in term emphasis in the work of bioethicists writing on SSRIs. Elliott, in *Better Than Well*, provides a good example of the move from agent or agency to scene. In his discussion about Prozac, Elliott begins an examination of the use of SSRIs for social phobia by first probing the history of the diagnosis and the manner in which the illness of social phobia seems to him to be actually closer to what we at one time simply referred to as shyness. But Elliott makes a shift from a discussion that features agency to one that instead focuses on scene. "The biology of social phobia is (for me, at any rate) a lot less intriguing than its cultural substrate, the social and historical forces that produce all these sweaty palms, shaky voices, and tense bladders."[26] Elliott then proceeds to compare notions of character across cultures, especially between German and Japanese cultures. And in this discussion, Elliott argues that "part of the reason American social phobia takes the form it does is connected to the particular architecture of the American self."[27] It becomes clear that the question of philosophical anthropology (a philosophical discussion of the nature of the self) becomes instead a question of social epistemology (a study of how society informs what we know).

To some degree it should not be surprising that bioethicists tend to shift terms in this manner. For as is noted above, Burke argues that the philosophical worldview behind the tendency to emphasize scene is that of materialism. This move oddly makes the philosophical questions about SSRIs quite simple. They no longer become moral issues embedded in human nature but instead elements of the scene that can be shifted only by changing the scene, a scene in this case American culture, that is essentially too great to change. It oddly takes responsibility away from bioethics to make any changes at all. The enhancement debate for many bioethicists has become a discussion of the American cultural environment in which it takes place; Elliott comes to conclude, "Every society gets the doctors it deserves, and our doctors are merely giving us what we demand."[28] Elliott sees the positive reaction to the power of SSRIs to transform selves as part of a general shift in American society away from God as the "locus of meaning" and instead toward psychology. Elliott argues that Americans no longer measure their success by the degree to which they have established a relationship to God but rather by their degree of psychological well-being.

I confess, however, that it is difficult to find evidence of this kind of shift. In a 1982 issue of the journal *Daedalus*, the cultural anthropologist Mary Douglas noted that academics had not expected—much less predicted—the extraordinary rise of traditional religious forms throughout the world.[29] She argues that there were a number of assumptions that academics made about religion that in some manner blinded them to this revival. One of the biases that caused this myopia was that we moderns are essentially different from prior generations because of the changes brought about by science and bureaucracy. Traditional religious views have fallen aside as our contemporary world has become secularized. That Elliott believes that Americans have in some manner transcended their need for transcendence seems particularly odd in the face of recurring polls by Gallup that show that more than 80 percent of Americans think of religion as being either fairly important or very important in their lives.[30] Elliott concludes his discussion by submitting that for Americans "enhancement technologies are not just instruments for self-improvement, or even self-transformation—they are tools for working on the soul."[31] It is this very feature of SSRIs that raises profound questions for religious thinkers, and the manner in which they respond to these questions in turn reveals those features of Burke's pentad that enable them to resolve the spiritual problems raised by allowing a soul to provide salvation.

In what follows I examine the definition of the problem by both Christians and Buddhists. It is important to note that these responses come from American Christians and Buddhists. While the writing is addressed to a general Christian or Buddhist audience, I believe that responses from different Christians and Buddhists could potentially produce different descriptions. It should also be noted that these American Christians and Buddhists differ in their relationship to the tradition. I suspect that most of the Christians writing about this issue at the very least were raised in a Christian tradition. They may have later adopted a stronger Christian practice, but, as Edwards observes, Christianity remains for most Americans a part of the landscape of their understanding of the world. The Buddhists discussed in this chapter tend to be from a very different background. Many of them were raised either Christian or Jewish and later converted to Buddhism. There is an ongoing debate within religious studies about how to delineate these converts from the other Buddhists in America, that is, those who are generally part of the first or second generation of immigrant families who were raised as Buddhists.[32]

FATHER, SON, HOLY GHOST, AND PROZAC

Consider the following case: a young seminarian is brought to the emergency room with his wife. He is convinced that he either is dying from cancer or is having a heart attack. He has been threatening to take his own life, has had crying spells, and is obsessively worrying. He has low energy, and he has lost all appetite, lost all sexual desire, and generally has little interest in anything. He wakes in the early morning hours in a panic. He reports hearing Satan tell him to "curse the Holy Spirit" and believes he has done so. He has extraordinary guilt watching pornography. Unable to afford a private facility and unwilling to go to a state-run institution, the man is treated as an outpatient with both antidepressants and antipsychotics as well as ongoing "Christian psychotherapy." With this treatment, he recovers fully, finishes his studies, and becomes a successful pastor.

This case is from the beginning of an essay by David Colvard and William Wilson, both psychiatrists, in which they make the argument that Christians should feel comfortable taking antidepressant medication. They warn against Christians experiencing prolonged depression, which—as illustrated in one of their cases—can lead to suicide. They charge,

> Many Spirit-filled, Bible-believing Christians who would not hesitate to permit a non-Christian surgeon to perform a coronary bypass operation or a pediatrician to inject an antibiotic, perceive taking an antidepressant medication as lack of faith in God's ability to heal them. Some believe that depression is demonic or a punishment sent by the Lord or caused by some other spiritual problem. Some mistakenly believe that a good Christian cannot suffer depression, adding a layer of false guilt and shame to the depression.[33]

Colvard and Wilson argue that "a loving and just God," as Christians understand to be part of the essential nature of the divinity, would use medication to relieve the suffering of the human creature. Antidepressants are for them "truly heaven sent" and, in combination with prayer and counseling, are a "powerful tool" to use in response to human suffering.

But compare Colvard and Wilson's case to the following cases presented by Clark Barshinger, Lojan LaRowe, and André Tapia in an essay in *Christianity Today*.

> Francisco Morales is a thirty-five year old Christian who has had ongoing struggle with both depression and OCD. He was put on a course of the SSRI Zoloft but soon found that in a fundamental manner he no longer needed God. He explains, "living without OCD has lowered my drive to deal with my sins. I've had to ask myself, Why am I a Christian? I now realize that before Zoloft, much of my motivation to follow Christ was out of desperation to feel good about myself. But if I can now feel good without God, why follow him?"[34]
>
> Don Timons was an executive in an evangelical organization. He had suffered for 10 years with depression, which often was manifested by uncontrollable angry outbursts at his co-workers. After each outburst, Timons would both repent for his actions and plea to God for help with

> his fury, but his depression and anger continued to plague him. After he had been put on Prozac for three weeks, he found his depression had disappeared and with it, his uncontrolled angry outbursts. He reveals that this transmogrification was "akin to how I felt during my conversion experience."[35]

These two cases are presented in the article "The Gospel According to Prozac," which has become the urtext of Christian responses to SSRIs. While Colvard and Wilson's case of the depressed seminarian ends with recovery, Barshinger, LaRowe, and Tapia's cases follow the same pattern but then bring forth the unintended side effects of the treatment, side effects that have for them profound theological consequences. In response to cases like this, they wonder, "Can it be that a pill can do what the Holy Spirit or human will could not?"[36]

They are also concerned with the cases described by Kramer, but they apply a different hermeneutics in their analysis from the way bioethicists have analyzed the cases. For example, consider the case of "Sam," whom Kramer presents in the introduction to *Listening to Prozac*. Sam was an architect who had been suffering from a "prolonged bout of melancholy." Kramer characterizes Sam as charming, independent, and quirky. A key problem in Sam's marriage was the issue of pornography. Sam not only had an active interest in hardcore pornography but also insisted that his wife watch the films with him; she found the films unpalatable, and Sam thought that her reaction was simply the result of being repressed and provincial. Kramer and Sam both came to see that the source of his melancholy was the failure of his business and the recent death of his parents; these events were entangled because Sam had hoped to take over his family's farm, but these plans would never be fulfilled. But contra Freud, the knowledge of the root of his depression (assuming, of course, that this was the root) did not help Sam overcome his melancholy. Kramer thought that in his history it seemed that there was a pattern of obsessional behavior and that this might also be factoring in to explain the ongoing sadness. Prozac had been out for less than a year when Kramer began his treatment of Sam, and it had a reputation for helping some patients who suffered from compulsiveness. When Kramer discussed with Sam the possibility of using the new drug to treat his condition, Sam agreed. Kramer relates, "The change, when it came, was remarkable: Sam not only recovered from his depression, he declared himself 'better than well.' "[37] But perhaps most interesting about Sam's case is that he lost interest in watching pornography. It was not that he enjoyed sex less than before being on Prozac but that one element of his sexuality had simply dissolved. Kramer even notes that Sam would still rent pornography videos, but it became a "chore" for him to watch them, and he did so only to not have to acknowledge to his wife that this had been in some manner related to his illness. For Sam, his "interest" with pornography became retranslated into a "biological tic." Sam comes to conclude that his obsession with pornography "had been mere physiological obsessionality."[38] Kramer is concerned primarily for the way in which the drug had "redefined what was essential and what contingent about his own personality."[39]

Barshinger, LaRowe, and Tapia, however, focus on something quite different. Religion is never mentioned in Kramer's presentation of Sam's case, but I suspect that the reason that Barshinger, LaRowe, and Tapia are interested in his case is because Prozac eliminates what from a Christian perspective they mark as inappropriate sexual interests. In fact, Sam himself is not troubled by what he describes to Kramer as "his independent style in sexual matters."[40] Barshinger, LaRowe, and Tapia are in many ways concerned that Sam no longer sins not because he came to any revelation about the moral nature of his action but because he no longer has that desire, and in turn interprets the desire as simply a result of biology rather than of moral choice. It would be as if just after the serpent tempts Eve in the Garden of Eden, a happy little rabbit shows up and gives her a pill that takes away any temptation she has for eating the forbidden fruit and disobeying God. If this were to happen, would we feel that Eve had lost free will? Can humans be human, from the Christian worldview, if they are saved from sin not by the development of a virtuous character but simply because they no longer have the desire to sin? "Prozac's dramatic effect on people's lives raises a key question for many Christians: What is sin and what is biology?"[41] Almost universally the various theologians, Christian philosophers, and pastors the authors ask have a perspective similar to that of Colvard and Wilson: they strongly reject the notion that in some manner Christians should not avail themselves of medical treatment for depression, yet these thinkers are also profoundly concerned about those cases in which an SSRI is prescribed for depression and then has a profound effect on the person's spiritual life or those in which the self that is healed is no longer the kind of self that can have a relationship to God. Morales, the doctoral student who had an ongoing problem with obsessive-compulsive behavior, also reports that he has become comfortable with his sinful nature. "I've become almost too comfortable with my sinfulness. It's such a heady thing feeling so free. There are days I feel hedonistic; it's like being on vacation from the person I used to be."[42] In this situation, it would be as if Adam and Eve ate the fruit of the Tree of Knowledge and then, confronted by God, felt neither guilty nor ashamed about being nude.

In the end, unlike Kramer, Barshinger, LaRowe, and Tapia move the discussion from one about identity (i.e., one focused on the agent) to one that focuses on how the individual relates to God (i.e., one focused on agency). "Ultimately, the primary concern for Christians is not what Prozac will do to them but the whole idea of relying on a miracle drug for emotional and psychological well-being rather than on the God of miracles."[43] The authors look at the issue from a variety of perspectives, which in turn often reflect an aspect of Burke's pentad. They discuss the American medical context, in which it seems everything is treated with a pill. They discuss the concern over identity and the existential crisis that can result when one feels that oneself is essentially mechanical. They discuss the issue of purpose that has informed a great deal of the discussion. There seems to be a general consensus that the drug should be given to people only with the purpose of relieving a clinical depression. But at each part of their discussion the central term that dominates the discussion is *agency*. The authors discuss the importance of pain as "a vital component of determining what is profitable in life and faith," for "[t]he key question remains: Is Prozac being seen as a shortcut?"[44]

As mentioned above, for Burke, those who emphasize agency in a discussion reflect a philosophy of pragmatism, a philosophy that emphasizes the instrumental elements of a problem. And it is interesting that in their final discussion about Prozac, Barshinger, LaRowe, and Tapia emphasize that this is simply another form of technology that Christians will have to learn how to respond to, as they have had to do for other forms of technology. In response to their final question, "Will Prozac replace religion?" they quote Lewis Smedes, who observes, "If religion is only to make people happy, then Prozac can replace religion. But religion is to bring people into contact with ultimate reality, then Prozac cannot. Happiness is a bonus, not the end goal."

In a direct response to "The Gospel According to Prozac," Michael Boivin, in "Finding God in Prozac or Finding Prozac in God," radically reshapes the issues raised by Barshinger, LaRowe, and Tapia by redescribing the problem and, in doing so, shifting the controlling term. Boivin acknowledges that this new generation of antidepressants has become profoundly entangled within contemporary American society and that it challenges Christians to rethink the nature of their religious life. Boivin, however, believes that we need to see Prozac's dramatic success as one part of a larger revolution in neuroscience that demands that we rethink the relationship between our brains and faith experiences. He notes the work done by neuroscientists to produce, through brain stimulation, religious experiences on people who are identified as unreligious. In one case, an individual, upon this stimulation, reported seeing Christ in a strobe light that was flashing during the experiment.

Boivin discusses the work that is being done in neurotheology, which looks at the relationship between transcendent experiences and changes in the brain. He summarizes this revolution in the following manner: "[W]ithin modern technological society, the essential aspects of personhood are being re-defined in psychobiological terms. This is due not only to such mood altering drugs as Prozac, but also due to a variety of technological advances in the biomedical, biogenetic, and behavioral neuroscience fields as illustrated in recent developments in neurotheology."[45] It would seem at first that Boivin is emphasizing scene over and against agency, agent, act, and purpose: fundamental theological notions are being challenged simply because of the times in which we are living. But Boivin's argument shifts as he argues that the real problem is that science to some degree is simply revealing a notion of the human person that was central to the way early Christians understood the body. Our notion of a radical dualism between body and soul is the result of the adaptation of certain Greek notions, especially Platonic ones, of the nature of self and reality. The Hebraic model of the person rejected any notion of there being a nonphysical entity that constituted an essential component of the human animal: "According to Old Testament thought, persons do not 'have' bodies but are bodies, such that all the important theological dimensions of personhood (i.e., soul, spirit, will, conscience, mind, heart) emerge or emanate from our physical beings."[46]

One might conclude that the key pentadic term in this part of his argument is that of act, for Boivin seems to shift away from the context as the determining factor and instead seems to ask us to reconsider the very act of taking an SSRI for depression. The act is not one in which a person's soul is being influenced by the physical alterations brought about by the drug, but rather the act is simply an interaction of different physical elements of the human person. So Boivin comes to the conclusion that the "enhanced spiritual well-being" a depressed person may experience following a course of Prozac is "authentic." At this point in his argument, however, he shifts the discussion again and emphasizes that the act must be understood within a larger religious vision. Boivin turns the discussion away from the act to the purpose of the act, but it is not the purpose of the act for the person of faith but the purpose of the act within the purpose of God. Boivin returns to the cases discussed in "The Gospel According to Prozac" and comes to see that "Prozac has its limitations in achieving such full and enduring restoration to emotional life in the garden, completely free of fear, shame, anger, and despair. Yet, such medications do not entirely miss a core aspect of the hope that awaits those destined to be fully restored emotional and psychobiological beings in God's Kingdom."[47] If we experience a form of redemption through Prozac, it is simply part of the physical resurrection and redemption that all will experience within God's stated plan for the earth. For Burke, to emphasize the term of purpose is an expression of the philosophical worldview of mysticism. As Burke explains, "Often the element of unity *per se* is treated as the essence of mysticism. We should contend, however, that not mere unity, but unity of the individual with some *cosmic* or *universal purpose* is the mark of mysticism."[48] And Boivin's redescription of what is happening when Christians take Prozac reveals a form of mystical philosophy. If we abandon the Platonic view of a divided world, the physical world and the world of salvation are the same thing: all is one.

In "Neuroscience and the Modification of Human Beings," D. Gareth Jones explicitly addresses the questions raised by Barshinger, LaRowe, and Tapia, and he draws upon Boivin's interpretation of Prozac's status within God's creation. He argues that regardless of how one answers the questions posed by Barshinger, LaRowe, and Tapia (Can a pill do what we normally think only the Holy Spirit can do?), one needs "to assert that there is an inextricable link between the biochemistry of the brain, who we are as persons, and how we relate to each other and to God."[49] Yet while he concurs with Boivin on the materiality of the human capacity to experience the eternal, he shifts his argument away from Boivin's larger vision of seeing SSRIs as a part of the redemption of human beings within God's purpose:

> It appears then that Prozac can have a role in healing emotional afflictions because we are persons who are part of God's physical creation, a creation that is maladaptive and in need of redemption. Prozac provides a limited means of redressing brain systems that have been warped by many forms of maladaptation and by itself is one means of effecting short-term restoration. Conversely, brain systems may also be redressed at least to some extent by restoring one's relationship to God.[50]

In this, we see Jones' shift from Boivin's worldview to that implied in Barshinger, LaRowe, and Tapia's description of the issue. Prozac is not part of a larger mystical vision that displays purpose as the key pentadic term, for his dominant describer of action is agency. And with that his argument of the larger question of a Christian response to neuroscience's relationship to the modifications of humans becomes governed by a pragmatist worldview. Christians should judge Prozac by its instrumentalism. For Jones, "what counts is the nature of the effect upon the individual as a person responsive to God and their world,"[51] so what matters is primarily our ability to judge the effect of any treatment to humans on their ability to respond in a manner that is judged appropriate by the Christian worldview.

PROZAC AND THE BUDDHIST MIND

To most people, Leslie did not seem depressed, but for those who knew her well, she suffered from "brooding rages" and had eventually alienated almost everyone in her life. For the past ten years she had been a devout Buddhist and for the past five years had undergone psychotherapy, but neither of these could help her. Her therapist recommended that she try a treatment of Prozac, but Leslie "was insulted, feeling that such an action would violate her Buddhist precepts."[52]

This is the case that Mark Epstein, a psychiatrist and Buddhist, presents at the beginning of his essay "Awakening with Prozac," which was published in the Buddhist magazine *Tricycle*. Epstein notes that for many Buddhists there is an expectation that if one properly follows the dharma and intensively practices meditation, one should be able to transcend these emotional problems or, even better, be able to use those emotional problems as grist for the mill of enlightenment. But while the concept of the mind has been dissected and examined closely in traditional Buddhist texts, there is little discussion in Buddhist philosophy of how one should respond to situations in which the mind is damaged to the degree that it cannot be healed through mediation. Like the Christian thinkers discussed above, Epstein argues that medical treatments for recognized mental illnesses do not in any manner violate the central precepts of the Buddhist faith. He notes that in the Tibetan Buddhist tradition there is an explicit recognition of illness for which the recommended treatment is pharmaceutical. Epstein points out that in this tradition there is recognition not only that one should not first seek meditation as the cure but also that meditation could actually exacerbate the illness.

There are, however, many practicing Buddhists who do not recognize this difference. Epstein presents a case of one of his patients who had been a practicing Buddhist since graduate school. Epstein says that this man was a brilliant mathematician but had suffered most of his life from debilitating depression, manic phases, and psychotic breaks (similar to the seminarian's problems). One episode was so severe that he was hospitalized. This man, however, refused to acknowledge that he was manic depressive and consequently refused to take any medications that would potentially prevent the episodes from recurring. In response to the suggestion that he needed medication, he quoted "the dharma to the effect of 'letting the mind rest in its natural state.' "[53] In the end, Epstein argues for Buddhists to respond to this issue by following the Buddha's teaching concerning the Middle Path. The Buddha taught that one should not seek enlightenment either through an excessive lifestyle or through ascetic practice but instead through a balanced path between them. Epstein concludes, "To suffer from psychiatric illness willfully, when treatment is mercifully available, is but a contemporary ascetic practice. The Buddha himself tried such ascetic practices, but gave them up. His counsel is worth keeping."[54]

Like Epstein, Judith Hooper, in "Prozac and Enlightened Mind: Can Antidepressants Help or Hinder Waking Up?," points out that traditionally Buddhist students who reported that they were depressed would be "prescribed more dharma." Today, she notes, there has become more acceptance of the use of medication for depression, but she also contends that Prozac raises some very "special problems" for Buddhists. "If one's object of inquiry is the mind, then the question becomes: Does altering this landscape affect the nature or efficacy of practice? Can Prozac help or hinder this process? Also, the question is tinged with a moral quandary: If I decide in favor of Prozac, am I somehow 'cheating' in my practice? Or, if I need such a drug, have I failed in my practice?"[55] In this view there are clearly some parallels to the way many Christians feel about Prozac. Does conquering depression through a drug rather than through God mean in some manner one has avoided the kind of growth in character that we expect of Christians? But the notion of "cheating" adds an additional twist in the Buddhist, for it poses enlightenment as akin to a game that one must "play" by the rules or it does not really count. From this perspective, achieving enlightenment is like participating in a marathon, but suppose instead of running the race one takes a taxi to the finish line. Has one won the race? If the objective is simply to arrive at a destination twenty-six miles away, then one could say that one has succeeded, but if the goal in some manner is competing fairly with others, then the addition of a car invalidates one's success.

Hooper observes that for many Buddhists enlightenment is attained not by adding elements to oneself but rather by diminishing the false understanding of the self. Prozac simply adds to one's trouble rather than taking the troubles away. It is a bit like being stuck in the illusions of Plato's cave, and instead of leaving the false shadows, one gets a high-definition TV that makes one see things as more authentic. Making the self more content is not the goal of Buddhism, for the goal is to see the self as an illusion itself.

Hooper discusses the perspective of Bernard Weitzman, who practices "contemplative psychotherapy." Weitzman sees depressed people to be in some manner "blessed," for they have lost any delusions they might have already possessed about reality, "they see things as they are." Following the cognitive approach to depression, he views these feelings as a manifestation of faulty thinking. Depression should be viewed as just grist for the mill in one's pursuit of the Buddhist goal of awakening. "No aspect of one's mind need be feared or obstructed. When you befriend all these tendencies, when you're willing to sit there in maitri practice and see, hear, and feel all that internally generated misery, then you become a person who is trustworthy to herself. A person who is not willing to include the texture of depression in her emotional space is not going to be compassionate." He believes that people, when they are put on Prozac, care less and a new personality takes control of their lives. Simply put, "I think it's a disaster."

An example of this particular attitude toward depression can be found in Philip Martin's *The Zen Path through Depression*, which Hooper quotes from extensively in her article. Martin himself suffered a profound depression and utilized his Zen Buddhist training to view the depression as an opportunity for growth in his spiritual path. Martin does on occasion make a brief (and oddly vague) mention of using medication, but he frames this as one choice that can be taken among others in response to depression:

> We have a fundamental choice. We can run from these feelings, which will only make them stronger. We can try to fit them into a framework of belief—either our own or someone else's. We can see depression in moral terms and believe that it is a sign of weakness. We can view it in medical terms and seek treatment with a physician. We can believe it is psychological and seek in our past for the answers. Or, before seeking any concept or explanation, we can do as Buddha did and look at things as they are. . . . We can examine ourselves without running, without fighting, without preconceptions, before any thought of a solution.[56]

It should be noted that Martin does refer to a notion of a Buddhist Middle Path between attempting to solve all of one's problems through medication and the equally extreme view of refusing medication as an option. But his view is very close to Weitzman's in that there is in his writing a prevailing theme that one should use depression as a tool to further one's goals of enlightenment. Martin also clearly indicates that he sees his response as akin to that taken by the Buddha himself. As many have noted, there are interesting similarities between the Buddha's own despondency that led him to abandon his wealth and family to seek an answer to questions about the nature of the world and the presentation of clinical depression.[57] And others, such as the popular Buddhist teacher Pema Chödrön, have clearly indicated that their "call" to Buddhism came through what they feel would now be classified as depression.[58]

Hooper presents the story of a friend who was on Paxil for three and a half years. Her friend described her emotional state as akin to the weather in California, always pleasant. "Everything was always fine. I didn't want to hear about anyone else's problems; I thought everyone should just be happy—like me. Now that I'm off it I have my feelings back. Of course, I have to admit it got me out of my depression." Hooper notes that Buddhism's First Noble Truth is life is dukkha, often translated as suffering but perhaps better translated as "unsatisfactoriness." But if an SSRI eliminates dukkha, one in many ways has reached a place that is similar to Christian concern that one becomes so content with life—including sin—that one feels no need to pursue the eternal: "But if I can now feel good without meditation, why do it?" Hooper observes that her friend's California state of mind is quite similar to the Buddhist goal of a detached mind, and she comes to conclude that "one's view of enlightenment informs how one thinks about depression."

Both Epstein and Hooper, as well as the various Buddhist thinkers they draw upon, emphasize the same pentadic term: *agent*. The philosophical worldview that emphasizes agent, for Burke, is idealism: "Idealistic philosophies think in terms of the 'ego,' the 'self,' the 'super-ego,' 'consciousness,' 'will,' the 'generalized I,' the 'subjective,' 'mind,' 'spirit,' the 'oversoul.'"[59] In his article Epstein quotes the Tibetan meditation master Kalu Rinpoche: "Nothing other than mind makes the universe, and nothing other than mind experiences it. Yet, still ultimately speaking, mind is fundamentally empty, no 'thing' in and of itself."[60] The ironic feature of using this controlling term in their discussions about depression and SSRIs is that while the controlling term is that of the agent, the personal self is from the Buddhist perspective itself an illusion. Interestingly, when Hooper discusses the extreme idealism of Bernard Weitzman, she glosses his position by asking, "Does this purist view mark Weitzman as part of the old guard in his community, or has he held out bravely against the inroads of an Americanized conception of enlightened mind?" The question implicitly supports the idealism expressed and the fear that the scene, contemporary American Buddhism, is in some manner the actual controlling feature that shapes one's particular definition of enlightenment. To Americanize Buddhism would in turn mean to question the universality of the worldview.

Conclusion: Describing Enhancement

In this chapter I have examined some of the reactions to SSRIs from some religious thinkers in two faith traditions. When the problem, assuming one believes there is a problem, is defined through particular controlling terms, the solution to the problem follows. Each form of problem setting in turn implicitly performs the solution. Some of the controlling terms imply a solution that is well beyond the power of any individual. The tendency of many bioethicists to define the problem through scene reflects a solution that would require the implied solution to be a radical transformation of the scene in which Prozac is taken. Our approval or disapproval of the medication relates to the degree by which we evaluate the American scene.

It is, of course, not surprising that religious thinkers evaluate Prozac within their worldview of the human capacity to have direct contact with the eternal. The degree to which Prozac challenges the religious worldview relates to how one describes its interaction within the faith tradition. Barshinger, LaRowe, and Tapia evaluate Prozac through agency and, in doing so, take on a pragmatic philosophy of instrumentalism, "you will know them by their fruits." Boivin provides a solution to the same problem by redescribing Prozac's interaction with Christians within a mystical view that emphasizes God's purpose. Essentially Boivin redescribes the problem in a manner that makes it not a problem. If one has the broader vision of the human world from God's perspective, Prozac is simply another component in salvation. The Buddhist reactions, however, cannot make this rhetorical move, for they do not have a personal God for whom they serve a larger purpose. While one could imagine that a Buddhist would also emphasize agency, the Buddhist worldview sees agency as simply part of the agent. If Prozac affects the agent, it also affects the core of Buddhism. For some, Prozac cannot provide liberation for it simply layers the agent with additional illusions to overcome. If there is acceptance of the use of Prozac, it is an acceptance for having it take away any barriers the agent might have to attaining enlightenment.

Behind this debate lies a greater question, and that is the very definition of enhancement. For most of the Christians and the Buddhists cited here, if Prozac is used as a cure it is acceptable, but if it is used as a form of spiritual enhancement it is deemed questionable. Boivin, however, redescribes Prozac as part of a larger cure for a fallen world, and thus dissolves the binary division that has defined the debate. The most powerful rhetorical move in the debate over enhancement technology is the ability to either depict a medical intervention as an enhancement or show that the division between treatment and enhancement is a false dichotomy. In the end, Burke's pentadic method provides a means of exposing this rhetorical move and thus seeing that in the end the key feature of the debate over enhancement technology is a debate over the definition of the problem.

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"LEAVE YOUR MEDICINE OUTSIDE"

Bioethics, Spirituality, and the Rhetoric of Appalachian Serpent Handlers

Bill J. Leonard

> A lot of people don't understand us. We are just normal people but we believe God's word.
>
> —Rev. Gene Sherbert[1]

> On August 6, [1995], Melinda [Duvall Brown] was bitten by a black timber rattler during services at the Full Gospel Tabernacle in Jesus Name in Middlesboro, Kentucky. She was twenty-eight years old and the mother of five. Before she reached for the serpent, she had begun to speak in tongues, which meant that she was fully anointed. The family grieves that it was her husband, Punkin, who handed her the snake, just as he had handed Melinda dozens of serpents in the past, and just as he himself had received them hundreds of times.[2]

So Fred Brown and Jeanne McDonald describe a dramatic moment in the annals of American serpent handlers, that small, theologically rarefied, and widely studied Appalachian Pentecostal-Holiness sect. The family saga continued when, barely three years later, Punkin Brown himself was dead, collapsing midsermon after being caught by the fangs of another rattler, dying near the pulpit of the Rock House Holiness Church in Macedonia, Alabama, on October 3, 1998. In life and death the Browns, Melinda and John (known as Punkin), might be considered poignant symbols of the nature of the serpent handling movement, its spirituality, dangers, and bioethical challenges. Indeed, the deaths of the Browns and other serpent handlers open the door to multiple religio-medical issues, a collision of bioethics and sectarian spirituality that may well be larger than the serpent handling tradition itself. For one thing, the Browns, like most other "serpent-bit" members of their sect, refused medical treatment. Melinda Brown lingered for some time after she was bitten, and Punkin recalled that when he urged her to go to hospital, she replied, "Have you lost your faith?" Punkin later reflected,

> Well, they wouldn't have treated her as long as she *refused* treatment. . . . She was twenty-eight years, buddy. They wouldn't have took her. She never lost her mind, never was out of her head. Yes, sir, I guarantee you she would have refused treatment at the hospital. She done did.[3]

Brown recalled his own experience with EMS after one of the numerous occasions when he was bitten but survived, commenting,

> I got bit [one time] and they called the ambulance to come and get me. I don't know who called them. But they come. I was living in a little ole trailer, and the ambulance driver stuck his head in. He wouldn't even come in the door. That was in Georgia. He said, "We hear there was a snakebite victim here." I was laying on the couch. I said, "Yeah, me." He said, "Do you want treatment?" I said, "No, I don't want no treatment." I said, "I got bit in church. That's what I believe in. . . ." He said, "Well, we had to come and ask you. Do you care to sign this paper releasing us, saying that we come?" I said, "No, I'll sign your paper, *but leave your medicine outside*." So he come in, and I signed his paper, and he set there a minute, and he left.[4]

Brown's words, "Leave your medicine outside," provide a powerful image for examining elements of the serpent handling sect, a faith community that stretches certain medical and bioethical issues to the limit as they act on their beliefs in ways they think authenticate the total trustworthiness of God's word.

Through the rhetoric of gospel preaching, serpent handlers articulate their theological and hermeneutical identity in remarkably creative ways. In one sense, the Appalachian serpent handlers offer alternative approaches to medical treatment based on their distinct approach to biblical literalism and Pentecostal spirituality. Their extreme form of holiness asceticism sets them against "standard" medical procedures in certain matters of faith, authority, and toxic substances. Their actions are distinct from but parallel to health and ethics issues raised by Jehovah's Witnesses, Christian Science practitioners, and other faith healing movements. As they see it, their serpent handling, poison-drinking pursuits point beyond themselves by "confirming the word" of God for the entire Christian church. The phrase "confirming the word with signs following" comes from Mark 16:17-20 in the so-called "long ending" of Mark's gospel. As "King James only" Christians, they affirm the inerrant inspiration of that specific biblical text, reading,

> And these signs shall follow them that believe; In my name shall they cast out devils; they shall speak with new tongues; They shall take up serpents; and if they drink any deadly thing, it shall not hurt them; they shall lay hands on the sick, and they shall recover. So then after the Lord had spoken unto them, he was received up into heaven, and sat on the right hand of God. And they went forth, and preached everywhere, the Lord working with them, and confirming the word with signs following.[5]

In their worship life serpent handlers physically enact each of these "signs," all with significant biological consequences. They *speak* in tongues (glossolalia), a public and personal language of prayer, adoration, and communication with the Divine, a sign of Spirit anointing. They *lay hands* on the sick, responding to sickness and disease with spiritual resources. They *cast out* demons, seeking to rid the body of forces that produce spiritual and physical devastation. They *take up* poisonous serpents that can and do bite them with varying physical, neurological consequences. They *drink* poison—strychnine, battery acid, and other solutions—ingesting deadly substances into their bodies of their own free will. Likewise, their descriptions of the *anointing*, a source of divine empowerment that leads them to take up serpents and drink poison, illustrate another spirit/body response to the presence of the Holy Spirit in the life of the believer. Although most serpent handlers do not eschew medical care all together, these biblically motivated practices seem to produce a sense of divine protection or providential acceptance that compels them to refuse medical treatment when their charismatic activities turn into self-inflicted wounds. When such a calling or anointing occurs, they simply refuse to accommodate emergency medical responses. Thus the Markan text becomes its own bioethical formula, and their hermeneutic put them at odds with the medical majority.

The Bioethical Implications of Serpent Handling

Despite their liturgical eccentricities and deep piety, despite the popular caricatures and extensive media attention thrust upon them, serpent handlers in no way represent a normative religious community in the Appalachian region. Rather they are a tiny sect grounded in biblical literalism and a

Pentecostal spirituality with particular emphasis on one specific gospel text that informs the intensity of their actions and identity. On numerous levels they demonstrate alternative responses to varying bioethics-related issues. While the serpent handlers have been the subject of various historical, theological, and phenomenological studies, limited attention has been given to the bioethical implications of their unique faith and practice.[6]

This chapter examines the Appalachian serpent-handling tradition as an illustration of ways in which religious belief and rhetoric collide with bioethics to inform specific types of medical treatment, faith healing, and certain self-induced medical crises that raise numerous end-of-life questions. It suggests that serpent handlers constitute a religious community that applies classic biblical texts in ways that impact broader discussions of rhetoric, religious experience, and medical ethics in Appalachia and beyond. Likewise, the rhetorical ethos of the serpent handlers demonstrates what might be called a premodern response to biblical criticism, Christian experience, and medical treatment, not only in cases in which believers are bitten by snakes, but also in the overall implication of a literalist theology for interpreting personal spirituality, faith healing, and individual mortality. If nothing else, Appalachian serpent handlers resist ecclesiastical, governmental, and biotechnological efforts to domesticate their alternative spirituality and their premodern hermeneutical approach to ancient texts.

In what ways might the actions and beliefs of the serpent-handling sect engage or encounter bioethical issues? Among the many defining elements of the discipline of bioethics, the following seem most pertinent to consideration of the beliefs and actions of the serpent handlers. They include

- The study of value judgments pertaining to human conduct in the areas of biology and biotechnology
- The study and consideration of what is right and wrong in biological advances and activities such as . . . the care of the terminally ill
- The study of the moral and ethical choices scientists and doctors face in medical research and in the treatment of patients
- The exploration of moral and ethical questions surrounding life, health, science, medicine, and the environment.[7]

How then are students of bioethics to engage the serpent-handling community, their practices, and resulting biomedical issues? After asserting that "[t]he bioethicist and audience or constituency are interdependent," Boston

College ethicist Lisa Sowle Cahill contemplates the role of biblical images or theological concepts that may unite or divide such constituencies.[8] She notes that in any discourse, biblical texts may be used on either side of a given ethical question. For example, she acknowledges that the image of creation may be used by some persons "to rule out certain biomedical acts or practices as 'playing God,' " or by others to "underwrite human freedom as part of what it means to be a cocreator with God." Cahill concludes, "The uses of images depend in part on the practices and communities in which they are embedded and the practices and policies they are meant to encourage or discourage."[9] At the same time, she refuses to accept "all types of religious advocacy as morally equal or equally representative of the ideals of the Christian biblical and theological traditions."[10] Thus, we may ask, what biblical and theological "ideals" do the serpent handlers represent? Are their ideas and actions "morally equal" to those of the larger Christian tradition or simply a strange sectarian anomaly?

Cahill's insights outline the dilemma that ethicists confront in examining questions and images raised by the serpent handlers. Are their practices and resulting bioethical implications "born of human freedom" as colaborers with God, or are they simply serpent-handling, poison-drinking attempts at "playing God"? When Cahill calls for energizing and renewing "a theological ethics of inclusion, participation, equality and empowerment, especially for the least well-off," would she incorporate the serpent handlers into such a constituency?[11] Are their serpent-handling practices an obedient response to the teaching of the New Testament as they perceive it or simply a misguided form of assisted suicide with frenetic biblical overtones? What are the implications for the medical system when serpent handlers refuse treatment after having been bitten? In such situations, where does religious liberty end and medical protection begin?

One important response to such questions comes from Ralph W. Hood Jr., University of Tennessee (Chattanooga) psychology professor, in an essay titled "When the Spirit Maims and Kills: Social Psychological Considerations of the History of Serpent Handling Sects and the Narrative of Handlers." Hood, who has written extensively on serpent-handling sects, introduces the essay by insisting that serpent handlers "are not a bizarre aberration of religion doomed to extinction. They are a deviant religious sect with importance both for the scientific study of religion and for the theological implications of their beliefs and practices. The textual justification for serpent handling presented in typical believer narratives reveals a rich tradition whose practices and rituals are within Pentecostalism."[12]

Hood contends that while the larger Pentecostal movements "accommodated" elements of modernity and institutionalization, the serpent handlers refused to do so. He concludes, "It is the serpent that helps maintain a powerful protest against modernity and hence, inhibits the growth that accommodations to modernity can produce." Hood believes that their approach, centered in unique "theological understandings" and a "search for textual justification of intense emotionality," "remains ultimately uncontrollable" by social, religious, and medical establishments.[13]

THE RHETORIC OF THE SERPENT HANDLERS

The serpent handlers' rhetoric seems equally "uncontrollable." In a sense, the links between written and spoken word are so close as to make the rhetoric of the serpent handlers a distinct illustration of the power of oral tradition in galvanizing actions and identity in a specific faith community. Deborah McCauley says, "It is a preaching tradition that relies exclusively on what is experienced and perceived to be the direct inspiration of the Holy Ghost. . . . [Thus] God speaks through the preach who does everything in his (or her) power to step aside, simply to be a 'willing instrument' and not get too much in the way."[14] Through the Spirit-led spontaneity of their preaching and their use of biblical texts and images committed to memory, serpent-handling preachers illustrate something of another era of oral tradition in American preaching, not unlike that present in frontier revivals and camp meetings.[15]

In their use of the biblical text, whether in sermon or personal testimony, serpent handlers offer a dramatic illustration of David Tracy's assertion that ancient texts resist "domestication." Tracy writes that our "temptation to domesticate all reality is a temptation that any classic text will resist. The classics resist our ingrained laziness and self-satisfaction. Their claim to attention must be heeded."[16] As a vehicle for proclaiming the word of God, the rhetoric of the serpent handlers represents a refusal to be domesticated by institutionalized Protestant-Pentecostalism in approaching particular texts (especially Mark 16:17-20) and in the implications of those texts for informing issues of religious experience, life, death, and biology.

Eleanor Dickinson cited West Virginia preacher Elzie Preast's sermonic commentary on the necessity of serpent handling:

> But it does say, "They shall take up serpents." And Jesus is the one's doing the talking. Said, "They shall take them up." Well, I've got to do it, or

> somebody's got to do it, or else it makes Jesus out a liar, because if I tell you shall go out that door, it means that you've got to go out there, one way or the other. . . . If we don't do it, Jesus can raise up a people that will do it.[17]

Other preachers consistently echo that belief. I witnessed my first serpent handling in June 1990 at a Saylor family reunion and revival service near Berea, Kentucky. Brother Byron, one of several preachers present, was a colorful rhetorician, vigorously articulating his theology while handling a serpent then and again throughout the sermon. At one point, cradling the reptile in his arms, he declared, "When it [the Holy Ghost] moves just right this thing [the serpent] ain't more than just a little bitty baby. Glory be to the Most High God!"[18] Brother Byron recalled a time when he was bitten by a serpent: "I suffered real bad from that thing, but I went and I flipped the word of God open and I read Mark 16 and it said 'They shall take up serpents.' It didn't change cause I got bit and hurt. I believed it so strong even [though] bit and hurt, I took it up [again] anyhow. . . . If it's good enough to live by, it's good enough to die by. . . . If the Lord said, 'They shall rassle grizzly bears' I'd go get me one. That's how much I believe the word."[19] He concluded with a warning to the compromisers: "We're living in a modern time; you can take your modernism and go on to hell!"[20]

For the serpent handlers, as for members of most Christian communities, the spoken word says what the enacted word means. Through their pulpit rhetoric serpent handlers offer their own "words of institution" that inform their liturgical actions in immersion baptism, communion, foot washing, and the "five signs" they believe mandated in Mark 16. This link between word and action led Mary Lee Daugherty to describe "serpent-handling as a sacrament" for a religious community that minimized the Lord's Supper in favor of another "outward and visible sign of an inward and spiritual grace." She wrote, "Time and again they prove to themselves that Jesus has the power to deliver them from death here and now." Even when serpents are handled at the funerals of persons dying from snake bite, the action, she believed, seemed to replicate the way "a Catholic priest may lift up the host at a mass for the dead, indicating belief that in the life and death of Jesus there is victory over death."[21]

The authority for serpent handling comes from the "anointing," a profound sense of the power of the Holy Spirit that comes over the believer. Preacher Liston Pack described it: "When I get anointed, numbness starts in my face and in my hands, and it feels like oil dripping out of my fingers. It's symbolic, too, if your arm went plumb to sleep. But it's full of joy. . . . I feel like I'm walking in another world. It's hard to explain."[22] Preacher Robert Grooms calls the anointing "like feeling the heat from a light bulb. It's tremendous. It came over me in such a fantastic way. I felt it through my whole body. I just went plumb out in under the power. But I knew exactly what it was for. God was telling me to take up the serpent."[23] Even the decision to handle serpents has physiological overtones.

As I have written elsewhere, for serpent handlers the sacrament is alive and can kill you, and every time you gather for worship it is a matter of life and death, an experience of the real presence of Christ made known through the Holy Ghost and the victory over the serpent.[24] They join the larger Pentecostal community in both affirming and practicing elements of faith healing but with a poignant approach to the physical and spiritual implications of their own crisis-inducing exploits with poisonous reptiles. Their rhetoric is clearly in the style of Appalachian mountain preachers, but with decided theological distinctions voiced from an inerrant text.

The idea of an enacted word may well have overtones for recent studies in "visual rhetoric" as described by Robert Hariman and John Louis Lucaites in a 2007 study. They write that such "public discourse is understood to channel social energies through structures of representation that can be labeled rhetorical, ideological, aesthetic, political, and more. Public texts are complex mediations of experience. In every case the focus is on how the material practice enables and constrains actors and audiences alike as they try to acquire knowledge, apply values, and otherwise do the work of making agreements and building consent."[25] While they in no way reference serpent handlers in their study, they raise questions that are worth asking of the spoken and enacted word clearly evident in serpent-handling communities. Viewing the serpent-handling acts in person, on film, or in photos requires no caption, and the images take on the form of icons that "make some beliefs and actions more intelligible, probable, and appealing, and others less so."[26]

A Theology for Serpent Handling

The resistance of many, but not all, serpent handlers to post-snake-bite medical attention is at once a response to "man-made" science, biblical constancy, and the providential sovereignty of the Divine. Indeed, serpent handler Gregory Coots summarized the realities of divine providence in his assessment of Punkin Brown's way of death:

> Only God can give life and take life. Punkin had an appointed time. The serpent was the way for him to go. That was his appointed time. It didn't matter how many doctors, or who was there. That was his appointed time then. He went through many a bite, so if that hadn't been his appointed time right then, he'd still be here today. Whenever your appointed time comes, that the end.[27]

As Coots' comments indicate, serpent handlers confront bioethical issues in multiple ways. Each time they take up the dreaded serpent they knowingly face the spiritual and physical possibility of introducing a toxin into their bodies that, while unwelcome, is itself (1) a physiological sign of the validation of scripture, (2) an act of faith or spiritual anointing, and (3) a potentially sacrificial death as decisive as that of any apostolic martyr. Even those who are bitten and live may actually "bear in their body the marks of the Lord Jesus" (Gal 6:17) since the poison can permanently maim them. Indeed, their actions with serpents often seem to parallel stories of some of the early Christian martyrs who apparently did not wait for danger to come to them, but offered themselves to a life-and-death sacrifice in the cause of Christ. This kind of self-sacrifice was practiced but generally not encouraged in the early Christian centuries.[28] Yet the serpent handlers themselves resist the idea that they are seeking martyrdom. Rather, they are simply "confirming the word" whatever the providential results of such procedures may be. Death, however, brings at least implicit martyrdom as the faith community works to explain or at least respond to the serpent-generated end of life of one of their own.

For them, the words in Mark 16 are a postresurrection mandate from the living Christ. The "signs" that "follow them that believe" are the ultimate verification of genuine faith. They assist believers in discerning true and false Christianity. They share three of those signs—casting devils, speaking with "new tongues" (glossolalia), and laying hands on the sick—with the larger Pentecostal movement, tracing their roots to early twentieth-century America with Charles Fox Parham in Kansas City and William Seymour at the Azusa Street Mission in Los Angeles. In their extensive analysis of serpent handling, Ralph Hood Jr. and W. Paul Williamson suggest that the beginnings of Pentecostalism are tied not only to the Church of God and the Church of God Prophecy, but also to "their bastard children who persist as the renegade Churches of God."[29] Indications are that many of the early Church of God leaders linked their own biblical literalism with the Mark 16 text and at least acknowledged the possibility that these Pentecostal gifts could be restored, backing off such assertions as they established a larger identity within American Protestantism.[30]

In his study of American Pentecostalism, Grant Wacker insists that a major spiritual emphasis of the movement involved a "longing for direct contact with the divine." He calls that emphasis "otherworldliness, sometimes heavenly mindedness." Wacker concludes,

> Most often, however, I call it *primitivism*, for that term seems most precisely to register the impulse's exact nature. Primitivism suggests, in accord with its Latin root *primus*, a determination to return to first things, original things, fundamental things. It denotes believers' yearning to be guided solely by God's Spirit in every aspect of their lives, however great or small. With this term I hope to connote not so much an upward reach for transcendence as a downward or even backward quest for the infinitely pure and powerful fount of being itself.[31]

Such primitivism may also be understood as a form of Christian restorationism, a desire to replicate the spiritual power and dynamic of the earliest Christians at Pentecost and beyond.

Serpent handlers are thus a subsect of the Pentecostal-Holiness tradition, reflecting a spirituality that is both theologically and regionally distinct, evident in what Deborah McCauley calls "Appalachian mountain religion," with "its own historical integrity that informs its uniqueness."[32] McCauley notes that "mountain religion has consciously continued doctrinal traditions of *grace* and the *Holy Spirit*, especially by maintaining the centrality of *religious experience* (from the ordinary to the extraordinary) in the worship life of mountain church communities."[33] In her widely cited study McCauley acknowledged that "serpent handlers are, of course, what an overwhelming majority of 'outsiders' consider to be mountain religion's most fascinating tradition and its primary claim to fame." Yet she noted that many scholars fail to acknowledge the regional and doctrinal differences inside the serpent-handling movement itself, especially in distinctions that divide Trinitarian and Jesus Only serpent handlers.[34] The former affirm traditional Trinitarian understanding of the Godhead as Father, Son, and Holy Spirit, while the latter insist that Jesus is the complete embodiment of the Christian deity.[35]

McCauley suggested that while the serpent-handling phenomenon in Appalachia began with a Church of God preacher named George Hensley around 1909–10, academic interest in the movement did not begin until sometime in the 1940s. She challenged their prominence as the religious movement most characteristic of the Appalachian region, insisting, "From popular culture to social science research, they were elevated to the position of being the primary representative of what is special and unique about 'religion in Appalachia' only in the late 1950s to early 1960s."[36] At the same time, serpent handlers are sons and daughters of Appalachia, sharing many elements of the faith with their mountain Pentecostal counterparts.

As part of the Pentecostal family, serpent handlers are conversionists, demanding a "personal experience with Jesus" (justification by grace through faith) of all who would claim to be Christians. They are also sanctificationists, insisting that Christian discipleship requires the baptism of the Holy Ghost evidenced by speaking in tongues. Sanctification—living toward Christian perfection—mandates holiness of life. In fact, when asked to identify their kind of Christianity, most serpent handlers are likely to say, "We are holiness," evident in sanctification by the Holy Spirit that leads to an ethic of strictly regulated behavior. Most churches forbid members to drink alcohol or use tobacco, watch movies, dance or go to night clubs. Most women wear dresses that cover their body, arms, and legs; men wear long sleeves but often refuse to wear neckties since doing so implies worldliness and a lack of humility. Other believers use tobacco, wear suits, and have less rigorous dress codes. Some permit televisions in their homes but with careful regulations, especially for children. Generally, women in the serpent-handling churches refuse to cut their hair, while men keep their hair closely trimmed as required by 1 Corinthians 11:14-15: "Doth not even nature itself teach you, that if a man have long hair it is a shame unto him? But if a woman have long hair, it is a glory to her: for her hair is given her for a covering."[37]

Such holiness codes can spill over into such bioethical issues as sexual orientation and physical relationships. The serpent handling preacher Arnold Saylor told researcher David Kimbrough,

> I am against women cutting their hair, and I will tell you why. If a woman says she is cutting the dead ends off her hair, the next thing she does is cut off to her shoulders, because she claims it is hot. Then she cuts it off like a man's next. The next time you see her she will be wearing britches. I believe that cutting off the first dead end of hair is a gradual, step-by-step process to developing the spirit of a homosexual. It is a sin for a woman to act like a man. One thing leads to another. Even the small things.[38]

Serpent-handling pastor Jimmy Morrow offers his own theological speculation about the origins of homosexuality, asserting,

> After the flood the fallen angels, or demons, entered man at Sodom and Gomorrah and they became homosexuals. . . . The homosexuals were not born that way—a demon has entered them. The angels that were created cannot reproduce and knew that they cannot, so Lucifer and his fallen angels entered into the human race and both men and women become homosexuals whom [*sic*] cannot reproduce. . . . The homosexuals can be set free from the demons that have overtaken their minds. If they would go to church, a church that believes in the five signs with a true preacher of God would cast out their demons in the name of Jesus Christ, they would be saved.[39]

Amid concerns about homosexuality, many members of serpent-handling congregations adhere to passages such as 2 Corinthians 12–13, "Greet one another with a holy kiss," a practice that many holiness folk believe should only be between members of the same sex. In certain contexts, serpent-handling males kiss other males on the mouth, and married couples may also exchange such kisses. Arnold Saylor commented, "You have to use wisdom. Men shouldn't be kissing women other than their wife. If I would encourage that kind of stuff, it wouldn't be long before they would be kissing for reasons other than religion."[40] Likewise, foot-washing observances reflect a physical intimacy, generally regulated between the sexes.[41]

SERPENT HANDLERS AND FAITH HEALING: THE QUESTION OF MEDICAL TREATMENT

Serpent handlers believe in faith healing, not only in response to snake bites, but also in their overall approach to medical treatment. In *The Serpent Handlers*, Brown and McDonald include a verbatim quote from Gregory Coots, who details his medical treatment for a "fungus" that required him to take Septra DS and then Dilantin for seizures. When the seizures continued even with increased Dilantin, Coots attended a service in which he felt inspired to ask the preacher to "come over, [and] put his arm around me." Before the words were out of his mouth the preacher did exactly that. Coots reported, "And from that time to this, I've never took another Dilantin. Lord healed me of that then, that night I asked him. He healed me that night, and I've not took no more medicine since then and never had a seizure since then. . . . If I get sick [now], I just wait on the Lord to move it. . . . So I don't take nothin'. I'd rather trust the Lord to take care of it than take medicine."[42] In a sense, serpent handlers live with a preference for faith healing. They take advantage of medical care, but appear ready to bypass or negotiate it through the experience of faith healing.

Some serpent handlers feel or experience the alienation of their commitments when they seek institutional-based health care. Linda Smith Coots asserted,

> But I'll tell you the reason that some people that handle serpents and get bit don't go to the hospital. We get a bad rap, and we get talked real bad about. [If you're a serpent handler and] you go to the hospital, [you'll] see how they talk to you. They treat you like dirt. They talk to you like a dog because you were handling serpents. . . . And professionally, they have no right treating you [badly]. But what are you going to do? It's your word against theirs, against the hospital.[43]

Coots' comments reflect the ethical complexity confronted by medical professionals in the Appalachian region. While medical practitioners have a right to their interpretations of serpent-handling practices, how are they to respond to individuals whose actions they dismiss? What techniques for responding to serpent handlers or practitioners in other isolated communities of faith might they employ?

When bites do occur, many, perhaps most, serpent handlers choose to "suffer out the bite" without benefit of hospital care. Bishop Kelly Williams offered one interpretation after his son's death. "When death comes to a man, God has done it. Had this boy gone to the hospital and then died, it might have hurt their [other believers'] faith. But he refused to take any medicine. Seeing this boy's victory of faith strengthens theirs." He concluded, "I'm not proud of my son dying . . . but I'm glad he died in the faith."[44]

In a 1976 interview serpent handling farmer Lester Ricker reported being bitten and suffering for twelve hours. When asked if he went to hospital, he replied, "No, Ma'am, I don't believe in going to a doctor when I get serpent bit. See, if God lets the serpent bite you, I don't see that you have the right to do anything to it. God can heal you." Ricker's pastor, Liston Pack, further explained, "Anyone who participates in the serpent handling, we don't tell them what to do, but we'd rather if they're going to handle serpents and get bit, just to trust the Lord even if it takes them to the hillside to be buried."[45]

Nonetheless, death from snake bite is no easy "home going." When Reverend Randy "Mack" Wolford died in West Virginia in May 2012, *Washington Post* photographer Lauren Pond was present and, with the family's permission, documented his dying. Afterward, she wrote,

> This is what I saw through my camera lens: . . . Wolford, tossing and turning on the couch in his mother-in-law's West Virginia trailer, suffering from the pain of a rattlesnake bite he had received earlier in the day. Parishioners surrounding him in prayer in the stifling heat. His mother stroking his feet, her expression a mixture of concern, sorrow and, eventually, acceptance: This is how her eldest son—a legend in the local Pentecostal serpent-handling community—would die. Camera in hand, I watched as the man I'd photographed and gotten to know over the past year writhed, turned pale and slipped away, a victim of his unwavering faith, but also a testament to it. A family member called paramedics when Mack finally allowed it, but it was too late. Mack Wolford drew his final, labored breaths late Sunday night. He was 44.[46]

In her essay, Pond asks the larger ethical question:

> As a photojournalist, what role did I have in this tragedy, and what is it now, in the aftermath? Was it right for me to remain in the background taking pictures, as I did, and not seek medical attention for the dying pastor, whose beliefs forbade it? Or should I have intervened and called paramedics earlier, which would have undermined Mack's wishes?[47]

She cites one serpent handler who confessed, "Sometimes, I feel like we're all guilty of negligent homicide," and asked, "I was face-to-face with him and watched him die a gruesome death. . . . Is this really what God wants?"[48]

Of her personal dilemma Pond concluded that although her profession demands noninterference, "when someone is hurt and suffering, we have to balance our instincts as professionals with basic human decency and care." She concluded, "In my mind, Mack's situation was different from that of a starving child or a civilian wounded in war. He was a competent adult who decided to stand by what he understood to be the word of God, no matter the consequences. And so I've started to come to peace with the fact that everyone in the crowded trailer, including myself, *let Mack die as a man true to his faith.*"[49]

CONCLUSIONS

Pastor Wolford's death serves as a case study for varied reflections on the ethical quandaries posed by serpent handlers. First, there is clearly much for outsiders to critique in the serpent-handling sect. Their primary proof text in Mark 16 was added to scripture in the second century, their rhetoric is extreme, and their spirituality seems to promote an irrational obsession with life-threatening, orphan-generating liturgies of death. Indeed, the hard edges of serpent handlers' spirituality—poisonous serpents and battery acid—make it difficult if not impossible to sentimentalize the movement in response to the deep faith and piety of the practitioners.

Second, amid the criticisms, the serpent handlers may serve as twenty-first-century counterparts to a variety of nonconformist, eccentric, and marginalized sects throughout Christian history, textual extremists who put their lives on the line in a quest for the meaning of text and truth. While their practices may be unique to the Appalachian Mountains, their spirituality is evident in early Christian martyrologies and the Spirit-obsessed Montanist movement of the second-century church. Like the medieval Cathari (Albigensians), against whom Pope Innocent III instigated a crusade, they tamper with sacramental theology. The Cathari abandoned the baptism and Eucharist of a "false church" for the *endura*, an ascetic ordinance that involved starving oneself to death. Like assorted mystics and desert stylites, the serpent handlers have chosen to pursue an immoderate literalism, anchored in holiness and life-threatening liturgy. Christian history itself is rife with accounts of saints, ascetics, and heretics whose spirituality was inseparable from body-assaulting extremes. Their actions may be unique, but their body-related spirituality is nothing new.

Third, the serpent handlers' responses to the medical establishment raise multiple issues that have implications for bioethics. These include (1) the treatment of serpent handlers by health care providers, not simply medically, but culturally as well; (2) an understanding of the serpent handlers in the context of groups whose actions stretch health care norms, including not only Jehovah's Witnesses, Christian Science practitioners, and other Pentecostals, but also NASCAR drivers, bungee jumpers, and climbers of Mount Everest; and (3) an understanding that studies in bioethics should not overlook the presence and practices of radical faith healers, including their promises and over-promises.

Fourth, serpent handlers also illustrate numerous issues related to the nature of religion and rhetoric. These include (1) the continuing power of oral tradition in a specific isolated faith community; (2) the powerful links between the written, spoken, and enacted word, and (3) a peculiar, a singular illustration perhaps, of the impact of religious, sectarian "visual rhetoric," a phenomenon well worth further study.

Fifth, an apt description of their faith and practices may be found in borrowing Roger Gottlieb's phrase, "the spirituality of resistance."[50] This kind of spirituality is dangerous, ornery, intense, and problematic all at once. It is found in those for whom the truth of a particular religious ideology cannot be compromised by modernity, pluralism, institutionalization, or medical sanctuary from the dangers of faith. Such dissenting spirituality is difficult if not impossible to civilize. It resists easy compliance with any spiritual process that seems to compromise genuine religious experience, authoritative witness, or mystical transformation.

Finally, in many ways, the statement of Punkin Brown, "*leave your medicine outside*," and Lauren Pond's hesitant comment, "*everyone . . . let Mack [Wolford] die as a man true to his faith*," reflect the bioethical dilemma created by the serpent-handling sect. It is one thing to handle serpents in response to a perceived biblical imperative, and another to refuse medical treatment when the serpent follows its natural defensive inclinations. If medical care is limited only to certifying death by serpent handling, if patient consent is absolute, and if serpent handling endures, then others will surely follow Brown and Wolford to their eternal reward. Until the Spirit offers another revelation, medical communities will have to live the biological and ethical dilemmas raised by a people committed to "confirming the word with signs following."

8

Biovaluable Stories and a Narrative Ethics of Reconfigurable Bodies

Arthur W. Frank

The dream is very old. The ancient historian Thucydides describes the curious effect that plague in Athens had on those who survived it. They realized they were now immune, unlikely to contract the disease again, and if they did, unlikely to die. These people then generalized that sense of immunity. Thucydides writes, "They themselves were so elated at the time of their recovery that they fondly imagined that they could *never die of any other disease in the future*."[1] Reading Thucydides today, we might well ask, was he reporting a dream, or was he creating one?

This chapter, written at the intersection of science and technology studies, narrative theory, and bioethics, concerns *biovalue*, a useful neologism coined by Catherine Waldby.[2] Waldby defines biovalue as "the yield of vitality produced by the biotechnical reformulation of living processes . . . biotechnology produces a margin of biovalue, a surplus of fragmentary vitality." Waldby distinguishes two forms of biovalue, adapting Karl Marx's distinction between use value and exchange value. The use value is the "hope . . . of some viable contribution to human health." The exchange value is "the production . . . of biological commodities that can be bought and sold," including the patenting of cell lines that "as intellectual property" become "possible sources of profit for their investors."[3]

A rich academic literature depicts how biovalue is created; besides Waldby's work, frequently cited studies include the research of Sarah Franklin, Donna Haraway, Carlos Novas, Paul Rabinow, and Nikolas Rose. These studies combine ethnography of laboratory science with analyses of texts that publicize this science and make claims for it. Biovalue reached the best-seller lists in the journalist Rebecca Skloot's investigative report, *The Immortal Life of Henrietta Lacks*, telling the story of how cells taken from Mrs. Lacks during surgery were used to generate the HeLa cell line, but without the knowledge of Mrs. Lacks or her surviving family.[4] This story has generated bioethics discussion of what seems wrong about what happened and what remedy might be available.[5]

This chapter, as a narrative analysis, examines how stories of biovalue become what I call biovaluable stories. Biovalue, I argue, depends crucially on stories, for the following simple reason. Biovalue's current exchange value—potential sources of profit and thus present reasons for investment—depends on promises of its eventual use value. Like all promises, promises of future uses for biotechnology are performative: they are enacted by being stated.[6] Before biovalue takes the form of actual treatments and remedies—before it has actual use value—it acquires exchange value through claims made in the form of stories that promise future use.

Biovaluable stories generate biovalue. Some biovaluable stories are told with the strategic purpose of generating exchange value, and other stories generate biovalue as an unintended effect. My argument, as a narrative theorist rather than an ethnographer of scientific practice, is that the production of biovalue takes place in multiple media and genres of storytelling. Diverse forms and venues of storytelling include popular science writing, business reports for investors, annual reports of companies, scientific journal articles, and, especially important for this chapter, bioethics commentaries and opinions. To address the bioethics of biovalue, attention to storytelling is as important as tracing movements from laboratories to eventual product marketing and clinical application. Again, biovaluable stories are crucial because most of biovalue's use value remains speculative; it is promissory rather than deliverable. Only biovaluable stories can generate exchange value, which they do by doing what stories have a particular capacity for: making people believe something is real.[7]

Belief in the value of biovalue has multiple effects, but two are obvious and crucial. One side is investor confidence, whether those investors are private, including venture capital, or public, including national scientific granting councils. The other side is public expectation and acceptance. Biovaluable stories condition the public toward an uncanny sense that future clinical applications of biovalue have already happened. That future-perfect understanding—referring to the will-have-been verb tense—has multiple functions, but especially important, it forecloses critical objection. I argue that this future-perfect understanding of new technologies is distinctly modern.

As pervasive as biovaluable stories are, few stories are ever uncontested. A different collection of stories expresses fear of a world dominated by biovalue. These stories perpetuate a tradition summarized by novelist and cultural critic Margaret Atwood: "In the latter half of the twentieth century, two visionary books cast their shadows over our futures. One was George Orwell's 1949 novel, *Nineteen Eighty-Four*, with its horrific vision of a brutal, mind-controlling, totalitarian state. . . . The other was Aldous Huxley's *Brave New World* (1932), which proposed a different and softer form of totalitarianism."[8] Atwood herself is a noted practitioner within this tradition, having written three novels of future dystopias, two of which are based on misuse or failure of biotechnology.[9] If biovaluable stories inflate the promises of biotechnology, and thus its exchange value, dystopian stories are deflationary, eliciting fear of what could have potential benefit.

This chapter begins by saying more about what biovalue is, and in particular, what kind of medicine utilizes and increasingly depends upon biovalue and what kind of human bodies biovalue imagines and creates. I then pose the central ethical question of which stories we ought to believe: the inflationary or the deflationary. Or is there a possibility of holding both kinds of stories in some form of tension? Asking those questions already demonstrates a narrative ethics of biotechnology, its stories, and its bodies. Such an ethics does not propose any template for choosing, but it can inform choices, not least by observing the curious symbiosis between biovaluable stories and stories of biotechnological dystopias.

What Is Biovalue?

In the 1950s I was among the first cohort of schoolchildren to receive the Salk vaccine to prevent polio. In medical history books I see grainy photos of children lined up in school gyms, and I remember being there myself. I had already had other vaccinations, but that one was historically memorable. As I was vaccinated, my body—specifically my immune system—was reconfigured. The difference might have been invisible, but at a time when polio was a fearful reality, the effect of that reconfiguration was real. I had had my first experience of biovalue. In Waldby terms, my margin of vitality was increased. And I began to think differently of what was an appropriate, even necessary, means of caring for myself.

Biovalue is created by and then instigates fundamental changes in what counts as medicine in the twenty-first century. The sociologist Nikolas Rose presents an excellent short summary:

> "Medicine" . . . has become technomedicine, highly dependent on sophisticated diagnostic and therapeutic equipment. It has been fractured by a complex division of labor among specialists. Doctors have lost the monopoly of the diagnostic gaze and of therapeutic calculation: the clinical judgment of the practicing physician is hemmed in and constrained . . . [the] treatment of health and illness [is] merely another field for calculations of corporate profitability."[10]

Rose emphasizes how medicine has been "reshaped by its intense capitalization"; how "human vitality has been opened up, at the molecular level, for technological innovation, economic exploitation, and for highly competitive forms of bioeconomics."[11]

Physicians have not simply lost their monopoly of the diagnostic gaze; their pride of place within medicine has been displaced by multiple new actors who understand physicians as their agents, not vice versa: venture capitalists, corporate CEOs and shareholders (dependent on selling pharmaceuticals, medical equipment, and insurance, among other products), political policy makers (who determine reimbursement schedules and public/private cost allocations), and patient advocacy groups (which both fundraise and can affect participation in clinical trials), among many other new actors.[12] Each of these actors is engaged in and depends upon the production of biovalue, in the most general sense of the exchange value of medical products and services.

Waldby's usage of biovalue is more specific. Summarizing the developments in organ transplantation, IVF, and the creation of stem cell lines, Waldby writes, "the human body can be disaggregated into fragments that are derived from a particular person, but are no longer constitutive of human identity."[13] Or at least biovalue's claim is that these fragments are no longer constitutive of human identity. Waldby points out that biovalue requires the transition from a gift economy, in which blood or organs are donated in acts of altruism, to a capitalized economy in which biotechnology collects fragments, processes them, and then sells them, yielding biovalue. For the sales model to be legitimate, what is sold must "be interpreted in non-personified ways, as . . . the product not of human donation but medical ingenuity."[14]

The much-publicized case of Henrietta Lacks exemplifies how the generation of biovalue requires legal validation that value depends not on the original gift but on the medical ingenuity that turns tissue into research value and eventually therapeutic value. The front-cover description of the book offers a popularized narrative of biovalue: "Doctors took her cells without asking. Those cells never died. They launched a medical revolution and a multimillion-dollar industry. More than twenty years later, her children found out. *Their lives would never be the same.*"[15] What exactly is contested here is not biovalue itself—the medical value of the cells is affirmed—but rather lack of consent and one-sided allocation of the profits. The closing lines of the book underscore the overall ambivalence about what wrong was done to Henrietta Lacks and her family and what remedy is appropriate. One of the surviving family members says, "I don't want to cause problems for science . . . besides, I'm proud of my mother and what she done for science. I just hope [Johns] Hopkins and some of the other folks who benefitted off her cells will do something to honor her and make right with the family."[16]

One among many troublesome issues in this statement is what counts as science. The statement is understood quite different when it is heard in the context of Skloot's earlier interview with Nobel Prize–winning scientist Baruch Blumberg, who generally affirms the value of commercialization but adds, "Researchers have become entrepreneurs. That's boomed our economy and created incentives to do research. But it's also brought problems, like secrecy and arguments over who owns what."[17]

Who owns what was most famously contested in the lawsuit brought by John Moore against researchers who derived a stem cell line from tissues taken from him first during surgery and later in biopsies conducted without informing Moore of their purpose. The court found that Moore's physician had violated fiduciary interest, but it found against Moore's financial claims. Skloot summarizes the judgment: "It said that ruling in Moore's favor might 'destroy the economic incentive to conduct important medical research,' and that giving patients property rights in their tissues might 'hinder research by restricting access to the necessary raw materials.' "[18] Thus, when the Lacks family member asks for Johns Hopkins University, as principal beneficiary of the cell line's profits, to "make right with the family," a far-reaching precedent is involved, affecting acknowledgment of who is entitled to share in the profits generated by tissue economies. As Waldby writes, researchers (who are also entrepreneurs) have to claim that medical ingenuity alone adds value to what the court in Moore calls "raw materials."

John Moore never had a best-selling book written about his case; Henrietta Lacks, for reasons that deserve a chapter of their own, makes a better story. Rebecca Skloot's book might be called a biovalue-cynical story, but it is not a bio-dystopia. Skloot never questions the value of the knowledge made possible by the HeLa cell line, but she also makes it clear that the individuals and institutions that benefitted did not "make right" with the Lacks family—nothing even close to right. From a narrative perspective, and eventually from a bioethics perspective, Skloot's popularization of the Lacks story works to effect the cultural shift glossed by Rose as "human beings [coming] to experience themselves in new ways as biological creatures, as biological selves, their vital existence [becoming] . . . a target of novel forms of authority and expertise . . . an expanding territory for bioeconomic exploitation."[19]

A narrative perspective begins with asking exactly how people experience themselves in new ways. Books like *The Immortal Life of Henrietta Lacks* participate in generating a new experience of oneself. To a reader with my demographics, the story of the Lacks family might at first seem to be about things that happen to other people, things from which I am safeguarded, until I reach Skloot's Afterword, where she points out, "When you go to the doctor for a routine blood test or to have a mole removed, when you have an appendectomy, tonsillectomy, or any other kind of *ectomy*, the stuff you leave behind doesn't always get thrown out. Doctors, hospitals, and laboratories keep it. Often indefinitely."[20] I then think about all my tissues that are . . . somewhere. I think of myself as "raw material" but perhaps as a beneficiary of the use value of future discovery. In either role, as unwitting donor or as recipient, I am a reconfigured body. I learn to be this body, I learn how to experience it, by hearing stories like that of Henrietta Lacks, from which I learn to tell my own stories.

Biotechnology is an occasion for storytelling, and storytelling creates and contests biovalue. Human beings always come to experience themselves in new ways by telling stories that reshape the past according to how we understand the present, or perhaps want to understand the present. We tell stories about the present that select what supports our hopes and justifies our fears about the future. And we tell stories about the future that call for or render questionable ways of acting in the present. Before directly engaging biovaluable stories, a short excursus is necessary, arguing what is distinctively modern in the assumptions that generate our stories about biovalue.

BIOVALUE AND MODERNITY

The sociologist Norbert Elias, in his magisterial work *The Civilizing Process*, tells the following story about a technology that once was new.[21] "In the eleventh century," Elias writes, "a Venetian doge married a Greek princess. In her Byzantine circle the fork was clearly in use. At any rate, we hear that she lifted food to her mouth 'by means of little golden forks with two prongs.'

This gave rise in Venice to a dreadful scandal: 'This novelty was regarded as so excessive a sign of refinement that the dogaressa was severely rebuked by the ecclesiastics who called down divine wrath upon her. Shortly afterward she was afflicted by a repulsive illness and St Bonaventure did not hesitate to declare that this was a punishment of God.'"[22]

To say that the eleventh-century Venetians were clearly not what we would call early adopters is more than a quip. The *early adopter* describes a distinctly contemporary type of person who is more than someone who wants the newest technogadgets. The early adopter exemplifies a distinctly modern desire to acquire something new with only vague expectations for its use but with a willingness, even a hope, to change one's life in response to what the new acquisition makes possible. The relevant question of acquisition is not "What will I use it for?" but rather "Do I trust it to guide me to do new things and so to experience myself in a new way?" In phrasing this latter question, I believe *trust* is the relevant verb, but the early adopter does not make a conscious decision to trust. There never was a decision: trusting the new is as much a modern assumption about how to live as the eleventh-century Venetians trusted God to punish transgression.

Yet something about the story of the unfortunate Greek princess cuts across time. We moderns retain some premodern distrust of the new. Atwood provides a selective genealogy of literary expressions of distrust specifically in science. Her earliest example is Jonathan Swift's *Gulliver's Travels*, which Swift began around 1721.[23] In book 3 Gulliver discovers "the Grand Academy of Lagado with its five hundred scientific experiments, and the immortal Struldbrugs of Luggnagg," for whom immortality works out very badly. The scientists in the Grand Academy—a satire of the Royal Society—perform absurd experiments, although some of these can be interpreted as remarkably prescient of later science. These scientists are not wicked, "and they aren't really demented" Atwood writes. "But they have tunnel vision, much like a present-day scientist quoted recently, who, when asked why he'd created a polio virus from scratch, answered that he'd done it because the polio virus was a simple one, and that next time he'd create a more complex virus. A question most of us would have understood to have meant, 'Why would you do such a potentially dangerous thing?'—a question about ends—was taken by him to be a question about means." Atwood's conclusion expresses much of what worries people today about biotechnology: "[Scientists] don't intend to cause harm, but by refusing to admit the adverse consequences of their actions, they cause it anyway."[24]

"Science was just coming into being in the age of Swift," Atwood writes. "Now it's fully formed, but we're still afraid of it." Afraid, yet fascinated. Atwood notes that H. G. Wells' *The Island of Doctor Moreau*, published in 1896, has inspired three films. More than these specific retellings, "The story has taken on a life of its own, and, like the offspring of Mary Shelley's *Frankenstein*, has acquired attributes and meanings not present in the original."[25] Stories proliferate about science creating monsters that then turn upon people; in the fortunate phrase of storyteller Terry Pratchett, some stories grow "fat on the retelling," eventually etching "grooves deep enough for people to follow in the same way water follows certain paths down a mountainside."[26]

Modernity's ambivalence about science reflects a deeper ambivalence about life itself. I find this ambivalence best expressed by the poet Constantine Cavafy, writing in 1898. His poem "Waiting for the Barbarians" is truly a fable, a story in verse. The ancient Romans gather in the square because today is the day the barbarians are supposed to arrive. The emperor has awoken early to welcome the barbarian leader; the senators have given up making new laws; and the orators have given up speaking, of which people were bored anyway. Then there is uneasiness and confusion; faces grow serious. The barbarians have not come, and worse yet, messengers from the frontier report there are no barbarians anymore. What is to become of us, the narrator asks. "Those people were a sort of solution."[27]

Victor Frankenstein's creature with its excessive vitality and Dr. Jekyll's transformations in Mr. Hyde are sorts of solutions. These creatures are to be feared, but the greater fear is that they might not arrive. That ambivalence haunts modernity and sets the stage for the present generation of biotechnology. What is new is biovalue. Neither Dr. Frankenstein nor Dr. Jekyll was an entrepreneur, much less fronting a corporation and answering to investors.

WHAT STORIES WILL YOU BELIEVE?

Another lesson from the story of the Greek princess is that any technology—whether it is forks or stem cells—requires recognition in order to be implemented. Recognition entails some measure of belief in the desirability and necessity of such a technology, and that belief precedes tests of efficacy: the Venetian ecclesiastics did not try the forks before condemning them. Tests of efficacy make sense only when people already believe in the principle of the technology—what it is trying to do. I have argued that in modernity, we are primed to believe that the new can be a solution. We await solutions to a world that risks boring us—Cavafy's ancient Romans are us moderns in costume. Stories about biotechnology become biovaluable when they create recognition and desire for a future permeated by biotechnologies. Is it possible we might actually be less interested in the eventual product than in continuing the stories about future products?

Atwood suggests four types of human alteration that biotechnology most frequently offers: genetic alteration, nanotechnology ("single-atom-layer gizmos that can replicate themselves and assemble and disassemble matter," used to effect body repair), cybernetics ("the melding of man with machine"), and cryogenics ("getting yourself or your budget-version head flash-frozen until such time as the yellow-brick road to immortality has been built").[28] Biovaluable stories can be specifically about claims for particular proto-technologies—annual reports and investment prospectuses are sources for such stories—but this chapter focuses on two very different stories that illustrate the diversity and complexity of how narrative creates biovalue. One story is a mass-media report of a biotechnology that is all too readily available right now, and the other is a futuristic speculation written for a specialized bioethics readership. I represent these stories not as generalizable types of biovaluable stories, but only as usefully diverse examples of how stories create biovalue.

The first story, or collection of stories, is a feature in the *New York Times* that presented stories posted by high school students who were asked to write about their use of "study drugs," that is, prescription drugs (Adderall is given as an example) that students take in order to improve academic performance, often at especially competitive junctures such as examinations.[29] The students' stories follow a similar narrative template with remarkably little variation. The student is in stressful period; a friend offers a pill that is unexpectedly effective; continuing use of the drug is blamed on parents imposing high expectations for performance; finally, in some stories, unwanted side effects are reported, limiting use. No prolonged adverse effects are reported. In a couple of stories, moral reservations are expressed.

This feature is presented in the journalistic genre of social problems report, yet the students' stories become biovaluable because they are easily read as testimonials for drug use. For example, "It worked. I was thinking faster, harder, there was no fog—and nothing could distract me. I felt like Sherlock Holmes or something." That endorsement is qualified by the student adding that because he had not studied, his grade was still disappointing, but he learns that lesson and his later use "saved my grades that quarter, kept me alert and awake even without sleep, they made me more sociable, more quick-witted, and I finished every task or project I started." Eventually, there is a "comedown" that includes hand shaking, appetite loss, and feeling "like dying," but the story leaves open whether those effects could have been mitigated by more careful dosage. The testimonial value is clearly qualified, but it is still a testimonial. Other stories repeat the same message: "I was surprised how effortlessly my work got done," a remark that is especially interesting for its use of the passive voice.

The *New York Times* feature presents responses to an invitation that reads in part, "Have you or fellow classmates taken study drugs . . . ? Please describe your experiences with these drugs." A genre for these stories is proposed: "Are they a problem in your school?" But the responses do not fit the proposed genre. The students, asked to describe what the journalist understands as a social problem, write stronger product claims than regulators would allow pharmaceutical companies to advertise. What can be read as a "problem" story for schools and society can also be read as a "solution" story for individual students. We see here how stories are inherently *out of control*; "once a story is put into play, it will have effects that neither [the] storyteller nor [the] listeners can control."[30] Stories "can always be told to a different effect."[31]

The title of this section—What Stories Will You Believe?—thus expresses only half the issue. People have to choose not only which stories to believe, but also how to believe any single story. The "study-drugs" stories can be heard as utopian or dystopian. To a critic appalled by what Rose calls "neurochemical selves,"[32] the study-drugs stories are dystopian. To a student struggling to meet what seem to be unattainable expectations, the stories can be heard as utopian, encouraging the use of study drugs as effective (if dangerous in excess) and also morally permissible insofar as actual study is still required. The drugs allow emergence only of an optimal version of a true self. As one student posts, "They let you use what you have, nothing more, and nothing less. That is enough. You can use what you have for longer, and it works more effectively."

All the students' stories agree is that study drugs confer biovalue, thus the stories are biovaluable. The neurochemical self produced through drug use is more successful according to measures imposed by schools. Some students express moral reservations—"I knew that I had cheated"—but in most stories biovalue trumps moral compunction: "I feel pressured to use them or suffer the consequences of being ethical."

In choosing these stories of biovalue, my essential point is that biovaluable stories are already ubiquitous, and while many are told strategically to elicit investment, others are told for diverse purposes—even to oppose biotechnology—but end up being biovaluable despite the teller's intentions. The stories affirm what Rose calls "neurochemical citizenship,"[33] because the characters in these stories model asking oneself, as a first response to almost any physical ailment or simple limitation, "Isn't there something I could take for this?" The constant potential for added vitality becomes an assumption of selfhood, and lines blur between ought-to-take (as in good medical citizenship requiring completion of the full course of an antibiotic) and morally questionable (Should a student feel guilty for taking study drugs? On whom should any guilt fall, given what systems demand?).

The nature of modernity, from the telegraph through trains to jet planes, is to fracture what were previously considered natural limits to which humans were subject. Transportation and communications systems reorder time and space; biotechnology continues that process. As Waldby writes, "The biovalue produced by stem cell technologies depends on complex temporal reconfigurations, the engineering of cellular, embryonic and ultimately ontological time. I would argue that the manipulation of the time scales and trajectories of biological fragments is one of the major biotechnological strategies for the production of biovalue."[34]

The ultimate reordering of what has seemed to be the natural trajectory of life involves claims for immortality, and my focus now shifts from a readily available biotechnology to the kind of biotechnical speculation that is characterized as transhumanist. The philosopher Michael Hauskeller finds the origin of that term in the writing of Julian Huxley in 1927. Huxley proposed that "the human species can and should transcend itself 'by realizing new possibilities' of and for human nature."[35]

One of Hauskeller's contemporary exemplars of transhumanism is the philosopher and bioethicist Nick Bostrom. Bostrom's 2005 article "The Fable of the Dragon Tyrant" might seem so speculative as to be dismissible, unless we read it with the study-drugs stories still resonating.[36] The students in those stories were introduced to cognitive enhancement drugs by friends who offered oral biovaluable stories, testifying to the efficacy of the drugs. Bostrom presents himself as just that sort of friend, who in this case recognizes that we humans are what the students would call "stressed" by the prospect of death. No pill is already on the market, but Bostrom tells a story that prepares humans—beginning with the specialized inner circle of those who read the *Journal of Medical Ethics*—to think differently about their biological limits, to be willing to act differently upon their biological selves, and, in the short term, to mobilize investment in biotechnological research that will realize the dream of immortality.

Bostrom's article, until the last page, truly is a fable, beginning, "Once upon a time, the planet was tyrannised by a giant dragon." The dragon demands a tribute of ten thousand men and woman a day; "the misery inflicted by the dragon tyrant was incalculable." Humanity adjusts, with promises of life after death easing the misery. "Other orators argued that the dragon had its place in the natural order . . . it was part of the very meaning of being human to end up in the dragon's stomach." A "cadre of dragonologists" study the dragon's physiology and behaviour, at first concluding that "the general perception of its invincibility was confirmed." There were, however, "a few iconoclastic dragonologists" who argued that killing the dragon was possible but required a new technology: "The manufacture of the needed quantity of the composite material [capable of piercing the dragon's scales] would . . . be expensive."[37]

Progress on the dragon-killing technology is slowed down by other demands on the king and his finances: a killer tiger has to be eliminated and then an infestation of snakes. Moreover, people are skeptical: "They had been taught in school that the dragon tyrant was invincible and that the sacrifices it demanded had to be accepted as a fact of life." Economic interest supported this skepticism: "The dragon administration provided many jobs that would be lost if the dragon was slaughtered." Finally, arguments about the blessings of finite human life are overcome when a little boy—as in any good fable, the truth teller is a child—says he wants his dead Granny back. Opinion shifts. "Mass rallies raised money for the projectile project and urged the king to increase the level of state support. The king responded to these appeals . . . [passing] an extra appropriations bill to support the project at a high level of funding."[38]

The climax is delayed by multiple crises of confidence, but finally the projectile is launched and the dragon killed. The king's immediate response is remorse: "Yes, we did it, we killed the dragon today. But damn, why did we start so late? This could have been done five, maybe ten years ago! Millions of people wouldn't have had to die."[39]

Bostrom is self-consciously telling a counterstory to what he understands as traditional "'deathist' stories and ideologies, which counsel passive acceptance" of death. Such stories "are no longer harmless sources of consolation. They are reckless and dangerous barriers to urgently needed action." He goes on to make a typically modernist claim that past attempts to end dying are no precedent for contemporary possibilities: "They failed to take into account accelerated technological progress."[40] Taking a utilitarian line, Bostrom castigates the king for having the wrong priorities when he diverted funds to shorter-term projects of getting rid of the tiger and the snakes. Those actions served too few people, allowing a far greater number of deaths to occur. "Searching for a cure for aging is not just a nice thing that we should perhaps one day get around to," Bostrom concludes; "It is an urgent, screaming moral imperative. The sooner we start a focused research programme, the sooner we will get results."[41]

Bostrom's argument is anticipated by Atwood, writing about Swift's projectors in his Grand Academy of Lagado. "All we have to do is give them more money and more time and let them have their way, and everything will get a lot better very soon. It's a likely story, and one we've heard many times since the advent of applied science."[42] Atwood acknowledges that "[s]ometimes this story ends well, at least for a while—science did lower the mortality rate" and has provided other apparent benefits. "But," and here Atwood provides a model of the skeptical narrative of biotechnology, "the doctrine of unanticipated consequences applies quite regularly to the results of scientific 'improvements,' " and she provides numerous examples of how science has "promised freedom" and ended up delivering "servitude."[43] To which the transhumanist response is that accelerated technological progress *now* makes it possible to deliver without what have been, due to past technological limitations, unanticipated consequences.[44]

Supporting Atwood's skepticism, Hauskeller demonstrates how the narrative form of transhumanist arguments "not only evoke mythical places such as the Land of Cockaigne, the Isles of the Blessed, or the Golden Age, in which men lived like gods; they also echo the promises of alchemy and later of modern science to secure wealth and happiness for all human beings."[45] These resonances of older stories give transhumanist fables like Bostrom's their power to affect listeners' imaginations, but their danger is that "they effectively conceal the fact that we actually have no idea whether the suggested transformations of the human body and mind would really work out as suggested."[46] Bostrom is at his most speculative about what life without death would actually look like: "Maybe people will have to learn to have children later and less frequently. Maybe they can find ways to sustain a larger population by using more efficient technology."[47] Bostrom has no idea how the massive investment he calls for would actually be used. What if the king, having developed this new projectile, now decides to use it to subjugate the neighboring kingdom?

Which story or counterstory will you believe? The sociologist Philip Smith writes that conflicts over policy—Smith's specific concern is decision making about going to war—are less about facts and more about "interpretive frames" within which facts are understood as indicating courses of action.[48] "We can think of this agonistic struggle as a genre war in which the interested parties try to impose their version of reality by providing not simply generic statements of position, but rather by attempting to institutionalize and disseminate a broader, more diffuse and therefore more powerful genre of interpretation through the public sphere." Smith later quotes the literary scholar E. D. Hirsch, writing, "[E]very disagreement about an interpretation is usually a disagreement about genre."[49] The agonistic struggle between transhumanists like Bostrom, who tell stories that inflate biovalue, and skeptics like Atwood and Hauskeller, who deflate biovalue, can be understood as a disagreement about genre, but that implies that the utopian and dystopian genres are opposed to one another, and their relation seems more complex.

What makes thinking about biovalue so difficult is that utopias and dystopias are more symbiotic than agonistic. Their surface agonism generates an energy on which both depend—stories in each genre are compelling because the background possibility of the other genre, as an interpretive frame, provides dramatic tension. Atwood, noting this symbiosis, coins the term *ustopia* to "combine utopia and dystopia—the imagined perfect society and its opposite—because, in my view, each contains a latent version of the other."[50] As evidence that Atwood is correct, reconsider the study-drugs stories solicited by the *New York Times*. Whether we read those stories as deflating biovalue by reporting abuse of prescription drugs or as increasing biovalue by reporting the relative efficacy of cognitive enhancement drugs is, as Smith and Hirsch argue, a disagreement about genre in the broad sense of interpretive frame. But as each interpretation deconstructs its apparent opposite, Atwood's conclusion gets at the deeper connection between the two interpretations. As Atwood says, "[E]ach contains a latent version of the other."[51]

The issue is more complicated than deciding which story to believe or which genre provides the better framework for interpretation. Biovaluable stories sustain their fascination because the inflations and deflations of biovalue each feed off the other. We truly live in Atwood's ustopia, and the question is how best to live there.

A NARRATIVE ETHICS OF BIOVALUABLE STORIES

If biovalue is constituted in stories—whether these are reports of current activity, as in the study-drugs stories, or imaginative projections of the future, as in Bostrom's tyrant dragon fable—then to respond to a world in which biovaluable stories will continue to be told, we need a narrative ethic. *Narrative ethics* has two complementary phases: analyzing stories and telling its own stories.[52] A narrative ethics of biotechnology must have both a capacity to analyze stories that create recognition of possibilities and shape action and also a capacity to generate not necessarily counterstories, but stories that expand human imaginations of how to use biotechnology; that is, how biotechnology can fit into or disrupt projects of human flourishing.[53]

The narrative-ethics work of analyzing biovaluable stories is to argue what is wrong about Bostrom's fable as an allegory. My principal objection is that his story encourages thinking about densely networked assemblages as if they were unified wholes. Death is not singular; to imagine death in the persona of the dragon—a single being with its own goals and demands—is mistaken. "Death" is a catchall description for the outcome of multiple complex processes: interactions between aging and deterioration, disease, and injury. Death is not some Other that, as in Bostrom's version, has a specific physical being and location. Of course Bostrom knows this, but his story requires thinking of death as singular, to make it sensible to have a research-driven War on Death.

Because death is multiple, there can be no single projectile launched to destroy it. Instead, multiple remedies will be developed *and sold* to individuals for specific deteriorations and diseases—which takes us back to biovalue as exchange. Bostrom's fable leads readers to imagine a massive *public* project, the benefits of which are immediately equally distributed. Much of the investment in biotechnologies is private, and private investment expects returns. Any benefits of biotechnology, as these accrue in fragments, will be marketed and unequally distributed.

The figure of the king is the complementary distortion. There could not be a single research project to end death, in part because death is multiple, and in part because *research* is a complex of endeavors, carried out with different objectives (some closer to what is called pure science, some with more immediate, applied goals), different funding (public and private, although those often overlap), and different institutional bases. In Bostrom's fable, research has two tasks: discover a substance hard enough to pierce the dragon's scales and launch a projectile. In reality, biotechnology comprises innumerable projects driven by constant, everyday decisions with diverse expected outcomes. There is no equivalent of the figure of the king, nor could there be.

By unifying both death and research into the single figures of the dragon and the king, Bostrom encourages thinking in terms of a take-it-or-leave-it response to biotechnology; his fable imagines a one-time, for-or-against decision, representing the consensus of a collectivity. Again, he knows that is not how the future will unfold. There will be innumerable local decisions, hedged in various ways, each having a combination of intended and unintended outcomes, especially unintended in how the outcomes mutually reinforce each other. Instead of one big shall-we-or-shan't-we decision, actors with very different relevances and responsibilities—researchers, investors, point-of-sale prescribers or treatment providers, and patient/consumers—will make small decisions that have unanticipated cumulative effects, both in their personal lives and in the progress of the species.

The *New York Times* study-drugs stories depict this reality of small decisions. What happens mixes unanticipated combinations of prescription practices that end up making drugs available without prescription, the efficacy of medications being used off-label, the competitive demands of an education system and its terms of measuring achievement, and finally individual students' decisions to take a pill in one circumstance but not another. Behind or beyond the actual drug use lies a complexity of relationships among pharmaceutical companies, medical associations that set prescribing guidelines, drug regulatory bodies, schools, teachers, parents, organizations that produce standardized tests, universities that utilize those tests—the intersecting networks have no fixed boundaries. Decisions of multiple actors about how to act in these relationships—each deciding how to play his, her, or its part—all do come down to moments in which students ingest drugs. Someone puts pills in his or her mouth. But the stories show considerable nuance about which drugs are taken, in what circumstances, responding to what influences. The nuance continues in the stories from older students about when drug use stopped or simply seemed no longer worth doing.

My point is that moral life proceeds not in grand moments of collective will, but rather in variously considered daily acts that are affected by extensive networks of relationships.[54] This view seeks to balance individual moral responsibility with an awareness of the complex interactions that sustain the multiple networks that we call *biotechnology*, a usage that too readily lends itself to being imagined in some singular persona, like Bostrom's king.

To argue that Bostrom's fable is misleading for thinking about biotechnology and biovalue is not, however, to dismiss stories as *moral guidance systems*. Stories are indispensable guides, for several reasons. One is that there is a good reason why some stories grow fat on retelling; they inform life in useful ways. Stories' plot lines, showing connections between actions and consequences, are old, and while circumstances do change, traditional wisdom should not be dismissed. A second reason is that people live their lives as characters who are in the middle of a story and have no idea how it will end; we need guidance. So we tell stories that do have finite endings, and then we extrapolate from how things worked out for those characters to learn what we can for ourselves. Again, such guidance always risks being unreliable, but it may be the best that humans have available—if, and crucially, we have a sufficiently broad range of stories to guide us.[55] A lesson I take from human history is that people are most prone to act badly when they are guided by only one narrative that imperializes their imaginations, blocking consideration of stories that suggest other and often less happy endings to the acts being contemplated.

One crucial qualification to having responses to biotechnology guided by narrative ethics is suggested by Waldby, who argues the inadequacy of reasserting "the categories and morality of a humanist bioethics."[56] Narrative analyses frequently reflect humanist assumptions by making the consciousness of the storyteller central. My own approach to narrative analysis, informed by science and technology studies, seeks to decenter consciousness by understanding storytelling as relational activity in which humans are acted upon, even as they act. Crucially, stories are understood as provisionally independent of humans.[57]

Waldby's argument, with which I agree, depends on an understanding of the human body that recognizes we have already crossed the biotechnological threshold—recall my earlier anecdote about being among the first cohort of children to have my immune system reconfigured by the polio vaccine.[58] Waldby writes, "Stem cell technologies, like many other contemporary biotechnologies, make evident the fact that the human is not a natural, biological category but rather a status and being emerging from a complex network of technobiological production. Contemporary biotechnology demands a bioethics that can understand the complex reciprocities and technical mediations between human and non-human entities, and frame ways of living that acknowledge this"[59] On my reading, this acknowledgment is most usefully presented and developed in the work of Donna

Haraway, whose multiple contributions defy tagging by any single academic discipline.[60]

Whatever Haraway's topic, she asserts the centrality of the question, how do we tell stories that acknowledge the instability of boundaries, especially the boundaries of individual bodies and of humanity as a species, and embrace the multiple forms of *companionship* that define our being? Haraway's best-known figure, the cyborg, embraces her multiple parts and origins. The cyborg knows herself not as what Waldby characterizes as the humanist "natural, biological category," but rather as "emerging from a complex network of technobiological production."[61] At least in my version of narrative ethics, stories emerge from complex networks of narrative production. Yet humans can still decide which stories to tell and be guided by.

Narrative ethics, for me, is neither for nor against biotechnology, because biotechnology is nothing more, or less, than humans continuing to progressively change themselves and their environments. What narrative ethics can be against are biovaluable stories that inflate more than they deflate, for the obvious reason that exchange value—capitalization—depends on promises. These inflationary biovaluable stories are poor companions for responding to the serious questions that biotechnologies require confronting.

For all that is new, the core ethical questions that occur with biotechnology are old ones: Who will pay what price for what becomes others' benefit, and how will future benefits be distributed? Agricultural surplus raised these questions; railroads raised these questions; where I live, these questions are raised by natural resource development/exploitation; and study drugs raise these same questions. The kind of stories that narrative ethics needs to foster imagine bodies that acknowledge themselves living in multiple biological and narrative companionships, variously reconfigured by technological interventions, but sustaining what I believe remains viable in humanist ethics: the ideal that we humans can be guided for better or worse. We have some capacity to decide which stories are more reliable guides as we make the constant, limited, but cumulative decisions of acceptance and refusal that shape our personal and collective futures.

9

BLACKS AND THE LANGUAGE OF THEIR BIOTECHNOLOGICAL FUTURE

Ezra E. H. Griffith

In their introduction to this volume, the thoughtful editors suggest a definition that has biotechnology promising to renew damaged organs, restore lost vision or mobility, and extend life itself. So on its face, the promise stands for an almost majestically positive article of faith about what the future will hold. And yes, there is something religious sounding about the promise. It brings to mind the fifth verse of Psalm 30: "weeping may endure for a night, but joy cometh in the morning." This idea of what biotechnology may provide is almost akin to reaching the biblical promised land. Suffering will be reduced, and consequently a better life is in store for us—all of us—in the future. However, members of nondominant groups, such as blacks in the context of these United States, may have a more nuanced view of their relationship with biotechnological developments; hence, their use of language to describe their biotechnological future may in some ways be different from what we may expect to hear from others.

The experiences of blacks in the United States differ significantly from those of members of other ethnic groups, even when those other ethnic group members have experienced discrimination and oppression. It has been pointed out that the systematic relegation of blacks to second-class citizenship status in this country has made their oppression unique. Blacks' racial identity, as they emerged from this oppression, has in turn influenced their appraisals of situations and behaviors.[1] However, without exploring the extensive scholarship that has been carried out on the problem of blacks' racial identity, I wish to make the point that blacks may understandably have their own point of view about the subject of biotechnological advancement—one that may be linked to their sociocultural history in the United States. It therefore makes good sense to afford them some voice to make their own statement about the matter. It is "their significance of difference from the dominant other" that catalyzes curiosity about their views.[2]

I make the assumption, too, with some hopefulness, that the readers of this volume will be familiar with the cultural history of blacks in this country, particularly with reference to oppression. But in case it should be necessary, I reinforce this history with a glance at recent stories in the *New York Times*. One report mentioned that "a research grant application from a black scientist to the National Institutes of Health is markedly less likely to win approval than one from a white scientist."[3] The disparity here is obvious, and the differential impact on blacks needs no further explication. A similar note can be made of another story pointing out that New York City is about 30 percent black, while its fourteen-thousand-member Fire Department is about 3 percent black.[4] In citing these two stories, I do not simplify their inherent complexities. The causes of these disparities are not so obvious as they may at first blush appear, and neither are their solutions. However, the repeated exposure to this genre of problem, with blacks commonly at a disadvantage, evokes the common reaction from members of this group that translates their tiredness at being constantly on the negative end of these disparities.

I reference one last journalistic report from the *Times*, a recent story about the global failure of the international efforts to cope with the cholera outbreak in Haiti.[5] The outbreak and the efforts to contain it and to save black lives certainly represent a narrative in which a number of actors and organizations tried to apply biotechnological advances in a generous effort to do some good. However, as the reporter made clear in the story, the efforts were muddled, and the deaths have reached somewhere around seven thousand. Once again, even a cursory analysis of this event concludes that the causes of the errors were multifactorial. Still, it is hard to avoid the observation that this did not have to happen. The question then rears its head as to what role nondominant group status may have played in the unfolding of the story.

At any rate, my thesis is that such stories are likely to have an impact on the ways in which black people think about biotechnology and on the language they use in conceptualizing the phenomenon. After all, the stories persistently underscore the simple finding that blacks are not doing as well as whites in one or another arena of activity. But I understand that black individuals do not represent some monolithic view of all that they encounter. There is too much evidence supporting the now obvious conclusion that blacks represent substantive heterogeneity in their opinions. In fact, even their penchant for striking a pose of black political solidarity has been diluted of late. Roberts has confronted this point squarely in an examination of race-based medicine and has noted that blacks are articulating approaches to the topic that reflect divergent interests and understanding of racial justice.[6] Also, recent scholarship has emphasized blacks' heterogeneity in the domain of racial identity, even as it has confirmed that racial identity influences situational appraisals.[7]

Jane Sheldon and colleagues, for example, looked at the perspectives of a group of black Americans regarding applications and implications of advances in human genetics.[8] (This was a rare study examining the views of blacks about an aspect of biotechnology.) These authors found that some blacks believed that genetic advances could provide health care benefits. But other blacks recognized potential harm. Despite this obvious variability in perspective, there is no doubt that there has been considerable agreement within clinical medicine that racial and ethnic disparities exist, which has provoked powerful calls for research that would contribute to clarification of the factors involved in creating these racial disparities and progress toward eliminating the disparities.[9] However, the move to follow this advice has not been so easy. This has been clearly demonstrated in the celebrated case of the medication called BiDil, a combination of isosorbide dinitrate and hydralazine. Duster noted it was originally established as ineffective in the treatment of heart disease in the general population but then was later shown to work in blacks.[10] However, Temple and Stockbridge clarified that in clinical trials it was demonstrated that the combination drug was quite effective in self-identified black patients and had far smaller effects in white patients.[11]

BiDil was developed for the treatment of heart failure in self-identified black patients following the unanimous recommendation of an FDA advisory committee and promptly led to questions about whether commercial rather than medical considerations influenced the particularized indication of using this drug among blacks.[12] It also unleashed significant commentary about medical therapeutics and race and the use of race and ethnicity in medicine.[13] The commentary has crystallized into a debate about whether, on the one hand, racial distinctions can be based on genetic data, or whether race remains, on the other hand, a sociopolitically structured phenomenon, without biological underpinnings.[14] Regardless of which side one takes in the debate, however, it is clear from the argument surrounding BiDil that race is a relevant factor in any serious discussion about biomedical advances in this country.[15] In Root's terms, "race can be a biologically salient category even though there are no biological races."[16]

There is of course no need to do a major reprise of this kind of debate here. But it is worth mention, nevertheless, because these arguments underscore the passion that attaches easily to any mention of race in the biomedical context. It is easy to understand why. Try as we might, the disparities linked to being black in this country persist in medicine. We are vexed and perplexed by this state of affairs. We are tantalized by the notion dangled before us that the disparities may have some explanation in biology as opposed to the social constructions that accompany the black-white differentiation. So in the context of biomedicine, race (as a social construct) matters, which is to say that it is salient and not immaterial. Furthermore, I should emphasize that to keep matters clear, I use the word *black* in light of the long sociocultural history of the term and not in reference to biology-based meaning.

Biotechnological advances are certainly changing the ways in which we experience life, and perhaps even the ways in which we understand ourselves. Thus it seems timely and relevant to contemplate the intersection of biotechnology and the language used by blacks—a distinctively stigmatized nondominant group—to recount the narratives of their own lives. In this chapter, I intend to explore how some nondominant group members, defining themselves as black people, describe their views of the impact on their lives that biotechnological advances have had. Themes from these narratives are extracted and dissected to determine whether some coherent construct emerges from this tapestry. These unique narratives are not intended to represent the voices of all members of the black nondominant group. But these narratives should catalyze discussion about whether they may occupy some particularized space in the overall discourse about biotechnological advances and life stories.

The objective then in this chapter is to explore, in a limited qualitative study, what a group of blacks (self-defined and not based on genetic criteria) in this country have to say about the topic, and to report their own commentary. The point is to learn more about blacks' perspectives on this construct called biotechnological advances, particularly as their history of discrimination in this country has included being barred from access to care in some situations and being victims of unethical research in other contexts.

METHOD

I developed the method with the understanding that qualitative scholarship is not focused on testing a given hypothesis. Rather, it is intended to generate information that might conceivably lead to the generation of hypotheses for further exploration. The emphasis is on the individual's response that provides perspective on a particular phenomenon. I conceptualized this work as a qualitative effort to obtain the views of blacks concerning their participation in the culture of biotechnological advances in the United States and to describe, in much of their own language, their perceptions, concerns, and evaluations of these biotechnological advances. The study was considered by the Yale School of Medicine's Human Investigation Committee to be exempt from institutional review board review.

I pursued purposive sampling and therefore selected a group of blacks who I believed would have ideas about biotechnology and its impact on blacks. I sought persons who voluntarily identified themselves as black and who I knew had some knowledge of biotechnology through work as professional caregivers, experience as patients, or engagement in health policy that concerned blacks. I sought individuals who I thought would have enough understanding of the history and culture of blacks in this country to be able, in light of this history, to see the interconnectedness of blacks and biotechnology. I also hoped that most of them would have come to terms with the task of being black and a member of a distinctive nondominant group in the United States, which does not imply that they would have resolved all of the problems emanating from that task. Consequently, I wanted a group whose members could reasonably be expected to possess understanding of the subject by integrating experience with biomedical advances and insight concerning their own lives.

All members of the sample consented to be interviewed by me, with the understanding that I would not use the information provided to me in a way that would identify them as participants. The subjects resided in several states of the northeastern United States. Five males and five females made up the group. One individual was age thirty-five, and one was eighty-five. The remaining eight had an average age of fifty-five. One male and one female had graduated from high school and had taken some college courses; the eight others had graduate degrees in psychology, medicine, social work, public health, and the ministry. The interviews generally lasted between forty-five minutes and one and a half hours, were open-ended, and took place in the first half of 2012. The interviews were conducted in person or by telephone. I opened the interviews by describing what was meant by biotechnology and providing obvious examples of what was meant by the term, such as mechanisms that lead to the renewal of damaged organs, the restoration of vision or mobility, or the extension of life. Then I invited them to speak about the association in their minds of biotechnology and blacks. From time to time I used prompts to clarify their responses.

RESULTS

The ten individuals, as would be expected, spontaneously erected structures on which to hang their thoughts and that led to formulations of ideas that in their expression took on unique and personal dimensions. That is to say, the respondents seemed to settle on ways of expressing their thoughts that were familiar to them and that allowed them to be authoritatively opinionated. As a result, some of the informants, in their responses, clearly reflected their professional training and habitually technical modes of saying things. Others spoke from critical encounters as patients, or as relatives of patients. Still others found it easy to muse about their years of accomplished dealings as caregivers. Of course, some also spoke in a combined form of these three techniques. As would be expected, the respondents had much to say in their dialogue with me. Consequently, I set about to summarize and bring meaning to the conversations by identifying the major ideas that emerged from their responses and classifying them into subject areas or themes. I identified five such major thematic categories. The thematic categories are arranged not in order of suggested importance, but in the order of their first appearance in the interviews.

Theme 1: Importance of Religion–Biotechnology as an Expression of God's Plan

Religion was a common topic and emerged in the conversation with several respondents. For example, one individual commented that, as a black Catholic, it was important to worry about the biomedical advances that are focused on the fetus. In this person's view, such activity constitutes movement into God's domain. In addition, it may have an important impact on the future of black culture, as advances related to genetics might impact on family values transmitted from one generation to the next.

Several informants explained that some blacks, after accepting the benefit conferred by an advanced biomedical device, ask themselves why they decided to make use of the product. Informants noted a number of questions: How much should one do to improve one's quality of life, and how should one define a good life or a better life? What role does God play in such decision making?

One informant made it clear that biotechnological advances enhanced life but did not extend it. If one believed in the sovereignty of God, one would understand that everything must work according to God's plan. An important aspect of this plan is one's time of death, which is ordained by God. This informant cited the biblical parable, recounted by Jesus, of the Good Samaritan, whose actions resulted in the extended life of another.[17] In this view, the Samaritan was God's tool in the extension of life. Thus, we should all work for good of the society, but without thinking that we can interfere with God's plan for us all. However, since we don't know God's plan, it makes sense to follow the dictum in Saint Matthew's gospel: "Occupy till I come." (After carefully searching, I assume that the informant was referring to Luke 19:13, where Jesus discussed a parable in which He noted that a nobleman went into a far country. But before doing so, the nobleman distributed money to servants and asked them to trade with the money until he returned. The servants who made profits on their investments were rewarded, and the one who did nothing with the money was punished.) The informant explained that this means we should busy ourselves in testifying about God's benevolence and doing some good ourselves, until Jesus comes again.

Yet another informant thanked God for living in a time with so much biotechnology and that living longer and better was possible. "We all accept our advantages without giving thought to how fortunate we are—how blessed we are. Alexander the Great had great empires, but not a dish of ice cream. Despite how smart he was, Socrates surely would have liked to have an air conditioner." This informant also believed that in one hundred years, blacks will have even more than they have now. Furthermore, "the selfishness of human beings will be compensated by the generosity of human beings. This is the innate power of human beings, and God is made manifest in that." This individual concluded that human beings have a natural compulsion to make things better in their lives. The major problem inherent in that relates to whether we wish to "distribute the bounty derived from our progress to everybody or only to some." The second important question is whether the progress is intended to be used for malevolent purposes.

This informant also wondered aloud about whether some advances might make us more or less religious and accepted that it was an important ethics question. But without directly answering the question, this individual believed we could avoid the question by being grateful and thankful for what we have.

Theme 2: Factors Limiting Access and Participation in Decision Making

Financial and Social Status

Several respondents considered the question of access as fundamentally linked to one's ability to pay for care. They questioned how many of the biotechnological advances will ever be readily available to black people who are among the working poor and have no access to the government-financed insurance schemes or, alternatively, have only second-rate medical insurance. Another informant raised the problem of "access for black and poor people" and linked it plainly to whether one had medical insurance. This individual believed that it was "an inherent danger" when an "uninsured patient walked through the door" of a hospital and that the danger was particularly elevated at "teaching institutions." This respondent, in addition to several others, mentioned the infamous Tuskegee experiments and suggested that poor whites still receive better medical care than poor blacks. "Poor blacks are subject to inferior treatment. Status counts, in addition to skin color. Status counts in health care." That was said as the individual emphasized the belief that a "light-skinned black man" receives a "better level of treatment" than that received by a dark-skinned black man.

Another informant described the horror at overhearing two nurses talking about the informant and assuming that the informant was "a welfare patient" who lacked private insurance. The informant stated, "I was furious about their assumption. I was so mad." And with that in mind, it was a short step to the conclusion that white caregivers treat black and white patients differently.

Education

The same individual raised another point related to blocked access: it is that some blacks, who have the proper insurance to take advantage of the biomedical advances, lack the education to discuss the advances in care that could be beneficial to them. And there is the suggestion here that black patients should not count on the goodwill of the care system to offer them all the possible options that should be recommended to the black patient suffering from a particular disorder and seeking care.

With respect to this lack of education, another informant stated that black, inner-city patients often consult specialist physicians (such as surgeons) seeking "specialized, but conservative care." They actually may consult a surgeon with a strong desire "to be fixed nonsurgically." Surgery is often seen as an intervention of last resort. The informant explained that blacks' fear of surgery often stemmed from their observations that friends and relatives had had a complicated outcome following surgery. However, they did not understand that the complicated outcomes had resulted from the fact that their friends and relatives had presented for surgery with comorbid conditions such as obesity, diabetes, and hypertension.

In addition, this individual believed that in contrast to whites, inner-city blacks rarely consult websites to inform themselves about what surgical options may exist, and the advantages and disadvantages of each option. Hence these black patients often need a period of significant education before they appreciate the contours of their consultation concerning access to the biomedical advance that may be useful for them.

Another informant emphasized this factor of education, stating that black people need greater general and specialized education in order to be full participants in the enterprise of advancing biotechnology and also benefitting from it. "Blacks should be involved in the business of developing and executing these ideas."

Caregivers

Several informants mentioned a third mechanism that contributes to impeding access to biomedical advances for blacks and to participation in decision making about those advances. This concerns their suspicion that some caregivers, such as physicians, do not make sustained efforts to distribute the advances equally to blacks and whites. Informants expressed concerns that facing the lack of informed sophistication displayed by some blacks about biomedical matters, white physicians become exasperated and fail to explain the full panoply of choices available to the patients.

A respondent stated that a close relative complained for years about hip and back pain without being referred by the family doctor to a specialist. Finally, several family members accompanied the patient to the family doctor and insisted on a referral, which took place. The relative soon had the hip surgery. The patient also had contributed to the stalling by asking the relatives not to complain to the doctor. The patient feared retaliation from the treating physician.

One informant also noted that since the presence of comorbid conditions in black patients increases the chances of their having complicated outcomes with the biomedical advances, physicians regularly hesitate to recommend the new technologies to blacks. Hence, this results in decreased access for blacks to the innovations in care. In the informant's language, blacks are not good receptacles for the advances because of their comorbidities.

Theme 3: Concern about Negative Outcomes

On several occasions, informants commented that some biomedical advances have not been all that positive for blacks. A simple example provided by a respondent was that some medications are metabolized differently by blacks and whites, with blacks having a more negative outcome. In a variant of this example, one informant noted observing blacks receive a medication regimen that then produced medication-induced osteoarthritis, a dysfunctional heart valve, and decreased competence to fight infection. While it may not be clear how much the negative effects of the pharmacological advances were linked to race, the informant worried that there might indeed be some relationship. And if that were true, it would certainly raise an alarm of caution about blacks' intemperate rush to avail themselves of the advances offered in the biomedical marketplace.

Theme 4: Enthusiasm Tempered by Caution and Vigilance

Respondents were quite pleased that there are always individuals interested in making new discoveries by being scientifically creative. One person noted, "People have a vision and they create new things." This informant recently attended a presentation by cardiac surgeons who discussed their ideas of cardiac care for the future. The presentation was impressive, and the informant thought of ways that relatives might benefit by these advances.

But another individual justified the cautious approach some blacks have to this phenomenon of biotechnological advances by pointing out that it "comes from just being black" in the United States. "There is always a vast distinction between blacks and whites regarding their reactions to big cultural events." "Physicians are less receptive to questions coming from blacks and they rarely want to explain the side effects of their treatments to blacks." The experiences as a black individual call for caution in moving to take advantage of biomedical advances. "Yes, whites may want to test the innovations on blacks. How can I really believe that whites have blacks' interests at heart? Biotech advances are good, but blacks should be very cautious."

Other respondents underscored this aspect of vigilance and suspicion, grounding this attitude in knowledge of the Tuskegee experiments and in the experience of witnessing the treatment of black patients at the hands of white caregivers. One informant described, with some anger, how a relative's white doctor spoke in a hurried manner to the patient. The result was that the informant's relative was always left unsure about what the doctor had said. And the doctor also never invited questions.

Another informant recounted the story of a black patient who was trying to explain to his white caregivers his own view of his delusions and hallucinations. The black patient was struggling to describe his experience of seeing white doves that were peaceful and that he believed represented an intervention by the Holy Spirit. He wanted to understand what God wanted from him. However, the caregivers were having none of it. They saw the patient as simply being psychotic, and in their attitude toward the patient ignored his struggles to make sense of his own experience. The informant was incensed and never forgot the white caregivers' conclusion that the patient's experiences were not important. In this informant's eyes, the staff treated the black man as though he did not exist, minimized him as a human being, and made him invisible.

This is not to say that this informant was against biomedical advances. Indeed, this individual praised the advances made in health care and admitted to having accepted use of them in the care of a personal chronic and serious medical condition. But that did not stop reflection about whether blacks "get a fair deal with regard to the distribution of the biotech advances." "I would hope so, but I don't think so." "The disparities are too obvious." "I hope that everyone will collude to make the disparities disappear."

Theme 5: Biotechnology by Itself Is No Panacea

Several respondents noted that biotechnology advances alone will not solve all the health problems of blacks. One informant remarked that other factors must be considered that take note of the cultural context in which blacks grow up and live out their lives. Blacks' daily encounters with racial discrimination, in their micro- and macro-traumatic forms, contribute to their mundane experiences of stress. Their degrees of inactivity and their unique diets are factors that impact their lives and, in turn, the expression of their genetic makeup. So, biomedical advances that impact on pathology will never be enough. The excessive and unilateral focus on biotechnology, without considering blacks' exposure to events early in their lives, disadvantages blacks.

This informant also pointed out that an excessive focus on biotechnology minimizes the potential impact of a prevention approach to health care in the lives of blacks. Prevention requires proper attention to social and community factors if fundamental change is to take place in the health care status of black people.

Another informant buttressed this view by noting that blacks are not just handicapped by the differential distribution of the biomedical advances. This informant emphasized that for many blacks the inequities start from the moment they are born, as the basics are allocated inequitably. Here the informant was referring to the unequal access to education, jobs, health care, good housing, healthful meals, two-parent families, appropriate child rearing, protection from violence, and so on.

Yet another informant insisted that the discussion of blacks and biotechnological advances had to be framed against the backdrop of racial disparities in U.S. health care. This individual spoke with some bitterness about the continuing problem of health disparities and expressed the belief that efforts to study these disparities focused too much on characterizing them and too little on understanding the causes. In this informant's view, there was not a robust commitment to eradicating the causes. Consequently, one should expect that the racial disparities are likely to show up again in the distribution of the biotechnological advances and their benefits. In a general sense, one should expect that whites will ultimately benefit more than blacks.

DISCUSSION

It must be reemphasized that the objective in this obviously limited qualitative study was not to make generalizations that could be said to apply across the population of black people in the United States. Rather, the aim was to seek insight concerning perspectives and attitudes that some members of the black group might have about the topic of biotechnological advances. The information obtained in this way could then stimulate other potential avenues worthy of scholarly exploration. Consequently, emphasis was placed on selecting a group thought likely to have experience with biotechnology. Socioeconomic status was not emphasized, although the educational status of the group was obviously high. As noted earlier, little attention has been paid to the perspectives of blacks concerning biotechnological progress.[18] But more attention has been focused on blacks' participation in clinical research.[19] The information gleaned from the group about religion and biotechnology was particularly instructive. It suggested a conservative approach to melding their religious convictions with ideas about biomedical advances. The black Catholic was directly hesitant about scientific exploration with a fetus and clearly made an association with the vexingly complicated topic of abortion and the use of human tissue. Still, this informant was not against making use of scientific progress to improve health, even while worrying that the advances might negatively impact on values transmitted from one generation of blacks to another. The most bothersome idea to this informant was that the advances could be seen as trifling with life itself, a domain that squarely belongs to God. This theme is similar to the one evoked by the informant who walked a fine line in distinguishing between enhancing life (where God works through biomedical scientists) and extending life (the exclusive territory of God).

Other informants were forthright in emphasizing that we should all thank God for the wonderful blessings bestowed through the mechanism of biomedical advances. And much of the ethics discussions concerning whether the advances interfere with our having been structured in God's image should take a backseat to the obligation we have to praise and thank God for the benefits we have enjoyed. Indeed, several informants noted that the most relevant ethics question flowing from the discussions evoked by biomedical progress should focus on the equitable distribution of the bounty derived from the progress. The other relevant ethics dilemma was inherent in the concern that biomedical advances should not be put to malignant uses.

There was a poignant element shrouded in the comment that we should "occupy" until Jesus comes again, meaning that those who are believers should seek ways to comfort and to benefit their neighbors. This idea is of course linked to the parable of the Good Samaritan. And we must recall that the parable was uttered in direct answer to the question about who is a neighbor. However, it is evident that the question has broader implications at the systemic level. Since we are talking here about blacks, the question would be extended to probe the broader tasks and commitment of the black church to "occupying." Washington argued several decades ago that the black church was obligated to develop its purpose in action and to focus its energy on taking care of the concerns that characterized the needs of black people.[20] Hence the black church needed to reflect on its activity in a way that could be seen as being more clearly political, although still religion based.

Chang and colleagues have articulated this position as applied to black churches in New Haven, Connecticut.[21] They presented the conceptualization of the black church as a social service organization with the potential to contribute to the broad public health needs of the black community. And Griffith has recently described similar efforts of the Spiritual Baptist Church in the Caribbean island of Barbados, where the island's population is predominantly black.[22] These efforts translate a significant appreciation that blacks should not just sit idly by awaiting the arrival of biomedical advances, especially as the advances may not fit neatly with other religion-based imperatives. But the admonition to be "occupied" until Jesus' return invokes the responsibility for vigorous personal action and the organizational action of the black church to contribute to the betterment of the group. It seems clear, then, that some of the informants linked efforts toward advancing biotechnology to a broader humanitarian task of making sure that all members of the society should benefit. In addition, we should all maintain a posture of gratitude to God for His countless blessings. Colleagues have made the point to me, and with much legitimacy, that dominant-group members such as whites in the United States are expected also to heed the call to occupy until the Second Coming of Christ. These colleagues argued that biomedical researchers do exactly that when they pursue their scholarly activities. They further insisted that the work of occupying is akin to the role of being stewards. So far so good, and their point is well taken. However, I reply that the important work of dominant-group members should not be carried out at the expense of the non-dominant-group members of the society. This concern was raised on several occasions by the informants in this study. They were fearful that blacks could not control things that happened to them in the context of research and even in the context of routine clinical care.

A number of respondents in this qualitative study made the point that in general blacks lacked access to health care in comparison to whites. They expected that this notion would be applicable to biotechnological advances also, meaning that blacks would have less chance of gaining access to the biomedical progress than whites. The respondents suggested three factors that might be causally related to this differential access to biomedical progress: socioeconomic status, education, and caregivers' passive or active efforts to block access.

The respondents' concerns about the difference in access to health care and therapeutic advances were, of course, at least partly justified. Over fifteen years ago it was noted that blacks were less likely than whites to receive renal transplants, receive hip or total knee replacements, and undergo gastrointestinal endoscopy. But blacks were more likely to undergo hysterectomy and amputation of the lower limb.[23] The respondents also seemed to suggest that having insurance would improve blacks' chances of receiving good care, which has not been readily borne out. Indeed Geiger explicitly pointed out that the provision of health insurance does not ensure equity in care, and therefore turned to consider unspecified cultural differences, undocumented patient preferences, and a lack of information about the need for care—which would include the respondents' mention of the education factor. Geiger also unabashedly contemplated the alternative explanation that physicians and health care institutions might be involved in racially discriminatory rationing. Geiger wondered what criteria are used by physicians in making their clinical judgments, whether the criteria are applied equitably or are influenced by racial stereotyping on the part of physicians. Bowser went further and, noting that black patients are less likely than whites to undergo cardiac bypass surgery for treatment of heart disease and to receive surgery for early-stage lung cancer, raised concern about racially biased health care decision making by some physicians.[24]

The respondents' responses shed light on their worries about health disparities that blacks endure while whites fare better. However, Kawachi, Daniels, and Robinson have argued tenaciously that social class is also a powerful factor in the creation and perpetuation of the health disparities in this country.[25] These authors have pointed out that class and race have independent and interactive effects in producing health disparities. These scholars prescribed a certain protocol for considering black-white disparities in health. Racial health disparities ought not be considered without the contribution of class disparities. This is important, since if we were able to eliminate racial disparities in health outcomes, most blacks would still have worse health than the U.S. average because of their class position.[26] But the authors maintained that not all disparities go in the positive direction for whites. For example, low birth weight, which contributes to infant mortality, increases in prevalence with higher levels of educational achievement. This example is not well understood, said the authors. However, it points out the need to think differentially about the contributions of race and class to the disparities dilemma.

It is also worth stating that this macro-analysis at the national level may not always apply at the local community level. Foster demonstrated that in the local Oklahoma communities he studied, intracommunity health practices varied among local black and white communities with similar economic status. He emphasized that "local variation with respect to intracommunity interactions and practices can be glossed over by aggregative racial and ethnic categories."[27]

The respondents' references to health care disparities do not entirely capture the climate of racial discrimination that has pervaded the culture for many years. Respondents from time to time mentioned the Tuskegee experiments on blacks afflicted with syphilis. Duster has effectively chronicled how racial discrimination has played a major role in biomedical scholarship, and Bowser has articulated his view that racial ideas tainted the behavior of physicians and even their training and professional socialization.[28] This likely underscores the respondents' views that noted how training institutions can be problematic places for blacks to seek care. This suggests that there is more to the disparities problem than altering class distinctions, and altering race-based health disparities will take considerable effort.

The respondents did voice concern about potential negative responses of blacks to some biomedical advances, and they mentioned, as an example, observed negative responses to medications of individuals they knew. This has been an increasing concern of physicians involved in clinical work, some of whom have argued that it must be acknowledged that blacks have different responses than whites to some medications. Therefore, a treating doctor should consider race in drawing up a treatment plan for a black patient. Indeed, this has been the cornerstone of Satel's argument. She announced boldly in the public media that she was a racially profiling doctor, and she justified it by pointing to a number of clinical situations in which blacks responded differently than whites to the same medication.[29] Examples she gave included antidepressants and antihypertensive medications.

Bowser contemplated Satel's claims and articulately raised serious questions about them one by one. I need consider only the most important here. First is that "race disappears when you look at the human genome," as racial differences relate to 0.01 percent of the body's estimated thirty-five thousand genes.[30] Furthermore, drug response is also influenced by many factors such as health, lifestyle, support system, education, and socioeconomic status. In addition, he noted that it would make more clinical sense to consider drug-metabolizing genes than skin color genes in arriving at the choice of a particular medication for a patient. But in research, there has been no correspondence found between gene clusters for drug metabolizing and genes related to racial classification. Hence, Bowser reached his conclusion that there is no solid link between skin color and drug metabolism. He also critically appraised the rational basis on which supporters of BiDil, mentioned earlier in this chapter, established arguments to justify the marketing of this antihypertensive drug to blacks. He marshaled substantial evidence to raise serious questions about the claims of BiDil's supporters.

Despite Bowser's obvious concern that race-based pharmacogenomics is potentially problematic for minority groups, I do not believe that any of the respondents meant to attack the drive to make progress in this research area. In fact, the example of genetics-based drug research encapsulates the paradox in which the respondents clearly found themselves trapped. They support biomedical advances, but also want to make sure that blacks are not hurt in the process. Evans and Relling, in an important review of individualized medicine with pharmacogenomics, concluded that progress toward individualized therapy using genetics required protecting against the misuse of genetic information.[31]

The caution and vigilance emphasized in theme 4 represent a thread that wound its way throughout the results of this small study. The genesis of this attitude seemed quite naturally to stem from blacks' experiences in the American health care system, as well as from their knowledge of historical events such as the Tuskegee affair. From her vantage point, Roberts saw this kind of recurrent commentary as reflecting blacks' interest in social justice.[32] Consequently, it should seem both understandable and justifiable that blacks should have a robust skepticism about biomedical advances—hoping to benefit from them while being simultaneously fearful that access to the advances will be limited for some reason or that the benefits will not be fully distributed to stigmatized nondominant groups.

It was striking that the respondents spoke so spontaneously and repeatedly about their historical awareness of Tuskegee. But I also noted how they referred to the medical abuse, to borrow terminology from Roberts, suffered at the hands of white clinicians. Roberts referred to this abuse as the oppressive use of medicine, which contradicts the traditional ethics-based physicians' claim that their activities are rooted in beneficence. In this regard, it should concern clinicians that a respondent reported a relative's belief that complaints about a physician might provoke retaliation from health care personnel. Assuming this example is true, it highlights Roberts' demand that this kind of attitude and behavior from health professionals be eliminated, as it fractures the trust and mutual respect that should characterize the relationship between patient and caregiver.[33]

The respondents' views collected under theme 5 are particularly significant. They clearly reflect the informants' familiarity with the subject of biotechnological advances, as well as their sophisticated integration of the topic with their experiences as blacks. The first deceptively simple point they made was that a concentrated focus on biotechnological advances ignores the life stories of many blacks living in this culture. These life stories encompass myriad mundane micro-aggressions that are rooted in race-based interactions.[34] The stress resulting from these interactions is thought to be a significant contributor to blacks' manifestation of disease and pathological disorders. Creating biomedical techniques in a singular effort to address these expressions of pathology will always disadvantage blacks, as the advances ignore the fundamental need to focus on prevention and to make efforts to reframe the traditional evolution of blacks' life histories.[35] One informant also emphasized the view that with all the talk about racial disparities in health care, there seemed to be no firm commitment to eradicating the causes. As a consequence, the informant expressed doubt that there would be equitable distribution of biotechnological advances.

Hummer and Chinn raised similar points in their recent discussion of race/ethnicity and U.S. adult mortality.[36] They noted that relative mortality differences between blacks and whites are modestly narrower when compared to ten years ago, but still remain very wide.[37] They pointed out that blacks have this higher mortality rate between birth and age eighty-five.[38] In seeking explanations, these authors observed that "decades of research have consistently documented the continued impacts of such systematic oppression and unequal treatment on the African American population, resulting in an array of disadvantages that play out in social institutions and in the everyday lives of Black individuals."[39] Examples of the disadvantages they noted were educational attainment, annual family income, race-based hassles and slights, disadvantaged neighborhoods, and poor schools. Hummer and Chinn concluded by observing that policy makers should understand the need to concentrate on the social and economic factors that basically drive black-white disparities in mortality. It should be easy to extrapolate from this argument about mortality to one about health care disparities and then to the informants' concerns about biotechnological advances.

The informants' arguments and suggested policy changes bring us inevitably to consideration of the debate that has been occupying multiple disciplines over the past decade. As Roberts so poignantly noted, "Debates about the scientific validity of race have reemerged in questions about the proper use of racial categories in genomic, biomedical, and biotechnology research."[40] As a consequence, policy makers and scholars are being forced to consider the competition between the principles of color blindness and race consciousness as scaffolds on which to structure one's attitude toward the treatment of race in social policy. Roberts put forward her proposition that "the legal regulation of race in biomedical research should aim to promote racial justice. This social justice approach holds that race is a socially constructed category without scientific basis that continues to produce health inequities, that these inequities require race-conscious legal remedies, and that biomedical research should be subject to legal regulation that promotes racial justice."[41] It is indeed hard to envision a way out of this quandary, presented by the existence of racial disparities in our culture, by adopting color-blind attitudes. The informants noted that in light of the presently existing evidence concerning health disparities, there seemed to be no robust will from policy makers to effect transformative changes. Hence, color blindness in policy would be expected to lead to a further lack of concern. At least that is the informants' belief. Time will tell whether Roberts' recommendation will bring a solution to the dilemma, one that in time will dilute the informants' stubborn reliance on caution and vigilance. Time will also tell whether the highest court in the land will support this approach to ending discrimination and inequity.

10

BIOETHICS, ECONOMISM, AND THE RHETORIC OF TECHNOLOGICAL INNOVATION

Howard Brody

The topic of this volume, "A Language for Our Biotechnological Future," invites us to explore the rhetorical system within which biomedical technology is depicted, and to reflect upon what the rhetoric reveals about ourselves and our society. However, we do not talk about biotechnology in a vacuum. Other discourses are already in place and shape the way we think about both ourselves and the technology. I want to explore in this chapter the relationship between the rhetoric of biotechnology and one of those background rhetorics, which I call *economism* and others call *neoliberalism*.[1]

I begin by describing how my major field of study, bioethics, has addressed technology in medicine since the 1960s. I then describe the rhetoric of economism and identify some of its salient features and the impact it has on society. Finally I describe how the background rhetoric of economism shapes the rhetoric of biotechnology, using the current debate over medical cost containment as a case study.

BIOETHICS AND MEDICAL TECHNOLOGY

One could say that bioethics emerged as a new way to think about the ethical issues raised by medicine and health care, in the mid- to late 1960s, in large part as a response to technological advances. Hans Jonas, one of the most thoughtful philosophers to help shape the new field, argued that the new technology of that day posed novel ethical questions for which traditional ethics offered no answers. The old ethics might address uses of technology that affected the people and things in its immediate surroundings in the present. But the new biotechnology threatened to reach well beyond those limits. Technology seemed capable of altering the earth and all life on earth in new ways, whose effects stretched far into the future. Technology also seemed to offer means to significantly alter living things themselves, including the human species. Jonas argued that only a new way of thinking about ethics would suffice to address these concerns.[2]

Others engaged in the new bioethics were less apocalyptic, and less willing to dispense with traditional ethical theory, than Jonas. But a common view emerged that new technologies presented us with novel ethical problems. There also arose the assumption that technologies had attached to them a sort of ethical window of opportunity. Presumably there was a magical time early in the life of a new technology when one could ponder its ethical implications and, if the risks seemed to substantially outweigh the benefits, call a halt to its use. However, if one waited beyond that window, the proverbial genie would be out of the bottle for good, and all one's ethical pontificating would be in vain.[3]

At the time, few questioned the hubris associated with this view of bioethics. To get one's ethical conclusions to fit into the magic window, one needed to be extremely prescient as to what impacts the technology would have on human life, both now and in the distant future. In hindsight, the idea that one could decide on the basis of such preliminary data and considerations that a technology ought or ought not be used, for all time henceforth, seems silly. But that did not matter very much, as I am not aware of a single biomedical technology that was put aside simply because a bioethicist warned of its dangers.

A Technology Case Study, 1900–1920

An instructive example of the difficulties in assessing any new technology from an ethics standpoint is provided by Joel Howell's study of the entry of new medical technologies into U.S. hospital practice during the first two decades of the twentieth century. Howell focused on two technologies, X-rays and routine laboratory tests of blood and urine. He found that both were hardly ever used in hospitals, despite the technology being available, around 1900 but that both were in widespread use by 1920.[4]

Howell next asked what explained the difference, and made a good case for implicating other technologies that made their way into the hospital during these same years. But the other technologies were not at all of the sort we usually classify as "medical." The responsible technologies were typewriters, adding machines, and standardized paper forms that could be pasted into the medical chart. Without these enabling technologies, physicians lacked a good way to incorporate X-rays and blood tests into the routine care of patients.

Howell next asked what accounted for the entry of these enabling technologies into the hospital, and discovered the answer in the participation of hospital managers in a larger movement that was sweeping American industry at that time, the efficiency movement. Bringing typewriters into the hospital to record X-ray findings on paper forms that then could be inserted into the patient's chart was the hospital equivalent of Henry Ford's Model T assembly line. The efficiency movement stressed breaking down all tasks in the "factory" into easily repeatable, simple steps that could then be standardized. As far as this movement was concerned, a hospital was just another sort of factory.

The nineteenth-century hospital, like its historical predecessors, was viewed primarily as a charitable enterprise, to care for and shelter those too poor to be able to afford medical treatment in their own homes. The twentieth-century hospital became a medical factory. Nineteenth-century hospital managers would have been puzzled at the very idea that a hospital could be a *profitable* enterprise. Technology played a role in this significant social transformation of health care; but as Howell revealed, it is easy to get wrong just what role technology played and what technologies actually played the key role.

The hospital example also shows that it is vital that we understand the background discourse that is going on around health care and technology in one's society. I turn next to today's dominant discourse.

THE RHETORIC OF ECONOMISM

The ideology that I call *economism* also has been given other labels, one of which, popular among some philosophers and historians, is *neoliberalism*. I prefer *economism* because the contrast between *economics* and *economism* parallels the contrast between *science* and *scientism*. Just as scientism represents a naïve and overextended faith in science, economism represents the misinformed idea that economics tells us all we need to know about virtually every aspect of human life. The parallel is not exact, however, because the boundary between economics and economism has become blurred as more and more of neoclassical economics, and of what is typically taught in economics classrooms, comes to resemble economism.[5]

As analyzed by Des Gasper in his survey of the ethics of international development, economism has several features:

- Economic calculation is the best way to understand, value, and manage every aspect of human life.
- People are, at core, economic beings. The laws of the marketplace describe virtually all of their behavior and the reasons for it. People are fundamentally beings of economic exchange, driven first to make money and then to spend it on the goods obtainable in the marketplace. They are not motivated by love, friendship, or justice.
- "The economy" is a separate and distinct sphere of society; yet it is also by far the most important part of society. Because it is separate and distinct, we can develop policies for the economy in isolation and without worrying about the rest of society. Because it is the most important part, we can talk (for instance) about countries in the developing world as "transitional economies" or "emerging economies," as if each nation were simply and solely an "economy."
- The economy, above all else, must be managed with an eye solely toward its own internal technical requirements—that is, what economists study. There ought to be no interference from politicians, moralists, or anyone else.[6]

I have referred to economism as an ideology; but it is more specifically a religious ideology. There are two reasons for the label "religious," logical and historical. Logically, economism, while portraying itself as factual and empirical, acts more like a religious belief system. In particular, it is singularly resistant to factual counterarguments. When policy makers try to run the world the way economism dictates, and the result is disastrous, advocates for economism never consider the possibility that their ideas are flawed; they argue rather that the markets were not sufficiently free of government interference, and if only the markets of the future were *really* free, this disaster would not happen again. The same reaction occurs when critics point out that the elegant mathematical models constructed by neoclassical economics fail to describe how humans behave in the real world; economism's defenders insist that the theories are right and the world is wrong.

The historical reason to view economism as religion is that its key ideas appear to have religious origins. Strands of economism have emerged from the evolved form of Puritanism present in eighteenth-century America and from the variety of evangelicalism prominent in England in the first half of the nineteenth century. Both religious roots have in common the idea that God designed every detail of the world that we live in, and so attempts to change the way the world is supposed to work—for example, by aiding poor people whom God intended to make poor because of their sinfulness—are both futile and heretical. The religious beliefs also have some important differences. The strain of Calvinism that became American Puritanism, and that later evolved into what Weber called the "Protestant ethic," placed a special emphasis on how working hard at one's appointed worldly task was the way one served the glory of God, so that if one became rich, that must mean that one had especially won God's favor. English nineteenth-century evangelicalism, on the other hand, was less deferential to the rich and indeed thought them at higher risk for eternal damnation. But that strain of evangelicalism thought that the poor would be saved from damnation precisely because the misery of their poverty would spur them to greater faith, so that anything that reduced the misery was a danger to their immortal souls (as well as being contrary to God's will). In short, the evangelical root tells us why economism today favors policies that refuse to help the poor, while the Puritan root explains economism's favoring policies that especially privilege the rich.[7]

Karl Polanyi saw economism rising in the early 1940s, and his *Great Transformation* is a warning against this movement (which he called "economic liberalism").[8] Economism in fact gained little ground until the economic malaise of the 1970s created an opening for the two great political leaders who advocated economism-style policies, Reagan in the United States and Thatcher in Britain. Over the past four decades we have had an opportunity to see what practical consequences arise from economism's teachings. The results have been dismal. In the United States we have seen phenomenal increases in wealth among the very rich while the great mass of the middle class and the poor have seen real income rise hardly at all, and as more and more Americans spend some portion of their lives in poverty. Across the world, nation after nation has fallen from reasonable self-sufficiency to permanent debtor status through the policies of the World Bank and the International Monetary Fund, in order to ensure that the workers and natural resources of those countries are made maximally available for exploitation by multinational corporations.[9]

These facts about real-life consequences have (as one would expect in a case of religious devotion) made no impact whatsoever on the advocates for economism. In the United States, policy makers and politicians looked upon the ruin wrought by unregulated financial markets in the Great Recession of 2008 and immediately called for a return to the same policies that had led to the market collapse. In Europe, as I write this early in 2012, supposedly shrewd policy makers demand more austerity to ease the Greek debt crisis, despite clear evidence that the austerity measures already imposed have worsened the situation and threaten to further constrict Greece's economy to the extent that it can never hope to repay its international debts—a fate already shared by numerous African, South American, and Asian nations, but not attracting world attention until the same happens to a European nation that was previously classified among the wealthier countries.

To return to the main theme of this discussion, the discourse promoted by economism looks at technology in two particular ways. First and most obvious, technology is a source of economic gain. Anything that can be bought and sold as a commodity in the marketplace is therefore a good thing according to economism. If a new technology can be sold for profit, and also threatens to subvert important social values, economism will dismiss the threat to basic values and focus upon the economic advantages, and the supposed right of anyone to trade freely in the marketplace.

Second, technology plays a privileged role in economism's discourse because of economism's theoretical dependence on neoclassical economics. Critics Philip Smith and Manfred Max-Neef characterize neoclassical economics as necessarily viewing economic growth as unrestricted. Restrictions on growth would invalidate some of the most important mathematical theories of the discipline, and as usual, when real-world considerations clash with theoretical elegance, neoclassical economics insists on the mathematical models. Therefore, it does not matter if science informs us that certain natural resources are finite and pose a real constraint on economic development. Neoclassical economics has to defend its theory and hence proclaims that these limitations in natural resources, or in the biosphere's capacity to withstand the effects of pollution, are only apparent and can always be overcome. The standard argument economism brings to the table, to explain why neoclassical models trump scientific evidence, is that new technology will always find a way to handle the resource limitation, so that the potential for growth remains infinite. In this way, faith in technology is added to the other elements of religious faith that make up the belief system and hence the rhetoric of economism.[10]

Bioethics, Biotechnology, and Economism

If bioethics came into existence in the late 1960s primarily as a result of the challenges posed by new medical technologies, one might think that by now bioethics would have a sensible way of addressing the ethics of technological development. Yet, perhaps for reasons illustrated by the case study of hospital technology a century ago, it does not seem we have made much headway.

James Rachels, a philosopher who periodically addressed bioethical issues, and John Evans, a sociologist writing about the genetic engineering debate, offered differing accounts of how bioethicists tend to react to new technological developments. Rachels criticized bioethicists for being scolds, and attributed this to their desire to be quoted on the evening news when contacted by journalists. Asked to respond in a few words to today's new technological breakthrough, the bioethicist is unlikely to get into the news story by saying, "It doesn't matter much" or "We'll just have to see how it plays out," but is almost assured of mention if she or he says, "The sky is falling!"[11] Evans, by contrast, thought that bioethicists at the start of the present century were all too ready to act as a cheering section for new (genetic) technologies, and compared them unfavorably to the scolds of previous times, who were generally theologically rather than philosophically trained.[12] It seems reasonable to think that people who pride themselves on the intellectual accomplishments typically claimed for bioethics ought to be capable of a more thoughtful and nuanced view of technological advances than either scolding or cheering suggests.

Both the potentials and the limitations of bioethical rhetoric applied to new technology may be illustrated by the work of Leon Kass, one of the most prominent members of the "scold" fraternity. In a widely cited article, "The Wisdom of Repugnance," Kass addressed human cloning. The central argument of this piece appeared to be that bioethicists typically offer arguments for and against the employment of a technology like cloning, and attempt rationally to balance the pros and cons. But there are times when one simply knows in one's gut that something is distasteful; and then one should trust one's gut, because it almost always is pointing toward deeper arguments that one cannot quite articulate but that are worthy of immense respect.[13] It is perhaps interesting that Kass presumably does not imagine one's gut ever being happy with a new technology; dyspepsia seems to be the gut reaction that he confidently anticipates. At any rate, a cheerful tummy would presumably not be worthy of the deep moral respect that he is willing to accord to repugnance.

There is something both promising and off-putting about Kass' argument, if it can even be elevated to the level of argument. Certain technologies, employed in certain ways, do in fact have the power to change the way we think of ourselves as human beings. Some of those changes might be good and others bad. And a mere listing of the obvious benefits and harms anticipated from the technology might well exclude mention of that deeper concern about the altered meaning of human existence. Furthermore, deep questions about the meaning of human life and its worthiness might be very difficult to articulate, especially in early days when the technology is just being proposed and its full impact only dimly glimpsed.

On the other hand, Kass' supposed argument has an unfortunate ad hominem quality. Kass, looking at human cloning (which I happen to oppose as a reproductive technology, incidentally) or whatever other technology may be in question, experiences this repugnance in his gut. Another bioethicist favors the technology and offers explicit reasons in its defense. Kass responds that he (via his gut) has discerned a deeper set of questions that the other bioethicist ignores. What are those questions? replies the other bioethicist; just tell me what they are and I'll attempt to address them. I can't say, responds Kass, but my gut, excellently calibrated moral instrument that it is, assures me that they are there, and that their implications for the use of this technology are dire. In short, there appears to be no possible reply to Kass' gut; and any bioethicist entering into this debate with Kass merely displays her or his own lack of moral sensitivity, as her or his own gut is so obviously too obtuse to pick up the delicate vibrations.[14]

What happens when we factor economism into the equation? The first thing that happens is that a problem arises for people of Kass' persuasion. The Kass "repugnance" posture is suspicious of the impact of new technologies on the deeper meaning of human life. This causes that group to be especially concerned about genetic and reproductive technologies. According to their argument, bioethicists who are less concerned about those technologies often rely on some sort of utilitarian reasoning. These superficial bioethicists see the immediate benefits of the technology and fail to look deeper to discern the possible harms. In today's society, people leaning toward the political right associate this form of crude utilitarianism with "liberals," and accuse those liberals of undermining important religious and social values ("family values") with their readiness to endorse sexual practices that violate traditional religious principles—in the worst case, abortion and gay marriage. If our society is morally going straight to hell, this group argues, it is all because of these "liberals" and their perverted utilitarianism.

One of the features they attribute to those liberal utilitarians is a crass materialism. They can see only the immediate and superficial applications of technology. If they were properly spiritually aware, they would understand how the technology violates deeper meanings of humanity.

This line of thought puts the Kass-type scolds into a quandary, however. Politically they are most at home among the right-leaning sort. But the political Right, today, represents the loudest cheering section for economism, which is the most crassly materialistic belief system imaginable. Economism in the end views all of human life and society as a set of commodities to be bought and sold. When we think of marriage or child rearing, for instance, economism urges us to imagine these practices as ways we might invest our resources and then ask whether the other parties provide us with a good return on investment. Economism insists above all that the best way to view the person in society is as an isolated, totally self-interested individual—not as a person with deep ties and relationships. How such an account of the person could possibly be consistent with "family values" is a conundrum that economism addresses purely by avoidance.

So we eventually get from many of bioethics's technology scolds an inconsistent and incomplete argument. They have generally bought sufficiently into the rhetoric of economism so as to be blind to its pervasive materialism and profoundly antispiritualistic nature—an odd posture, to be sure, for a belief system rooted in religion, but logical consistency has never been a striking feature of economism. They can then criticize new biomedical technologies, but the criticism must remain partial—they can never directly confront the larger social ideology that renders technologies practiced within it even more materialistic and antispiritualistic than they might otherwise be. Nor can these scolds address in any adequate way the profit motives of the developers and purveyors of this new technology, who care nothing for its potential risks (either superficial or deep) so long as they can make a buck.

OTHER ECONOMISM BLIND SPOTS

The argument I have just given, about why some bioethical criticisms of new technology are flawed and incomplete, depends upon a sociological and political assertion, that the bioethicists lodging the criticisms are likely to be found among a particular part of the political spectrum. Other ways that the rhetoric of bioethics may interact with the rhetoric of economism regarding technology are less dependent upon the individual political loyalties of the bioethicist.

Economism preaches that whatever outcome results from the supposedly "free" market is the best possible outcome for the good of society. The market is the ideal exercise of human freedom, and any interference with the market represents a diminution of that freedom. Within a public sphere dominated by the discourse of economism, and now conditioned by several decades of use to regard the economism rhetoric as simply the only rational way to discuss the truth about the world, how market forces might do damage to health care is therefore unlikely to emerge as a bioethical concern.

Let me turn to a different example of how new uses of technology change the meaning we attach to aspects of life. Jeremy Greene has explored the recent history of the rise of risk factor medicine, noting that the idea of a "risk factor" was actually foreign to medical thought as recently as 1950, but came into its own with the Framingham Heart Study soon after. Risk factor medicine quickly became associated with what Greene calls "medicine by numbers"—the idea that it was essential for the physician to know certain facts about the patient that could be expressed in simple numerical terms, and that treatment could be reliably guided by those numbers. No longer did one prescribe medications based on an overall assessment of the patient's health status; one now prescribed a statin for cholesterol, or an antidiabetic drug, simply based on the number recorded on a laboratory slip.[15]

We generally regard this recently developed form of medical thought and practice as "preventive medicine" and hence a great step forward. Greene reminds us, however, medicine did not happen upon "medicine by numbers" unaided. Important commercial interests, notably the pharmaceutical industry, found that their profits depended greatly on physicians coming to think about disease in this way. During those same years, medicine ceded a great deal of control over its research and continuing education apparatus to the pharmaceutical industry. Physicians came to rely more and more on drug detail representatives coming to their offices for information about drugs, the talks about drugs at continuing medical education conferences were largely paid for by the industry, and medical journal articles reporting on new drug research were mostly industry sponsored.[16]

We are only recently coming to learn how much bad science has been promulgated by this commercially biased system of "education." Few are aware, inside or outside of medicine, that as the number of prescriptions per capita has risen dramatically, deaths due to prescription drugs taken as directed now exceed one hundred thousand annually in the United States and thereby qualify to be considered the fourth largest cause of death.[17] How much of this excess death burden can be attributed directly or indirectly to the practice of "medicine by numbers" has yet to be worked out. But it certainly seems that we take many more medicines than is good for us, and that our physicians are moved to prescribe all these medicines for us because of a mode of thinking about treatment that appears to be scientifically grounded but that in fact contains a good bit of commercial bias. So long as this system brings profits to both drug firms and physicians, an economism-driven society is unlikely to ask searching questions about these practices. And bioethics itself was very slow to accept commercial influence over physician prescribing as an ethical issue worthy of its attention.

I now turn to an issue that is more likely to emerge from the "cheer" rather than the "scold" crowd of bioethicists when a new technology is announced. When breakthroughs occur that promise better treatments for dread diseases, such as "personalized medicine" for cancer based on genetic typing of one's individual tumor, bioethics often responds positively, and may criticize anyone standing in the way of progress in such a line of research. How likely is bioethics to raise the question of the way that any good that results from that technology will be distributed across society?

Solomon Benatar, Abdallah Daar, and Peter Singer, addressing the bioethics of global health, offered some sobering statistics for 1994 (with every reason to believe that more recent figures would show an even more dramatic divide). In that year, 45 percent of the world's population had to subsist on 4 percent of the world's gross domestic product. The richest 385 billionaires at that time had a level of personal wealth also equivalent to 4 percent of the world's GDP. They then asked which of these two groups could reasonably be expected to reap whatever rewards might come from new, and expensive, biomedical technologies. They drew the defensible conclusion that there is likely to be a highly disproportionate benefit accruing to the latter group.[18]

If one develops a new technology that can be predicted to be very expensive, then one can make some confident guesses as to which group of patients, and how many, are likely to benefit from the application of this technology. One might fondly hope that someday in the future, the technology, after proving its usefulness among the rich, might drop in price and become widely available to all, but in most cases in medicine this remains nothing but a pipe dream. Bioethicists seldom question the ethics of developing such a new technology under these conditions.

In the case of many expensive technologies, the very rich may benefit, but at least the poor do not suffer any more than they would have otherwise (assuming for the moment that there is no practical way to divert the funds the rich would spend on personalized cancer care, stem cell treatments, and so on and invest those funds instead in public health for resource-poor countries). The case of organ transplantation, by contrast, represents a starker example of what one might call class warfare across the globe. The current widespread practice of paying organ donors in poor nations means that the wealthy in those nations (or whose physicians have ties to those nations) can obtain life-saving organs, while the poor donor undergoes a dangerous and disfiguring surgery. After all the middlemen get their cut, the actual amount of money paid to the donor is often a pittance, a small fraction of the sum paid by the recipient. In short, the current international market in donor organs appears to represent massive exploitation of the poor by the rich.[19] Yet some in bioethics defend the ethics of such markets in organs, often based solely on a theory of free market exchanges and with no understanding of the on-the-ground conditions affecting the parties to this transaction.[20] It is hard to imagine that bioethics would be so dismissive of serious questions of equity and social justice related to medical technology if economism were not the dominant policy discourse in the United States.

ECONOMISM, TECHNOLOGY, AND COST CONTAINMENT

Health care cost containment is one of the most politically vexed issues facing the United States, with widespread agreement that current rates of cost increase are unsustainable, and with recent data to suggest that roughly 30 percent of the current expenditures go to purchase medical modalities that provide no benefit to patients, as best as can be determined.[21] In what ways does economism influence the discourse around the role of technology in rising medical costs?

One case study that might be instructive is the recent debate over the regulation of medical devices. Concern over the safety of devices such as implantable cardiac defibrillators, spurred by major product recalls, led to a study by the Institute of Medicine (IOM). The IOM committee concluded that there were major problems in how the Food and Drug Administration (FDA) regulates these devices.[22] Commonly, new devices are exempted from having to undergo rigorous safety testing by being declared essentially equivalent to already-marketed devices, some of which in turn underwent inadequate safety testing when they were first introduced. The IOM committee called for major changes to improve device approval and safety oversight.[23]

The prestige of the IOM is such that even those who disagree with their findings often at least pay lip service to its reports and are cautious in their criticisms. It is unusual for a group that disagrees with IOM findings to reply with a frontal assault on the report and the committee. Yet a preemptive frontal assault was what the medical device industry elected to launch in this instance. The rhetoric of the industry response stressed two factors. First, devices were portrayed as the most advanced modern technology, virtually guaranteed to provide significant health benefits to patients; safety concerns were downplayed. Second, the industry depicted itself as beleaguered by unnecessary government red tape, despite offering many Americans well-paying jobs in its factories—jobs, the industry darkly hinted, that would be moved overseas if the FDA were so incautious as to take the IOM's advice and tighten regulatory oversight. According to the industry rebuttal, the FDA ought to further loosen device regulation, not implement more stringent requirements.[24]

It appears unlikely that the device industry would have launched such an aggressive campaign unless it had confidence in its friends in the U.S. Congress. The congressional delegations of states such as Minnesota that are home to major device manufacturers quickly fell into line in support of the industry, support that included congresspeople of both major parties. This support seemed to have two bases in particular. The threat of job loss in the states affected, during a time of recession and high unemployment, struck a responsive chord. But additional lobbying muscle was provided by venture capitalists. These capitalists had invested heavily in device companies as firms best placed to offer very high returns on investment, and helping the industry to turn aside strict FDA regulations simply made good business sense in protecting past and future investments.[25] In this manner, elected representatives, who might have been thought to be open to appeals based on both scientific expertise and patient safety, instead rejected the IOM recommendations out of hand and lined up quickly with the industry.

I suggest that this lobbying campaign and public condemnation of the IOM report could occur most readily in a society that had been largely taken over by economism as a belief system. The elevation of business interests above science and patient safety, and the naïve faith that new device technology would offer only benefits and never cause harms, would have been much more open to challenge in a non-economism-dominated political discourse.

Moreover, the lobbying muscle of the industry and its venture capitalist cronies would have been much more limited in a society that restricts the role of corporate dollars in political campaigns. But especially since the *Citizens United* ruling of the U.S. Supreme Court, America has allowed the free flow of campaign donations to an even greater extent than before.[26] The legal campaign to reverse campaign finance reform that led to that court ruling was largely the result of the economism rhetoric and decades of the appointment of federal judges friendly to that system of thought.

Moving from the device example to the larger political framework, data showing that nearly a third of health spending produces no better health for anyone would suggest efforts to identify those interventions that fail to provide benefit, and then to implement measures to discourage or prevent doctors from ordering them.[27] This apparent political wisdom, however, runs afoul of a principle famously articulated by Princeton health economist Uwe Reinhardt, that health care expenditures equal health care incomes—that is, that money spent on any "care," even useless care, is money going into someone's pocket.[28] In country that spends more than 2.5 trillion dollars on health care, one can expect a pitched political battle as soon as one begins to target any medical modality for the fiscal chopping block. The particular rhetorical form that this battle has assumed is the talk of "death panels." At first, "death panel" talk was aimed at one particular provision in a draft of the Obama health reform act of 2010, which would have reimbursed physicians for having conversations with patients around advance care planning for the end of life—a measure that initially had broad bipartisan support, and that has been widely advocated by physician groups. Soon, however, the label of "death panels" was displaced to another provision of the new reform law—the Independent Payment Advisory Board, which would be charged with reviewing government health spending and could recommend targeted cuts in case of cost overruns.

The rhetoric of "death panels" suggests a narrative in which patients who might benefit from advanced but expensive medical technologies are denied those benefits by hard-hearted, unelected bureaucrats who are simply out to save a buck. This narrative ignores medically salient information. I have already mentioned the mounting evidence that as much as a third of current spending could be eliminated without depriving patients of any benefit. Perhaps even more important, the harm done to the public by the continued employment of so much nonbeneficial "care" goes well beyond direct monetary costs. Unneeded surgeries and other procedures cause complications. Unnecessary tests produce false-positive results, which then require follow-up and may lead to further, more invasive diagnostic procedures that in turn cause complications. The Good Stewardship Working Group of the National Physicians Alliance, which tried to identify the top five useless procedures in each of the three primary care specialties, characterized their effort as aimed not at saving money but at improving the quality of care—a framing that is amply justified by the scientific evidence.[29]

Other financially well-off and technologically advanced nations employ many fewer of these nonbeneficial modalities than does the United States, a fact that plays a large role in health care being relatively much more affordable there than here. It is doubtful that in any of those other countries, "death panel" rhetoric could have gained anything close to the political traction that it has enjoyed in America. I submit that that is a measure of how much more successful the belief system of economism has been in capturing the U.S. political discourse.[30]

CONCLUSION

My main thesis is that the rhetoric of economism must be challenged, and ideally driven from its role as the central political and policy discourse in the United States, before the bioethical inquiry into the appropriate use of new medical technologies can proceed reasonably free from distortion. Recently there have been signs that an early challenge to economism is finally being launched. The "Occupy" movement protests, followed by a Congressional Budget Office report on worsening income inequality in the United States, appear finally to have created a place for the issue of income inequality within the popular political discourse, where previously the issue was treated more or less as taboo by the mainstream media.[31] The fact that the political discourse has shifted is further hinted at by the reactions to the early days of the Mitt Romney campaign for the Republican presidential nomination, in which it became commonplace for challengers to note that as a very wealthy American, Romney was seriously out of touch with the travails of the middle class and poor. It remains to be seen, however, whether an enhanced discussion of relevant topics will occur within bioethics.

11

TECHNOLOGIES OF THE SELF AT THE END OF LIFE

Pastoral Power and the Rhetoric of Advance Care Planning

Lisa Keränen

INTRODUCTION: "TAKING RESPONSIBILITY FOR DEATH"

Following the Patient Self-Determination Act (PSDA) of 1990, health care providers and advocacy groups stepped up their efforts to persuade Americans to specify their end-of-life treatment preferences through advance health care plans before the onset of incapacitating illness.[1] Nearly thirty years later, in the midst of a protracted debate about his proposed health care legislation, Barack Obama became the first U.S. president to publicly endorse advance health care plans as "sensible" in a tele-address before the American Association of Retired Persons.[2] "I actually think it's a good idea to have a living will," he assured his audience, "I'd encourage everybody to get one."[3] More recently, when the Supreme Court was considering arguments about the constitutionality of President Obama's controversial health care plan, *Never Say Die* author Susan Jacoby published a *New York Times* op-ed, "Taking Responsibility for Death," in which she lamented the number of Americans who lack clear advance directives regarding their wishes for medical care at the end of life. "[E]nd-of-life planning is one of the few actions within the power of individuals who wish to help themselves and their society," she opined: "too few Americans are shouldering this responsibility."[4] President Obama's and Susan Jacoby's arguments in favor of adopting advance directives mirror widely circulating public claims that advance care planning documents help health care professionals and family members to honor a patient's wishes at the end of life.[5] Even in the face of persistent criticism about the utility of advance directives, advocacy groups extensively endorse their use.[6]

I begin this chapter with Obama's and Jacoby's statements in favor of advance care planning because I seek to turn our attention to the intersections of technology, religion, ethics, and death in the evolving rhetoric of end-of-life planning. More specifically, I want to explore what advance care planning rhetoric reveals about how we are asked to understand ourselves as biomedical subjects at the beginning of the twenty-first century. Although advance care plans such as living wills and the ubiquitous Five Wishes document promise patients a degree of control over their end-of-life care, their implementation offers less command than suggested.[7] Moreover, despite significant debates about their bioethical and practical entailments, the rhetorical operations of advance directives remain underscrutinized.[8] In an era when a sizable proportion of Americans can expect to die within the walls of health care institutions following decisions to limit medical intervention, considering the rhetoric of advance care plans allows us to investigate how technological developments prompt new language and subjectivities, which in turn raise their own sets of ethical and practical concerns.[9]

This chapter draws from Michel Foucault's concept of pastoral power to consider the interplay between patient advance care documents and medical or physician orders for life-sustaining treatment (MOST/POLST). Interweaving rhetorical analysis of leading advance care planning documents with broader discourse about the forms, this chapter argues that advance care plans represent a novel form of pastoral power concerned with the salvation of self through planning for a "good death."[10] Here, techniques of self-inspection/disclosure, individualization, and "responsibilization" direct subjects to specify how they want to leave this world, to choose which technologies they will allow in life's final hours, thus making death planning—and communication about the preferred terms of such death planning—a routine technology of the self.[11] For Foucault, processes of pastoral power—and indeed all forms of power—ultimately comprise questions of subjectivity. "All of these present struggles," he tells us "revolve around the question: Who are we?"[12] This chapter takes up this question, "Who are we?" by exploring what the evolving rhetoric of advance care planning suggests about how subjects are configured within the context of twenty-first-century biotechnological advancement.

By considering the rhetorical operations of end-of-life rhetorical forms in shaping health and medical subjectivities, this chapter contributes to three scholarly conversations. First, for rhetorical critics of biomedical and health texts, it adds to a growing literature that assesses the persuasive dimensions of the rhetorical forms that are evolving to meet the challenges posed by our contemporary health care system.[13] More specifically, it forms part of a conversation with rhetorical scholars such as Ellen Barton, Megan Foley, Michael Hyde, Robert Wade Kenney, Lisa Keränen, Todd McDorman, Judy Segal, and others, who seek to understand how rhetoric and death mutually shape one another in a legally and technologically saturated world.[14] While death as a biological process lies largely outside of linguistic intervention, a host of shifting discursive practices have evolved to help humans and health care institutions grapple with the complexities posed by medicines and machines that render "the timing of death—once a matter of fate"—"a matter of human choice."[15] Second, for those writing about advance care planning from ethical, legal, and pragmatic standpoints, such as Daniel Callahan, Ezekiel Emanuel, Linda Emanuel, Susan Hickman, Alan Meisel, Alvin Moss, Peter Mueller, Henry Perkins, Charles Sabatino, Peter Singer, Daniel Sulmasy, and many others, the chapter offers a philosophical perspective for thinking about the complex power and subject relations that converge around the end of life.[16] Finally, for readers of this book in particular, it offers an investigation into how language morphs to meet the opportunities and constraints presented by technologies that are deeply embedded in institutional life and how emerging language patterns index changing end-of-life subjectivities. Here, the chapter invites readers to consider the interrelations of power, technology, language, and subjectivity in some of the most commonly used documents that facilitate end-of-life care.

To advance these conversations, this chapter employs rhetorical criticism, a method of humanistic inquiry that seeks to uncover and evaluate the persuasive workings of discourse; it follows the critical method of stitching together fragments of broader cultural discourses into a "text suitable for criticism."[17] In this case, my broader text encompasses the two widely employed forms Five Wishes and Colorado's MOST, interviews conducted with Colorado-based palliative care practitioners in the spring and early summer of 2012, public patient and family statements about advance care planning, and broader academic publications about advance directives. It is important to note that from informal conversations with family and health care providers through formal palliative care consults, a host of rhetorical practices about end-of-life treatment preferences in particular and death and dying more generally surround the advance care communication addressed in this chapter. Accordingly, I do not want to suggest that deathbed agency resides in forms such as Five Wishes and MOST; rather, whatever agency is deployed in end-of-life decision making is enacted via an ensemble process in which various stakeholders participate in differing degrees in ways that are constrained by shifting material conditions.[18] For the purposes of this chapter, however, Five Wishes and MOST constitute useful analytic anchors because these documents make manifest some of the dynamics of end-of-life communication through distinct linguistic arrangements. Five Wishes and MOST merit investigation for what they can tell us about the contours of end-of-life communication.

The chapter begins by offering a brief sketch of the evolution of the rhetoric of advance care planning before examining Foucault's concept of pastoral power. Next, the chapter tracks specific mechanisms of pastoral power through Five Wishes, Colorado MOST, and related advance care planning discourse, and it concludes by examining the implications of advance care planning for contemporary notions of ethics and biological subjectivity. Ultimately, this chapter seeks to shed light on the discursive operations of some of the most emotionally complex and existentially impactful conversations in which most of us will ever participate, wherein distinct language patterns and life-sustaining technologies commingle in consequential ways that cultivate particular end-of-life subjectivities.

The Evolution of Advance Care Planning Rhetoric: From Living Wills to MOST

The moral, legal, practical, and communicative dilemmas of life sustained by machines, dramatized through mass-mediated spectacles surrounding the cases of Karen Ann Quinlan in 1975 and Nancy Beth Cruzan in 1990, came to a striking head in the international press once again in 2005. Here, the sensationalistic chatter of the twenty-four-hour news cycle chronicled the intensifying political theater and spreading familial anguish surrounding the case of Terri Schiavo.[19] Viewers watched as the husband and parents of Terri Schiavo struggled with each other, politicians, courts, advocacy groups, commentators, and the press over whether Schiavo, whom many doctors claimed was in a "persistent vegetative state," would be removed from life support. While courts had long recognized the rights of individuals to make their own health care decisions, the Schiavo controversy revolved around whether Schiavo's husband had the right to decide to have life support removed in the face of staunch opposition from her parents, who insisted that as a Catholic, Schiavo would have insisted on nutrition and hydration—delivered in this case through a tube surgically implanted in Schiavo's abdomen.[20] After an extended series of legal battles, the courts ordered the removal of Schiavo's feeding tube and she died, but not without invigorating the "right to life" movement, prompting questions about federal intervention into familial and health matters, raising disability rights arguments, and stirring public fears about mechanically sustained life. Joseph Barmakian, former president of the Living Will Registry, testified that the Schiavo case "brought the whole idea of advance directives and living wills into the national consciousness" and noted rising living will registrations during and after the Schiavo media storm.[21]

The Schiavo case served as a powerful illustration of the complex end-of-life decisions faced less publicly each day by countless families, patients, and health care workers. Indeed, medical professionals and advocacy groups had been making the case for decades that advance directives comprised an ethical response to the challenges of technological advancement, rising patient autonomy movements, and the fact that health care providers had become, in David Rothman's terms, "strangers at the bedside," meaning that the medical resident likely to be admitting a patient to the emergency room at two in the morning was unlikely to be familiar with that patient's history, preferences, and values.[22] In fact, by the time the Schiavo case erupted, it was widely recognized even beyond the medical establishment that the technological developments of the latter half of the twentieth century presented novel ways of sustaining life that raised significant questions about the nature of life, the changing face of death and dying, and the parameters of humane care. Cardiopulmonary resuscitation could pull patients from the precipice of death, and mechanical ventilation, chemical agents, and other modern medical marvels could sustain life—but at what toll? As Charles Sabatino explains, following the advent of CPR and life support, "it often became difficult to distinguish saving life from prolonging suffering and death."[23]

Against the backdrop of contentious public cases and growing legislation, medical professionals met the challenges posed by life-sustaining technologies by inventing and promoting a profusion of procedural and legal reforms geared around documenting and honoring a patient's desires regarding end-of-life care before the patient reached decisional incapacity.[24] Many of these reforms generated evolving genres of end-of-life communication that seek to elicit, record, and disseminate patient preferences for medical care.[25] As Carol Berkenkotter and Thomas Huckin observe, "[G]enres are dynamic rhetorical forms that develop from responses to recurrent situations and serve to stabilize experience and give it coherence and meaning."[26] Advance care plans arose as a rhetorical response to medicine's changing relationship to technology, the triumph of patient autonomy over physician paternalism, and rising consumerist models of medical practice that privilege individual consumer choice. These perceived challenges and changes prompted the development of a diverse cadre of advance directives, with each trying to improve on the perceived limitations of its predecessor. The main genres include living wills, health care proxy documents, cardiopulmonary resuscitation directives, values surveys, and hybrid documents that combine at least two of the other forms. In each of these genres, new rhetorical forms complemented and embellished but did not supplant the older forms, meaning that today's citizens encounter an ever-expanding array of options for documenting their anticipated health care preferences.

Whether patients identify a proxy decision maker, specify limits on future treatments, or elucidate values that might inform future decisions, advance directives reflect a constellation of values that arose in tandem with the twentieth century's changing technological and historical circumstances. More concretely, advance directives embody twin commitments to patient autonomy and beneficence: they enshrine the bioethical value of letting patients choose the terms of their medical care in ways that are meant to help the patient and the patient's family. While the stated goal of advance planning documents is honoring patient wishes, of "indicat[ing] what treatment [a patient] should not be given in the event that she is not competent to consent or refuse at the future moment in question," these forms also facilitate institutional practice by helping patients and their families navigate an emotionally saturated, technologically dense, and legally inundated terrain.[27] Moreover, advance care documents are predicated on the rhetoric of anticipatory imagining.[28] The documents ask users to envision possible future states and forecast their preferences.[29]

In the face of rising concerns about technological dependence, the earliest proposal for advance directives came from the Euthanasia Society in 1967.[30] Luis Kutner, the attorney who represented the society, described a "living will" as "a revocable or conditional trust with the patient's body as the res, the patient as the beneficiary and grantor, and the doctor and hospital as the trustees."[31] Modeled after estate planning, the concept of the living will posited that parties could specify their health care desires *before* they became unable to speak for themselves. Living wills therefore often include wishes regarding cardiopulmonary resuscitation, the administration of food and water, and even pain relief and antibiotics. Nearly every state has passed legislation supporting living wills.[32] However, more than forty years after their conception, fewer than a third of adult Americans have completed a living will, suggesting that most citizens resist completing these documents despite urging from medical ethicists, lawyers, and health care professionals.[33]

In addition, concerns that living wills often did not address the full range of potential future medical situations or that they did not provide enough information to lead family and practitioners in knowing and subsequently executing a patient's wishes spurred a second generation of advance directive: the medical durable power of attorney. Sometimes known as a health care proxy, this form of advance directive allows a person to specify a third party who will make health decisions on the patient's behalf if the patient is unable to do so. As early as 1983, the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research advocated the use of surrogates for health care decision making, even as the commission recognized the potential for abuse of this position.[34] An additional problem with naming a health care proxy decision maker, as Susan Hickman and her colleagues explain, is that such "advance directives typically do not include directions for the surrogate or health care professionals about treatment preferences unless special instructions are also provided."[35]

In recognition of the limits of living wills to anticipate the range of situations that an incapacitated person might face and the need for health care proxies to understand the values that might inform another's preferences, a new generation of advance directives was born. This "third generation" of advance directives sought to combine earlier living will/proxy documents with broader surveys of values. First proposed in 1988 by David Doukas and Lawrence McCullough of Georgetown, the "Values Survey" comprised two parts: "an explicit identification of values" and "the articulation of advance directives based on the patient's values."[36] Additional versions of values instruments, such as the "Medical Directive," flourished at this time. So did a bevy of CPR directives, do-not-resuscitate forms, code status sheets, and other paperwork designed to record patient preferences regarding end-of-life medical interventions; these were prompted in large measure by the PSDA's requirement to document patient preferences for life-sustaining treatment.[37] Over time, the discourse of advance directives would increasingly feature the terms *planning*, *communication*, and *conversations* to index the rising sentiment that end-of-life preferences should be revisited over time through a series of conversations among patients, their loved ones, and health care professionals.[38]

As pragmatic as the ideal underlying advance care plans may be, concerns abound that "[a]dvance directives simply promise more control over future care than is possible."[39] For instance, Henry Perkins observes that "health professionals can rightfully wonder whether past wishes written into advance directives remain valid in present crises."[40] Despite the fact that people cannot predict how they will feel when sick, that personal preferences change over time, and that patient wishes are not carried out because advance care documents are often unavailable when needed, the practice of patient and family education about advance directives remains legally and institutionally entrenched.[41] In a 2007 survey of U.S. home health and hospice agencies, 96 percent reported assessing whether a patient possesses advance directives on admission, 93 percent reported providing patient and family education about advance directives, and 80 percent provided advance directive forms to patients upon admission.[42] Two of the most common documents that patients and their families are likely to encounter in such circumstances—and the ones I analyze in this chapter—are Five Wishes and MOST.

Five Wishes constitutes an illuminating document for talking about the rhetoric of advance care planning because it demonstrates the intersection of worldly, spiritual, and practical aims.[43] As a "third-generation" advance directive, Five Wishes weaves a living will, a health proxy document, and a life values survey into one convenient form. Spanning twelve pages of light blue paper with medium blue font reminiscent of a muted hospital tone, Five Wishes directs clients and their families through a series of five major conversational prods, the five wishes after which it is named. The first two wishes are legal documents—a living will and a health care power of attorney—while the last three explore comfort care, spirituality, and forgiveness/memory. Developed in 1997 by a Florida nonprofit organization called Aging with Dignity, Five Wishes seeks to "affirm and safeguard the human dignity of individuals as they age and to promote better care for those near the end of life."[44] Although the Robert Wood Johnson Foundation provided funding for the initial development in English, a grant from the United Health Foundation helped to translate Five Wishes into twenty-six languages. According to Aging with Dignity, more than eighteen million people have used the form, making the document "America's most popular living will," an "easy to use legal document written in everyday language that lets adults of all ages plan how they want to be cared for in case they become seriously ill."[45] Five Wishes also boasts a prominent Internet presence. In 2011, Aging with Dignity introduced an online version of the Five Wishes, which allows users to complete their wishes using an online template or to print the wishes and complete them by hand. Noteworthy, too, is that one must pay to download the form; it is protected by copyright law, meaning that the process of disclosing one's deathbed preferences is bound up in the rising tide of health consumerism and intellectual property rights.[46]

Despite the ubiquity of Five Wishes, the document faces competition from another form that is steadily gaining nationwide traction: POLST (physician orders for life-sustaining treatment), which also goes by the acronyms MOLST (medical orders for life sustaining treatment) and MOST (medical orders for scope of treatment).[47] Initially developed in Oregon at the beginning of the 1990s, POLST/MOST is not an advance directive but a portable medical order that seeks to "convert patient preferences into immediately actionable medical orders that are readily accessible to medical personnel, including emergency medical technicians (EMTs)."[48] In Colorado, where I conducted interviews with palliative care practitioners, the Delegate Assembly passed an initiative to add MOST to the state's health care tools effective August 11, 2010. Statewide education campaigns accompanied the legislation and promoted the message that MOST is "Standardized. Efficient. Portable. Flexible. Updatable. Effective," indicating its inculcation of institutional values.[49] While POLST/MOST varies slightly by state, Colorado MOST is a double-sided form that health care professionals are recommended to photocopy on Vulcan green heavy-stock paper, although white paper copies are allowed too. The MOST form accompanies the patient; when signed by a physician, advance practice nurse, or physician's assistant, MOST becomes a set of medical orders that are intended to be executed at any health care facility.

Let me be clear at the outset that Five Wishes and MOST are documents designed for different purposes. Five Wishes aims to have patients establish a set of *wishes* in advance of incapacitation (although the establishment of a health care proxy is binding if executed according to state requirements), while MOST generates a set of *medical orders* that are often developed after the patient is closer to dying and that may be completed by a medical professional in conversation with a patient's proxy. Significant for the present analysis is that MOST has been described as a "new paradigm for the health care system," suggesting that it warrants attention for what it might offer beyond conventional advance directives such as Five Wishes.[50] A closer inspection of Five Wishes and MOST using the lens of pastoral power, however, shows that the two share a particular postmodern biomedical sensibility I term "the communicative imperative." But first, a review of pastoral power will help set the stage for my argument.

THE ANATOMY OF FOUCAULT'S PASTORAL POWER

Alternately revered, reviled, extended, and challenged, the late French philosopher Michel Foucault's work has prompted medical and health humanists to investigate the intersection of power, institutions, knowledge, and subjectivities across clinical, private, and public settings.[51] In this chapter, I seek to chronicle how the self-examination/disclosure, individualization, and "responsibilization" required to produce advance care plans constitute a deployment of what Michel Foucault calls pastoral power and to explore the implications of advance care planning for ethics and identity.[52] Foucault's thematic of biopower is well known to health humanities scholars and has been fruitfully employed to show the interrelations of power and knowledge in medical settings; yet his later ethical turn and investigations of governmentality provide an equally fertile perspective for examining how subjects are formed at the intersection of technology and rhetoric. Whether or not readers find his critique of conventional conceptions of power and macro-historical generalizations convincing, he is, as Arthur Frank and Tess Jones suggest, "good to think *with*."[53] Because his philosophy turns our attention to the intersection of power and subject formation, I hope to use Foucault's concept of pastoral power heuristically. However, I acknowledge the limits of the Foucauldian perspective, which include its sweeping historical glosses, scarcity of concrete examples, and rather pessimistic view regarding the ability to effectively counter the systems in which one is embedded. Nonetheless, the concept of pastoral power, as we will see below, supplies a framework for beginning a discussion about how advance care documents attempt to guide the conduct of patients and health care practitioners alike.

Foucault scholars often divide his work into three phases: the archaeological—when he was concerned with the historical analysis of systems of thought; the genealogical—when he examined the relations between forms of knowledge and power; and the governmental/ethical—when he addressed the diffuse roles that individuals, institutions, and other forms of governance play in structuring subjectivities. While medical humanities studies of governmentality have been growing since Alan Petersen's 2003 observation that medical humanists focused disproportionate attention on the early Foucault, much work remains to elucidate processes of governmentality across health care interactions, particularly in the context of advance care planning.[54] For Foucault, governmentality refers to "contact between the technologies of domination of others and those of the self."[55] In other words, government here concerns how the conduct of people or groups is directed, how the "possible field of action" is structured.[56] Governmentality differs from the other forms of domination that Foucault outlined earlier in his career in that governmentality asks us to examine how we act on the basis of what we believe to be true about ourselves and how these ways of acting in turn "give rise to different ways of producing truth."[57] Thus, governmentality turns our attention to the processes by which subjectivities are produced, negotiated, contested, and extended through discourses based on regimes of truth.[58]

Under the broader umbrella of governmentality, Foucault's concept of pastoral power references a technique of power previously exercised by the Christian church when priests guided members of their flock in order to "assure individual salvation in the next world."[59] Foucault explained that the pastor or cleric must "take charge of and observe daily life in order to form a never-ending knowledge of the behavior and conduct of the members of the flock he supervises."[60] Pastoral power is meant to shape the actions of particular members of a population using the priestly techniques of confession and self-examination. In its original form, pastoral power entailed one person acting as a guide to another; a priest or cleric served as a trusted benefactor who cared for the soul by watching over individual members of his spiritual community. In this way, for Foucault, pastoral power could not be deployed without "making [subjects] reveal their innermost secrets"; pastoral power thus intertwined confession and individualization because a cleric or priest must, among many other tasks, learn the deepest particulars of the souls in his care.[61]

In Foucault's account, pastoral power migrated out of the pastorate and spread throughout the broader social body in the sixteenth and seventeenth centuries; it now forms the deep background of contemporary state and institutional power.[62] Contemporary pastoral power transcends its original focus on salvation in the afterlife however, and instead seeks salvation in the present. Its new aims aspire to health, security, well-being, and wealth.[63] Moreover, the administrators of pastoral power have multiplied to span private ventures, philanthropic agencies, welfare organizations, and institutions of the state.[64] For Foucault, health care supplied a particularly salient context for evolving forms of pastoral power. From inducements to diet and exercise through persuasion about purchasing health insurance, health, security, wealth, and well-being are increasingly tied to individual conduct.[65]

It is important to note that pastoral power does not replace juridical power, the power of the law, or the disciplinary power aimed at controlling bodies and populations that Foucault elsewhere outlined.[66] Indeed, Five Wishes and MOST involve commingled deployments of juridical and pastoral power. Both, for instance, become legal documents when properly executed and entered into a patient's medical record, and MOST represents a binding medical order. Despite their juridical entailments, however, Five Wishes and MOST provide occasions for thinking through how pastoral power operates in end-of-life contexts and for examining the role that advance care planning documents and their accompanying discourses play in cultivating a sense of responsibility for planning the terms of death.

PASTORAL POWER IN FIVE WISHES AND MOST: PROMOTING THE COMMUNICATIVE IMPERATIVE REGARDING THE END OF LIFE

I argue that three tightly interwoven mechanisms of the new form of pastoral power characterize both Five Wishes and MOST: self-examination/confession, individualization, and "responsibilization."[67] Together, these mechanisms signify and promote what I term the "communication imperative" at the end of life. To link Five Wishes and MOST to both citizen discourse and palliative care professional discourse, I interweave throughout this section citizen posts to a *New York Times* blog about advance care plans, comments from interviews I conducted with palliative care professionals who use Five Wishes and Colorado MOST, and published academic literature on advance directives. My hope is that this divergent set of conversations about these documents will complicate our understanding of the interlacing of power, technology, rhetoric, and subjectivity at the end of life.

Self-Examination, Confession, and Individualization

First and foremost, Five Wishes and MOST are predicated on a notion of a self-examining subject who must come to know—and articulate—the "innermost secrets" of his or her end-of-life preferences and must do so, in the case of Five Wishes, in terms that exceed mere medical directives.[68] For instance, whether or not people have previously considered their end-of-life care preferences, Five Wishes leads users through a detailed twelve-page investigation of topics such as "The Person I Want to Make Health Care Decisions for Me When I Can't Make Them for Myself," "The Kind of Medical Treatment I Want or Don't Want," "How Comfortable I Want to Be," "How I Want People to Treat Me," and "What I Want My Loved Ones to Know."[69] For each section, the document allows prospective patients to specify the types of care they would like to receive, either by including open boxes for personalized text or by directing users of the form to cross out statements with which they disagree. Here, users are asked to develop an intimate form of self-knowledge that revolves around their end-of-life preferences but that expansively includes wishes regarding how loved ones should view the death of the patient, advice that the bereaved should seek counseling, and even reminders about how the dying wish to be remembered after death. That Five Wishes transcends mere medical directives to encompass the spiritual and familial well-being of its users signifies the extension of medicalized discourses into more terrains of human activity at the same time that it produces a personal knowledge of anticipated health care preferences.[70]

Five Wishes is further steeped in the language of forgiveness, bearing residue of the older form of pastoral power through the religious concept of redemption via confession. The final wish, in particular, indexes this point. Explicitly addressing forgiveness, "What I Want My Loved Ones to Know" prompts users to make peace with relatives by specifying options such as "I wish to be forgiven for the times I have hurt my family, friends and others"; "I wish to have my family, friends and others know that I forgive them for when they might have hurt me in my life"; and, in an even more expansive frame, "I wish for all of my family members to make peace with each other before my death." Here, the focus on forgiveness before death is meant to provide a kind of spiritual comfort in this world. The document penetrates human life more deeply, however, by including statements that suggest that family members view death and dying as a personal growth opportunity, that they seek counseling to handle the death, and that they resolve their differences. Five Wishes has extended the original technological reach of advance directives, making death planning more than a mere act of determining medical intervention but a life-encompassing strategy—and one that is deeply implicated in power relations. Patients are asked to be responsible not only for their own conduct, but also for directing the conduct of others in relation to their death.

By contrast to Five Wishes' sweeping examination of preferences across health care, interpersonal, and familial contexts, Colorado MOST simplifies the process to a one-page, double-sided form that also requires the production of a patient's personal health care preferences through five conveniently shaded check box spaces. These address cardiopulmonary resuscitation (yes or no), medical interventions (from comfort measures only to full treatment, which includes "intubation, advanced airway interventions, mechanical intervention, and cardioversion"), antibiotics (from none through comfort only through yes), artificially administered nutrition and hydration (none, defined trial period, long term), and finally a communication section that involves check boxes indicating with whom the wishes were discussed (patient, medical durable power of attorney, proxy, etc.). The check box simplicity of MOST is meant to counter the exhaustive summaries of Five Wishes, which, as one interviewee confessed, "doesn't give [the emergency medical technician] the information that they need in the five or ten seconds that they have to make a decision when they walk up to a patient's bedside when nine-one-one has been called." Despite its simpler format, MOST, like Five Wishes, signifies that contemporary subjects who encounter biomedical settings are asked to plumb their consciousness—or piece together the preferences of those for whom they serve as proxy decision makers—for their personal desires regarding these medical technologies. In this way, a completed Five Wishes or MOST document can be seen to have produced a certain sort of "truth" about the individual even as such truth is partial, layered, likely to change over time, and highly structured by institutional imperatives, technological capabilities, and professional needs and norms. Although their aims, scope, users, and intended timing slightly differ, both documents engender particular forms of knowledge production that cultivate subjects who come to plan for the technological (and in the case of Five Wishes, spiritual and interpersonal) terms of their and others' deaths.

For Foucault, technologies of the self "permit individuals to effect by their own means or with the help of others a certain number of operations on their own bodies and souls, thoughts, conduct, and way of being, so as to transform themselves in order to attain a certain state of happiness, purity, wisdom, perfection, or immortality."[71] As technologies of the self, these documents require not only self-examination but also a postmodern form of confession in which older, more sacred discourses associated with guilt, sin, soul salvation, and the afterlife have been supplemented by the need to disclose one's preferences in order to provide peace of mind for the foreseeable present. Both Five Wishes and MOST therefore work to transform health care providers and users of the form into postmodern priestly roles by requiring their participation in a project in which a patient's innermost desires are plumbed, confessed, documented, and shared. Whereas a dying patient may in previous times have been expected to confess his or her sins to a cleric before death to ensure salvation in the present, one is now asked to disclose one's preferences for care in order to ensure security of mind in this world. This analogy to priestly confession is not meant to suggest that many patients do not still seek religious and spiritual modes of communication, particularly at the end of life; the new form of pastoral power merely complements the old form. Patients are now asked to "soul search" regarding which end-of-life treatment preferences comport with their values and goals.

Five Wishes is particularly explicit about its capacity for reducing uncertainty regarding family decision making. A section titled "How Five Wishes Can Help You and Your Family" notes that Five Wishes "lets you talk with your family, friends, and doctor about how you want to be treated if you become seriously ill." But more than that, "it lets you say *exactly* what you want," and "Your family members *will not have to guess* what you want. It *protects them* if you become seriously ill because *they won't have to make hard choices* without *knowing* your wishes."[72] Cheryl from Longwood, Florida, testifies on the next to last page of Five Wishes, "It will be a year since my mother passed on. We knew what she wanted because she had the Five Wishes living will. When it came down to the end, my brother and I had no questions on what we needed to do. We had peace of mind."[73] In this way, Five Wishes attempts to convert patient preferences into a kind of secure knowledge to guide the conduct of the self, loved ones, and medical professionals.

The aim of affording protection through clarified preferences signifies pastoral aims transmuted to our secular society. Appeals to the benefits of clarified preferences appear across a wider swath of citizen advance planning commentary. For example, Ken Y. explains in a comment to a blog post about advance directives that "I agree with the poster above who says that this is a gift one gives to one's family . . . any guidance one can give their advocate in death will make it easier for all the survivors to cope."[74] Likewise, Kd writes, "Having the document in front of me, and in front of [a loved one's] health care providers made his wishes and his desire that I execute them, extra clear. This was a great support in a difficult time."[75] Pat further echoes the supportive function of advance directives in helping her face the death of her father from end-stage COPD. "I thank him every single day for [his advance directive]," she shares. "[I]t was such a blessing that he had made his wishes known so clearly, and to know that when I brought the paperwork to the hospital—at his very supportive doctor's suggestion—I wasn't making a heartbreaking decision but simply doing what he had made very clear he wanted, and needed, me to do."[76] Although Pat misses her dad "every single day," she knows "that he gave us both a huge gift by having the foresight and courage to make those plans."[77] In each of these examples, advance care documents are lauded for providing comfort in the knowledge of another's choices.

Despite potentially affording a limited "peace of mind," Five Wishes and other advance planning documents can never fully assuage the complex burdens many face at the end of life. Clif G., in comments to a *New York Times* blog about advance directives, astutely acknowledges that "on the one hand, these directives relieve caretakers of the responsibility of making a decision on their own, but I doubt if that does much to relieve guilt, and I imagine that many a son or daughter found themselves disagreeing with their parent's directive in the end."[78] As Clif's comment illustrates, a form can never supply the panacea for the complex messiness of human relations—particularly at the end of life—and the roiling emotions they may engender.

What these forms supply instead is a sense of direction based on the generation and disclosure of self-knowledge. Comments from both palliative care experts and nonexperts recognize both the practical utility of clarifying patient values and the self-knowledge-producing basis of advance directives. The palliative care practitioners I interviewed consistently pointed to the value of Five Wishes in helping patients discover their personal preferences. For instance, one geriatrician and hospice medical director mentioned,

> I think the really positive point with Five Wishes is that it really is a great tool for breaking the ice to open up and have the conversation. It enables patients to really begin thinking and putting some definition around what their values and their goals might be as they approach the end of their life. It's much more value and goal oriented than some of the other documents, which are much more treatment and disease focused.[79]

In this statement, what is important about Five Wishes is that it allows users to begin the process of self-examination that might lead to discovery of knowledge of the self, the truth of the individual of which Foucault writes. Similarly, Ken Y. acknowledges in a *New York Times* blog comment about advance directives that completing an advance directive helped him to develop a personal sort of knowledge. On the one hand, Ken Y. explains that he was spurred into completing an advance directive by a partner as well as "family dynamics" and "the keen desire to avoid a Terry Schiavo situation." On the other hand, he notes that the activity "gave me a chance to see myself in the larger context of my community—would I want to undergo organ transplants? What about my organs, do I want to donate?" The answers to each of these questions spur Ken not only to develop a kind of self-knowledge but also to define himself in relation to others; they help him to see the ethical ramifications of advance care decisions as extending well beyond his own care.

Although MOST is often introduced at a later stage of illness than is Five Wishes, the document affords a comparable type of knowledge to guide the patient, family, and practitioner alike. As one geriatrician explained to me, "If we, through the course of our discussion, already made decisions about you know, what limits the care, then what I'll usually say to patients is 'You know, we've talked about x, y, or z, and you've let me know there are certain kinds of care that you don't want, and to ensure that we protect your wishes, complete this [MOST] form.'" Here, MOST is meant to offer providers, patients, and families both a degree of control over what technologies are administered throughout the dying process and a sense of protection in knowing that preferences are being recorded and upheld. The document further functions to dispel doubt that medical practitioners might have about an appropriate course of action by supplying knowledge of individual preferences that have been rendered into medically actionable terms. One geriatrician and hospice medical director mentioned in my interviews,

> One of the things that I really realized using those [non-MOST advance directive] documents is how inexact the process was around those and how out of date those documents sometimes were relative to the current condition of the patient. That was actually one of the reasons that we wanted to move forward with something like MOST, which would get us at a place where it's—number one—more up to date in terms of the patient's wishes relative to their condition, and secondly, to give us the tools to help us facilitate those conversations and discussions around changing goals of care.

MOST's utility, then, lies in its ability to chart changing preferences for end-of-life care on a personal level in terms that are readily apparent to—and actionable by—medical professionals.

Closely intertwined with self-examination/confession is the individualizing function of pastoral power. Foucault observed that pastoral power works by globalizing quantitative knowledge of the population but also that it is "analytical, concerning the individual."[80] To be sure, Five Wishes and MOST both provide ritualized, standard language that is meant to be applicable across a broad population (even if in practice they may not be accessible to low-literacy and low-health-literacy populations); they supply the topoi that structure conversation about end-of-life preferences.[81] But these documents also allow for a wide range of interpretive freedom while asking that individuals confess their innermost wishes regarding end-of-life preferences. Five Wishes is particularly illustrative of this individualizing process. For each section, Five Wishes allows patients to specify the types of care they would like to receive, either by including personalized text or by crossing out statements with which they disagree. After reviewing the states that honor the document and explaining its legal standing, the first wish directs users to designate a health proxy decision maker and specifies the types of people who should and should not serve as a proxy. For instance, "A spouse or family member may not be the best choice because they are too emotionally involved. Sometimes they are the best choice. You know best."[82] In assuring users that they know best, the document evokes the values of autonomy and consumer choice. It then provides wishes to help guide the proxy and directs users to cross out anything with which they disagree. The wishes span a variety of possible future actions, ranging from organ donation to moving to assisted living facility and being moved out of state. The form further prods users to explain in their own words what the notoriously ambiguous term *life-sustaining treatment* means to them.

Five Wishes' versatility and expansive scope both resonates and repels depending on the patient, family, and practitioner, but it does try to generate person-specific preferences. One palliative care specialist told me, "It may be in Wish Three or Wish Four—if I am actively dying I want lavender oil rubbed on my hair while Yanni is playing in the background—whatever it is, you know, it's just really not real life." By contrast, another palliative care specialist pointed to the same section of Five Wishes, noting,

> I like the humanistic part of [Five Wishes], that you're actually having a conversation with the person of "what do you want done at your funeral—or as you're actively dying?" And I think that's what makes that special, because it allows for that—you know, not just checking [the] comfort care box on the MOST order, it really allows for, "I want ChapStick on my lips," "I want, you know, John Coltrane being played," you know, whatever it is. So, that to me is why I do the work I do.

In the latter comment, it is precisely the deeply intimate—and humane—knowledge afforded by Five Wishes that adorns the document with a pastoral and therefore individualizing power. This statement indexes the pastoral impulse to care for a broader range of human needs—spiritual, emotional—now spread throughout the social body into advocacy groups, health care practitioners, and even the subject herself.[83] It is no accident that Five Wishes' creators have called it the first "living will with a heart and soul."[84] With its expansive scope, Five Wishes allows for infinite customization of how one wants to be treated in life's dwindling days—even when such customization may or may not be medically or pragmatically feasible.

MOST, by contrast, is more circumspect; it conspicuously steers clear of spiritual, interpersonal, and familiar matters. MOST's rhetorical antecedent is the CPR directive, which suggests its impulse to winnow the range of discourse to medially relevant information. Yet despite its status as a medical order, MOST's efforts to honor patient wishes are similarly consistent with the individualizing aims of pastoral power. The form includes a boldfaced reminder to patients that "Everyone shall be treated with dignity and respect." MOST further affirms the individualizing impulse that "These Medical Orders are based on the person's medical condition and wishes," which simultaneously invokes the values of autonomy and beneficence even as it heads off potential charges of paternalism. Most salient for the present analysis, MOST retains the need for modern-day clinician-confessors. According to one social worker at a home hospice service whom I interviewed,

> With Five Wishes [patients] can complete it by themselves in the privacy of their own home. With MOST, I have found that a lot of them require a little more professional guidance in that it's not self explanatory . . . with the MOST, it is really important to have a skilled clinician to facilitate the discussion of that.

This final comment illustrates the primacy of communication to present configurations of advance care planning and reveals an additional rhetorical feature of advance care planning documents; namely, it reveals how documents such as Five Wishes and MOST cultivate a sense of responsibility for communicating about death.

Responsibilization and the Communicative Imperative

Having examined the intertwined workings of self-examination/disclosure and individualization, we can now see how Five Wishes and MOST work to instill a sense of responsibility for end-of-life planning across various sets of users—patients, families, health care professionals, lawyers, social workers, and so on—that represents a technology of the self. In extending Foucault's work, Paul Rabinow and Nikolas Rose call for exploring

> modes of subjectification, through which individuals are brought to work on themselves, under certain forms of authority, in relation to truth

> discourses, by means of practices of the self, in the name of their own life or health, that of their family or some other collectivity, or indeed in the name of the life or health of the population as a whole.[85]

In the context of health and medical matters, such modes of subjectification often take the form of *health responsibilization*, in which the subject comes to take on the work of individual health promotion. As Rose explains, responsibilization encourages the subject position of "a prudent yet enterprising individual, actively shaping his or her life course through acts of choice."[86] More specifically, twentieth- and twenty-first-century health promotion strategies mean that "every citizen must now become an active partner in the drive for health, accepting their responsibility for securing their own well-being."[87] A post by Amy K. to a *New York Times* advance care blog that "I can't even manage to register my car on time . . . but this is a good reminder that [completing an advance directive] is part of responsible planning. [*sic*] for everyone involved" and the comments by President Obama and Susan Jacoby that open this chapter signal how deeply and pervasively the doctrine of personal responsibility inheres in current configurations of advance care planning.[88]

But more than working to instill a sense of responsibility for making one's wishes known, advance care planning documents such as Five Wishes and MOST are emblematic of what we might call the communicative imperative about death whereby it is no longer enough simply to die. Now, the patient is asked to communicate—clearly and in detail—which technologies he or she wants administered when leaving this world and which person the patient wants to use the previously expressed patient's values to make decisions for him or her at the end of life. Likewise, health care providers who work in end-of-life contexts (and sometimes even in general practice) are asked to take on the burdens of, to bear *responsibility* for, initiating such end-of-life conversations. Hence, the responsibility for planning and communicating the terms of a "good death" penetrates a wide swath of the contemporary citizenry.

Five Wishes brings this responsibility into high relief, for one is prompted not only to communicate about medical preferences but also to reflect on and communicate about a broader set of social questions—forgiveness, how one wants to be remembered, whether one wants oil rubbed on one's skin or not. Five Wishes therefore encourages the constitution of the responsible subject who must articulate the terms of end-of-life care and terms of life surrounding the end of one's life, while MOST cultivates the responsible medical professional turned elicitor of patient preferences. In this way, both Five Wishes and MOST signify a secularized form of pastoral care in which one is asked to communicate about the preferred terms of death across a variety of contexts.

Nearly all of the palliative care professionals I interviewed emphasized the importance of communication throughout the advance care planning process, underscoring that the Five Wishes and MOST forms are useful only if the practitioners who introduce them are communicatively skilled. As one licensed social worker from a home-based hospice service observed,

> These are tools to facilitate discussion, but they are not meant to replace discussion. I think that that is the risk that we get in with some of these tools is that doctors or medical establishments use them solely as a tool to give to patients to complete it instead of initiating discussion around it. So anytime you admit to a hospital right now, you are handed a Five Wishes at the time of admit by an admissions clerk, but you would probably be very unlikely during that admission for anyone to actually sit down and go through it with you. . . . And I think that that active communication process between provider and patient is the most important part, because a tool is just a tool if we do not know how to use it.

This statement is rhetorically interesting as it affirms the communicative imperative by stressing the repeated and ongoing conversations that are expected to occur around such documents at the same time that it reveals a fissure in the expectation: it demonstrates that conversations sometimes do not occur around these documents, that the documents sometimes stand in for conversation.

Although the palliative care literature on advance care planning repeatedly reaffirms the communication imperative, it further suggests that the practice can often fall short of the ideal; repeated admonishments about the importance of communication throughout the process hint that such communication may not be as ubiquitous as palliative care experts would like. As Epstein, Volandes, and O'Reilly observe,

> The [advance care planning] meeting exemplified the therapeutic import of not only providing patients with the most sophisticated treatments but also engaging them in informative, tailored discussions regarding overall goals of care. Furthermore, the discourse suggests that advance care planning entails not only medical documentation such as living wills and proxy assignments but more importantly, the process by which physicians

> skillfully develop a continued understanding of the patient and his or her individual values.[89]

“Skillful,” “continued understanding of the patient and his or her individual values,” and “engaging them in informative, tailored discussions” all index the individualizing, pastoral, communicative technique. This statement demonstrates how, like a skilled confessor, the communicatively skilled care provider is expected to “help patients,” to elicit intimate knowledge of the patient’s preferences in order to guide conduct and care.

Rebecca Sudore clarifies that “a useful technique to help patients articulate their values is to have them discuss how they feel about the health states experienced by themselves or others.”[90] “Patients who have not personally been ill can reflect on stories in the media or on health care experiences of family or friends,” she advises.[91] Sudore even offers specific lines of conversation to assist other clinicians in eliciting patient knowledge and disclosure:

> Clinicians can ask, “If you were in this situation, what you would you hope for?” or “What would you be most worried about?” as well as “You told me in the past that [for example, not being able to leave the house independently] would not be acceptable to you. Now that this has happened to you, have you changed your opinion about the ways of being that would be unacceptable?”[92]

Sudore’s suggestions signify how medical professionals are being configured in advance planning discourse in terms consistent with the contemporary form of pastoral power; palliative care professionals are here expected to deploy inventive language strategies to elicit the individual truth of patient preferences in order to guide their passage into the great beyond. Such efforts signify the emergence of a doctrine of communicative responsibility that now surrounds the end of life and that often begins well before the dying process begins. Moreover, the preference elicitation strategies discussed thus far represent a small fraction of the communicative innovation around the end of life. Recent proposals extend calls for advance care planning to additional populations at the same time that they innovate for all patients by calling for poems, videos, decision tools, and narratives that help clarify values.[93] It is not a stretch to expect that these communicative, self-making tools will continue to coevolve alongside new end-of-life technologies in the years to come. In short, death preference communication is proliferating across multiple contexts and formats.

Within this array of expanding options, Five Wishes and MOST both confer a set of burdens and benefits. Recurrent strengths of Five Wishes identified by my interviewees included its comprehensive approach, its ability to spur conversation among family members and providers, and its clear explanations. Still, some, when asked about its limitations, expressed concerns that it was too long, too leading, and too personal. One expressed frustration that Five Wishes was not clear enough about CPR preferences, and another expressed regret that the document was not useful for low-literacy populations because it lacked pictures and was "too wordy." Another interviewee noted that Five Wishes documents could be unavailable or outdated and did not reflect changing medical circumstances. And more than one expressed ambivalence about the leading nature of the final concerns with forgiveness and "how I wish to be remembered." Although the final wishes may attempt to incorporate a humane element into death and dying, they also extend the reach of medicine in ways that made some of my palliative care interviewees uncomfortable.

While many of my interviewees appreciated the personalized and values-centered nature of Five Wishes, most of my palliative care experts shared the view that MOST improves on earlier forms of advance care planning documents because it is portable, introduced only when the need to elicit patient preferences becomes necessary, and is useful for translating preferences into actionable medical orders. The rhetorical appeal of MOST for health care practitioners is that it quickly supplies the information needed in emergency situations. Moreover, as one of my interviewees shared, MOST "speaks the language of health care providers."

Interviewees disagreed about the degree of interplay among living wills, advance care plans such as Five Wishes, and MOST, however. Some felt that there was little to no interaction between various forms of advance care plans, while others expressed the view that advance care plans like Five Wishes fed directly into MOST, that "the two go hand in hand." One observed that "MOST has been around such a short time here that it's still in transition, and how the two should, or whether they should fit together or not is still a little unclear in my head." Nonetheless, MOST's perceived convenience—coupled with a statewide education campaign—may be contributing to wider completion rates than Five Wishes, at least in Colorado. One licensed social worker specializing in palliative care testified that he had about 30 percent completion of Five Wishes in one of his initial visits but "now I am probably up to about 70 percent of completion on a first visit because of the use of MOST."[94] To be fair, MOST tends to be utilized when the need to limit care becomes apparent, such as upon admission to hospice, and one practitioner noted that he did not like that MOST does not include explication of patient values. But others I interviewed echoed that they appreciate MOST and are seeing it with increasing regularity. As one practitioner stated, "[T]he positive feedback from facilities has been absolutely incredible; a lot of facilities especially in the metro area that [*sic*] now have a MOST form on every single patient's chart." MOST appealed to most of the medical practitioners I interviewed because, in opposition to autonomy models that let patients decide, the document allows for practitioner involvement and traffics heavily in medical concerns. One of my interviewees attested that with MOST, "I'll be a little bit more paternalistic of you [*sic*] told me this so what makes sense is that we select this." In this way, MOST can overcome some of the limits of previous advance directives that included contradictory medical preferences.[95] However, particularly because it is often completed when a patient is incapacitated and attempts to translate patient wishes into medical orders, MOST reintroduces some potential for paternalistic substitutions of values—even though educational campaigns caution against this possibility.[96]

We thus discover that despite their impulse to blend patient choice and practitioner knowledge and their imperfect albeit practically useful attempt to bridge the gap between patients and the medical establishment at the end of life, advance care planning documents such as Five Wishes and MOST structure the terms of choice around the end of life. Ultimately, these documents work to produce subjects who are asked to take responsibility for choosing the technological terms of their death. They work to enshrine a doctrine of personal obligation and communicative requirement that affects the subjectivities of health care providers, patients, and families in consequential ways. The issue, from a Foucauldian perspective, in which power/knowledge is always both productive and repressive, is that regardless of how humane the impulse behind these efforts might be, advance care planning communication participates in the "more general contemporary 'regime of the self.' "[97] Advance care planning can thus be regarded as constituting a semicloaked form of social control in which individuals are encouraged to adopt the health identity of the responsible, death-planning, death-communicating subject.

CONCLUSION: POWER, ETHICS, SUBJECTIVITY, AND COMMUNICATION AT THE END OF LIFE

In the face of technologies that sustain life in ever more elaborate and extensive ways, people invent accompanying linguistic technologies to grapple with the complex existential challenges they entail. Emerging rhetorical forms associated with advance care planning—represented in this chapter by Five Wishes and MOST—signify potent subject-producing discourses that work to cultivate a sense of responsibility for determining and communicating the desired terms of our and others' deaths. To be sure, advance care planning is perhaps, in this day and age, as President Barack Obama observed, "sensible." But to ignore advance care planning's complicated power relations and how it functions as a contemporary form of subject producing pastoral power is to miss the opportunity for reflection about how our evolving end-of-life rhetorical forms cultivate particular health identities that ultimately require people to say no to technological sustainment. And indeed, evidence suggests that many of us—or our proxies—will ultimately decide to limit medical intervention in the final stages of our time on this earth.[98]

My use of the concept of pastoral power and analysis of the intricate power relations at the end of life is not meant to imply any ill intent on the part of health care practitioners who find themselves attempting to navigate legally, morally, existentially, and technologically thorny constellations as they try to help patients and families grapple with death. Rather, I am pointing out how the language of leading advance care planning forms structures medical care providers in a reconfigured pastoral relation to patients and how such rhetoric further configures patients and their loved ones too as responsible guardians of their own peace of mind, their own health security.[99] To be sure, the analogy to pastoral power is not absolute; there are moments wherein different types of power commingle, and juridical power is especially prominent in both Five Wishes and MOST. Nonetheless, these forms and related advance care planning documents entangle anxieties about life-sustaining technologies and shifting medical authority into standardized rhetorical forms that seek to know the truth of the individual by forcing introspection about and articulation of how one wishes to leave this world.

My analysis further reveals how care planning documents such as MOST and Five Wishes enshrine a communicative imperative regarding the end of life. In short, as the opening remarks by President Obama and Susan Jacoby also attest, contemporary Western subjects are encouraged to—and oftentimes have come to persuade themselves that they should—communicate clearly, vividly, and in an ongoing and extensive fashion about preferences regarding life-sustaining technologies. While such communication may be efficient, practical, and institutionally desirable, such advance care planning communication is also constraining. It structures contemporary health identities in terms of responsibility for planning and communicating about the technological terms of death.

With advance care planning seen in this light, we might inquire whether some portion of the low advance care plan completion rates can be understood from within the Foucauldian framework of resistance. The numbers bear out that despite rising awareness and increasing advance care planning initiatives, overall percentages of the U.S. population who complete advance care documents remain low. In fact, most studies estimate that a mere quarter to one-third of Americans have signed some form of advance directive.[100] On the one hand, while resistance to completing the forms may not make for efficient health care transactions, resistance may in fact represent an ethical move of self-care, an act of refusing institutionally sanctioned ways of structuring the experience of death and dying. On the other hand, caring for the self can also entail radical inspection of one's wishes for how to end this world, making the completion of advance care plans a highly ethical act. The point for Foucault would be to deeply question the entailments of these documents, what they make possible, and how they encourage particular subjectivities.

Despite well-documented ethical questions and practical problems with their execution, advance care planning documents are routinely heralded as "empowering"—and by some measures, they certainly can be. Yet if we adopt a Foucauldian perspective, we must also recognize how the proliferation of conversations about having advance care planning conversations and the documents that routinize and standardize such conversations are both productive of new types of subjects who plan the technological terms of their death and constraining in the sense that they structure conversation—and conduct—in institutionally driven ways. As Thomas Tierney reminds us, "It is only by becoming more, not less, aware of and involved with the networks of power in which medicine operates that physicians will become able to care for their patients in the manner desired by medical humanists."[101] Only through continued reflection of the benefits, burdens, and rhetorical operations of the forms we use to ease our inevitable encounters with death can we begin to envision other possibilities for future action.

12

SUFFERING AND THE RHETORIC OF CARE

Judy Z. Segal

Writing in the 1950s, biologist Jean Rostand (1894–1977) imagined an experimentally produced *homo biologicus* who might say of himself the following:

> I am the product of carefully selected semen irradiated with neutrons; my sex was predetermined and I was incubated by a mother who was not mine; I was given injections of hormones and DNA during gestation, and subjected to activation of the cortex; after I was born my intellectual development was stimulated by several grafts; at the present time I am having annual treatments to keep my mind at its best and my instincts in full vigour. I cannot complain of my body, my sex or my life. But what am I, in fact?[1]

Writing in 1969, historian of medicine Pedro Lain Entralgo took it upon himself to "complete Jean Rostand's joke, and reply to *homo biologicus*":

> You are a being capable of falling ill, and who will fall ill one of these days. And then, in the very depths of your being, you will feel a need to be cared for and helped by a man with special technical knowledge, who is prepared to treat you as a friend. In short, a good doctor.[2]

The joke, of course, was that there would someday be such a *homo biologicus*; I think we can agree there is, except in certain details, such a being. The joke's completion—that such a being will fall ill and need the care of a good doctor—is offered by Entralgo with a tinge of irony. Yet we can agree on this too: that even with technological advances, and in some cases because of them (who, for example, can interpret the images that imaging technologies produce?),[3] human beings will continue to need something we may be happy to call, the care of a good doctor.

I am interested in "care," the term itself—and the figure (sans gendering) of the "good doctor." Scholars have forwarded an *ethics of care* and a *logic of care*.[4] My project is to suggest some of the details of a *rhetoric of care*. If we are going to talk about care, we need to be clear what we are talking about.

Care—with its collocations and its functions as "inducement to action"[5]—circulates in health discourse promiscuously; it is eulogistic, even what Kenneth Burke might call a "God-term."[6] Care has persuasive force, but its meaning is underspecified: it is polysemous, but more. *Health care* is, in certain quarters, itself a contested phrase, with some scholars arguing that *health care policy* is an already invasive take on something that might better be called *health policy*.[7] *Caregiver* and *care receiver* have constituted care as a commodity and invoke a personal economics of care.[8] Care is distributed inequitably, which seems paradoxical: hardly caring. Care is often contrasted with *cure*—sometimes in an idiom in which nurses *care* and doctors *cure*, and sometimes in another idiom: for some commentators, cure ends when the *battle* against disease has been lost and care (meaning palliation) takes over, the emblem of defeat.[9] Practices subsumed under care, such as diagnostic and treatment procedures performed by physicians and technicians, are sometimes carried out without behaviors we would associate with care at all: coldly, perhaps from behind barriers, with human contact at a minimum. Care preceded by the adjective *pastoral* has a particular (and particularly Christian) meaning in clinical settings, and suggests that care can be spiritual in nature, and that when it is, it is a specialized kind of care.[10] Prefixed by *Medi-* or *Obama-*, care denotes something having to do with insurance coverage rather than *caring for*, *caring about*, or even *caring that*. To invoke care is not always to persuade us that what we will get, when we become sick, is to be conscientiously, and even tenderly (for that is suggested by care too), looked after.

In this chapter, I consider some ways in which care is materialized, especially in North American hospitals, and later I will consider the *good doctor*, in that context as well. I make two primary interventions: I argue that care requires a recognition of patients as human agents, and I suggest a novel curriculum for training doctors. While there are significant differences between Canada and the United States on matters of health policy, health insurance, and access to health services, literature across health and health studies disciplines suggests that, with respect to practitioner-patient interactions, differences are not as significant as one might expect. There are commonalities of practice in biomedical institutions, and, indeed, some of the studies that inform my chapter come from other medical jurisdictions, including New Zealand and Great Britain.

My study is, across locations, oriented to a biotechnological future. That future is characterized by advances in imaging technologies; micro and laser substitutes for typically more invasive surgeries; gene mapping, expanded predictive testing, and in vitro corrections; surgical procedures executed remotely by human experts, and others performed locally by robots; personalized genomics and personalized treatments, including an expanded realm of targeted pharmaceuticals; greater use of electronic health monitoring and health records, as well as electronically enabled health interventions that can be completed at home and in public places, perhaps by the use of specialized phone applications. And so on. In the future, moreover, we will increasingly seek medical services on the basis of anticipation of diseases we may expect to get although we do not have them already.[11] Experientially, we will further actualize what S. Lochlann Jain has called "living in prognosis,"[12] orienting life to future illness and death, while at the same time we experiment with calculated bio-additions (of, e.g., human growth hormone) and bio-subtractions (of, e.g., food) that mean to reclassify old age.

So, what does care mean now, and what will it mean in the biotechnological future? That question raises another, about medical education—for men and women who are medical students now may well be doctoring fifty years hence. How and what should they be learning?

COMPLICATING *CARE*: PATIENT EMPOWERMENT AND THE REALITY OF PATIENT EXPERIENCE

Answering questions about care and the good doctor requires, first, a review of two apparently similar literatures on patient care that turn out, on examination, to be incommensurable. One is a literature (coming primarily from sociology and ethics) on patient autonomy and empowerment, where informed decision making is part of an "egalitarian partnership" based on "mutual respect and understanding," rendering individuals able to take control of their own health care.[13] The other is a more didactic literature (coming primarily from medicine itself) on "whole person care"[14] or "person-centered care" or "seeing the person in the patient."[15] The two literatures seem at first to go in the same direction—increasing patient engagement in order to improve how patients are looked after—but they reveal different understandings of the current situation for patients.[16]

In an important essay on patient autonomy, bioethicist Rebecca Kukla describes "laypeople," at the moment of their encounter with medical professionals, as not having been simply vulnerable to the anxiety of using WebMD or susceptible to the dubious appeals of pharmaceutical marketers. Rather, Kukla argues that many laypeople have a well-formed epistemology of care, so well formed that it may include the rational desire to defer to experts. Kukla is so convincing on the matter of "conscientious autonomy" that one physician responds, in the pages of the *Hastings Center Report*, "Like many doctors, I sometimes view patients who question my reasoning as demanding or disagreeable. After reading Rebecca Kukla's article, however, I have to reconsider."[17] The physician, Anna Reisman, claims that, after reading Kukla, she wants to help her patients become "competent inquirers." Reisman offers as her example the case of a patient with chronic back pain who routinely brings to his medical appointments a magazine article "extolling some new, unproven treatment."[18] Reisman says that, before reading Kukla, she would have summarily dismissed her patient's contributions; now, she says, she takes time to read the material and then explain to her patient why it is useless. I notice that Reisman's approach is changed, but not her attitude toward her patient.[19] Her unchanged attitude is some evidence that empowerment literature begins from different assumptions than does a second literature on current problems in physicians' attitudes toward patients.

Alongside an essentially neoliberal literature that seems to suggest you could leave the medical system as it is, *add empowered patients, and stir*, is an abundant literature on the way many patients are treated by doctors who persist in seeing themselves—not necessarily incorrectly—as more knowledgeable and more powerful than the people they diagnose and treat. As Gwyn has pointed out, "a shared decision [is] made with the proviso that the patient's preferences are at least commensurable with their own best interests: interests which, ultimately, are determined by the doctor."[20] This second literature, while also keen on patient engagement and empowerment as desiderata, is replete with evidence of well-entrenched obstacles to clinical practice on egalitarian terms. For example, Robert Klitzman studies doctors who have become seriously ill themselves, and who have learned, through that experience, how they might treat patients more kindly: they might try harder to overcome their tendencies to "maintain rigid hierarchy and relational power";[21] they might adopt more principles of shared decision making;[22] they might go out of their way to get test results to patients as soon as they are available.[23] Klitzman, however, leaves readers wondering, "Before they got sick themselves, how did these doctors treat their patients?"

In a collection of essays on "whole person care," the authors, mostly Canadian physicians, argue the importance of treating patients as whole persons, but their essays, like Klitzman's book, are good evidence that patients are, in general, not being treated that way now. Meanwhile, in New Zealand, compassion is being legislated into existence, on the idea that it is not otherwise sufficiently available.[24] In Great Britain, the Point of Care project urges physicians, against their own impulses, apparently, to see "the person in the patient."[25] The current situation calls to mind a rhetorical-theoretical distinction: despite the *conviction* that patients are people too, many doctors are not necessarily *persuaded* that they are, and so they do not act on their conviction.[26] With a nod to this failure of persuasion in medical education, one of the physicians Klitzman interviewed for his study suggests that medical students be required to spend time as patients. She (the informant) says, "[Medical students] should be admitted through the ER—have people bustling back and forth, nobody saying what's going on, why they are doing particular evaluations, what anyone is thinking."[27] The pedagogical sentiment makes sense, but medical students are no more able, with role play, to take on the felt identity of a hospital patient than sociology students are able, with a few mandated days away from the comforts of home, to take on the felt identity of a homeless person.

So two sorts of ideas are trending in care literature. One is that patient autonomy is not only a value to be sought, but also a value that has already begun to change clinical practice. The other is that the health care system, in its current, most prevalent iteration, especially in hospitals, is characterized by problems that work against autonomy and empowerment, and among these problems is doctors' lack of compassion and empathy, and even respect, for patients. It is difficult for doctors to recognize autonomy in people about whom they know little and to whom they feel, by many accounts, simply superior. Yet the term care is at the center of virtually all medical discourse, used opportunistically to signify many things, including uncaring practice.

The existence of the somewhat uncaring care provider is well documented—not least in literature aimed at medical education and system reform. Medical educators ask, "How in the world is [the] capacity [for care] acquired?"[28] The Point of Care authors express general "unease" in the National Health System as to "how patients are treated, not in the sense of which medical intervention is offered, but how they are cared for, how they are looked after."[29] A Canadian physician, writing about possible changes in medical education, lists the problems inherent in setting empathy itself as a goal. Among them is the fact that physicians may sometimes experience, and must acknowledge, " 'dark' feelings of disgust and anger at another person's situation."[30] Further documented is that, even with the best medical education, physicians who began practicing as compassionate clinicians often become less compassionate the longer they practice.[31]

Perhaps the most that patients can hope for, then, is a doctor who, if he or she is not genuinely compassionate, is, at least, adequately *compassionish.* Such a doctor has learned to exhibit the behaviors of compassion, irrespective of what he or she actually feels. But the behaviors of a not-authentically compassionate physician may not be enough to qualify as the giving of *care.* Writing of the New Zealand experiment with mandating compassion, Paterson says, "[Compassion] is not the stuff of law. I may be deeply touched by the small act of a doctor gently touching my arm before a painful procedure; how would I feel if I knew that protocol 3.2 required this act?"[32] When Klitzman answers the question "Can empathy be taught?" he says that the *behaviors* of empathy can be taught.[33] In 2008, in the *New England Journal of Medicine*, Michael W. Kahn proposed "etiquette-based medicine," care on the model of the checklist, including directives such as "Sit down; smile if appropriate" and "Ask the patient how he or she is feeling about being in the hospital." Kahn explains,

> There have been many attempts to foster empathy, curiosity, and compassion in clinicians, but none that I know of to systematically teach good manners. . . . A doctor who has trouble feeling compassion for or even recognizing a patient's suffering can nonetheless behave in certain specified ways that will result in the patient's feeling well treated.[34]

WHAT MIGHT COUNT AS AUTHENTIC CARE? RECOGNIZING PATIENT AGENCY

I propose a version of care that approaches authenticity by virtue of involving, in the first instance, not one agent (the physician so much at the center of the literature on improvement in medical practice) but at least two: practitioner(s) and patient.[35] In this view, the patient is acknowledged as agentic to begin with. The patient need not be an expert in medical matters, although she may be,[36] and she need not necessarily be able to provide a different sort of expertise either: to be an articulate witness of her own experience. Much has been written about the patient's knowledge of her illness in terms of her own lifeworld;[37] sometimes this experiential authority is understood in narrative terms, and is set against "evidence-based medicine."[38] Bioethicist Anita Ho has written on "epistemic humility," a state in which the physician acknowledges the patient's expertise in matters of her own life, family, beliefs, and experiences.[39] Physician Rita Charon and other proponents of narrative medicine have gone further, charging doctors with eliciting the patient's expertise through stories from which the physician can help the patient construct meaning.[40] For authentic care to take place, however, patients must not *qualify* for agency; they must be recognized as human agents even when they are too ill, too incoherent, possibly too aphasic, to assert any sort of expertise at all.

The experience of the hospitalized patient should be at the center of the study of care.[41] The patient rides through the hospital on her back, watching the ceiling go by. She never knows quite where she is: where the CT scanner is located in relation to her bed in the Emergency Department, where the diagnostic ultrasound room is located in relation to her own room, where she is located in relation to anything. Over the course of her hospital stay, she is not credited for what she does. Perhaps she has endured eighteen hours in the Emergency Department, recalculating triage in her mind with every turn of the revolving door onto the ward. Perhaps she has answered the same questions over and over to every doctor and nurse who has asked them, never commenting on the seeming lack of communication, coordination, or attention among medical staff. Unacknowledged for this work, she may be credited, on the other hand, in the peculiar syntax of the hospital, with things she has not done at all. Doctors and nurses may say she has "closed her veins," "dropped her blood pressure," "failed her treatment."[42] They may note she has fasted, when, actually, she has been starved. There is deep institutional confusion about what patients can truly be held accountable for.[43]

Significantly, the hospital is a special scene for the deprivation of agency because, there, the rules of responsible self-care—the typical markers of health agency—are violated as a matter of course, and the patient is helpless against their violation. These are rules of diet, exercise, sleep, and hygiene. Hospital food is often cold, unappetizing, cheap, and nutritionally dubious: bread is white; meat is cured; juice is sweetened. Unless there is targeted physiotherapy, there will probably be no exercise: the daily workout of an ambulatory patient may max out at several turns to and from the nursing station. Nighttime sleep is interrupted by the sound of nurse-call alerts and the screams of neighboring patients. The door stays open and the room never goes dark. At 6 a.m., a nurse comes to deliver medication—because his shift is ending. Hygiene: in a multiday hospital stay, a patient may find her bathroom cleaned only once and herself, never: she may, if she can stand, "bathe" by her own efforts, at a small sink, with a bar of soap, a tiny washcloth and a barely bigger towel, and do it one-handed, while the other hand is bandaged to an IV line attached to the pole beside her. One-handed, though, she may be told to change her own bed linens: it is hospital policy to "encourage patient independence."[44] The effort of putting a fitted sheet on a slightly too-big-for-it mattress, with one hand, is, that day, the institutional proxy for patient autonomy.

Here, Kukla's "competent inquirer" meets the less able hospital patient. The patient may have arrived at the hospital with a view of herself as empowered; she may have Googled her symptoms before going to the ER; she may be able to recite her medications by their generic names; and she may be determined to give consent only when she is *really* informed—but, as she steps away from her lifeworld and through the gates of care , things change. Once she is a patient, what is she empowered to do? *What does empowerment look like from the supine position?* Sholom Glouberman, a health systems consultant, writes about his experience as a surgical patient at a Toronto hospital: "[Because of my status as a 'health care insider'], . . . I felt confident that when I became a patient, I would be able to handle the system pretty well. [But then] I became a patient and the system took over. My experience, understanding and sophistication stood for naught."[45]

As citizens of the hospital, patients are recruited, without training, into conversational genres that include them as untrained and ambivalent participants ("ambivalent" in the Mertonian sense: the patient is responsible for her health BUT she gives over responsibility for her health to others).[46] Conversations about them have taken place out of their range and produced the bedside conversation as part of a set of hospital genres, most of which have not involved them, except as objects of inquiry. Although patients are untutored in the rules of the conversation with the medical team, most seem to know how to behave. Lying down, while those around them stand, patients—if they are alert and well enough and if they are generally well socialized—will cooperate as fully as they can. They will answer questions put to them, and will be parsimonious in the questions they put to the team, for these people with badges are their guests, in a way, and they are the reclining hosts. If they have the wherewithal, there is a good chance that patients will try to be funny.

Hospital patients, in other words, are already disciplined into their role. They know, for example, that they are the only ones in the room who are not in a hurry, who do not have somewhere else to be. They know that their time is, of everyone's, the least valuable. Someone else's cell phone might ring or pager go off; patients take no calls. Notwithstanding that they are asked questions—How's your stomach feeling today? Were you able to eat anything?—patients understand that, with each passing day, the medical team knows more about them than they know about themselves; their testimony is redundant, once their history has set technology in motion. Their blood has been drawn; their bodily productions have been analyzed; they have been imaged using four different technologies and scoped using two more; bits of them (or bits not-them) have been extracted for biopsy. They are invited to contribute to their charts by performing speech acts they do not mean to perform, making statements that will be charted as "patient denies abdominal pain."[47] Physicians promoting narrative medicine may say they "listen not only for the content of [the patient's] narrative, but for its form—its temporal course, its images, its associated subplots, its silences,"[48] yet everyone in the patient's room, including the patient, knows this: Time is short; let's move this story along.

In practitioner-patient encounters, patients are routinely treated less like agents than like foils. Moreover, there is an epideictic rhetoric of the role: we all know a good patient when we see one. We have derived a set of patient virtues from observations (from television, from other patient experiences) of situations of praise and blame. In any case, much as on television medical procedurals, real patients are a temporary focus of attention for a drama that is about the continuing medical characters and the character of the hospital itself. Patients come and go; their tenancy, they hope, is brief. What is left to patients, insofar as they have agency at all? (I was going to write "are granted agency" instead of "have agency," which is telling in itself: Who grants agency to whom? Who is empowered to empower?) The patient's work is to be worked on.

Patients know this. They have arrived at the hospital by appointment to the admissions desk, by ambulance to the Emergency Department, by taxi in a panic. In any case, from the moment of their arrival, they are treated to a display of hierarchy. For example, almost always, a fair bit of waiting is involved. When the patient "is seen," the practitioner is dressed for work, while the patient is grasping at her back to keep her gown from gaping. The practitioner is addressed as "Doctor ___"; the patient typically has a first name only (unless he or she is quite old, in which case a different form of address may be used). In any case, all privacy is lost. At one Vancouver hospital, history and vital signs are taken while the patient sits on a chair in the hallway, halfway between the waiting room and the door to the Emergency Room. Inside the ER, and in semiprivate or multiple-occupancy rooms, a curtain is drawn for privacy, but the curtain is metonymic of privacy only. The person in the next bed cannot see the intimacy of physical examination, but he or she can hear it and can, almost has to, imagine the rest. Patients on both sides of the curtain may be too sick or bedraggled to mind; they are unlikely, in any case, to complain.

For a physician to care, or to give care, authentically, would mean fully to take into account these signs of undignified inequity (for many of which the physician is not directly responsible—one reason that making doctors more fabulous people is not going to solve care problems that are systemic), seek to remedy the worst elements of the situation, and acknowledge the humanity and the agency of the patient.

So, what are the actions of the patient as agent? Some patients follow medical advice (take their medication; refuse certain foods, even when they are delivered to their rooms). Some make decisions, like the decision to take up as little as possible of physicians' time, leaving more of it for other, sicker, patients. Some patients resist the limitations of a physician's mere etiquette by trying to make themselves memorable in some way, in order to elicit higher-quality attention.[49] Some patients use their smartphones and laptops to find out more about their conditions and then ask informed questions of the medical team when it arrives; some withhold consent to treatment. Even on the matter of consent, agency does not come easily under current conditions of care, Glouberman writes about a last-minute change of procedure before his colon surgery. He was told that the experienced laparoscopic surgeon who was supposed to attend the surgery was unavailable, and he was asked, just before his scheduled operation, for his choice: Did he wish to go ahead with the surgical plan (laparoscopic: smaller incision, faster recovery time) or have conventional, more invasive, surgery, or, although he had prepped for the operation for days, just reschedule? Glouberman signed the informed consent forms, agreeing to proceed with the laparoscopic surgery in the absence of the promised specialist. Surgical complications ensued. Was Glouberman informed and did he supply consent? Yes. Was his consent, in that moment, the consent of a free agent? Not really.

Sometimes all the patient can do with her whole self is suffer. The patient may be in pain or discomfort; she may feel alone, afraid, and agitated. In extremis, the patient may fear death or the continuation for a time of an unbearable life. While the patient may want, and request if she can, spiritual care, she also needs all the practitioners around her to acknowledge her existence and her suffering, and to understand that she is doing what she can do, even if all she can do is scream or moan or call for some kind of comfort. Or refuse to eat. Or pull out her feeding tube. Whether or not we, as theorists or practitioners, believe that suffering has meaning, or that a narrative of suffering has meaning, some patients are in a condition far beyond one in which suffering has meaning for them. In the name of care the suffering patient may be kept alive. Perhaps a chaplain will be sent in to administer a specialist's care. This is not enough. Every caregiver has to look that patient in the eye.

HOW TO MAKE THE DOCTOR GOOD?

What would it mean to educate doctors to look a patient in the eye, acknowledge her humanity and her agency, and, without necessarily feeling compassion or empathy in every case (for some patients will be more likable than others, some easier to identify with than others), look after ill people in a way that is not dehumanizing, diminishing, or humiliating. That acknowledgment is at the core of care. The more technological medicine becomes, the greater the need for care under this description. Who, in the future, will be the "good doctor," and how should that person be trained?

Questions about medical school curriculum and, in particular, the nature and the place of medical humanities in that curriculum, are asked often. A list of essays on varieties of, and pedagogies for, medical humanities is too long to include.[50] Many such essays still cite C. P. Snow's *The Two Cultures*, still ask if medicine is a science or an art or both, and still argue that medical students should write poems. One physician writes that his fellows "who lack a passion for language or who fail to see beauty will be at a loss to translate these wonders in the most meaningful terms for their lay patients and into the larger society around us."[51] Martha Nussbaum was among those who made the argument years ago that reading literature makes people more compassionate and more empathic.[52] But Byron Good has noted that what occupies medical students and doctors is not talking to patients, but presenting them—not interacting with patients, but interacting with other doctors about patients; what occupies them is "numbers and lab values and rounds and teaching." [53] Good adds that medical humanities is inevitably, then, marginalized in medical education. More recently, Delese Wear and others have argued that reading literature in medical school is, in any case, not enough to count as humanities education. Wear advises that reading must be done critically, in a "pedagogy of discomfort," and within the medical curriculum itself, not as a sidebar to it. Such an approach, she says, will help to counter the uncritical and simplistic teaching that happens under names such as "cultural competence." Wear notes that the "hidden curriculum"[54] can work against *respect for patients*, her primary concern. She writes, "[A]n unintended message students receive from cultural competency approaches that shy away from scrutiny on self and professional practices is that such critical examination is not necessary if one just learns, in a rational way, about 'other' cultures."[55]

While many authors argue that some kind of humanities education is good for doctors, there is little consensus about what that education ought to look like. Moreover, there is little evidence that medical humanities, in any form, actually produces better doctors and better patient outcomes.[56] Igor Polianski and Heiner Fangerau note that, paradoxically, while medical humanities courses are not always well regarded, the courses themselves are increasingly prominent.[57] It seems there is a sustained belief that some exposure to humanity/humanism/humanities is going to, at least, make doctors less likely to talk about "the liver in 421," or ask, "When is the cholec[ystectomy] going home?"

I believe that much of the discussion of medical humanities begins from the wrong question, for the question in medical education ought *not* to be, "What would you teach medical students in order to make them more human, more compassionate, more empathic?" In order to bring to light the rhetorical nature of the question itself, and the assumptions hidden within it, I invoke a comparison on the principle of genre. I then, on the idea of the "good doctor," suggest a possible approach to humanities study in a medical school curriculum.

For several years, I have been writing about breast cancer narratives as constituting a particular sort of genre.[58] My research has shown certainly that the most typical breast cancer stories, the ones told most often in public, run something like this: "I found a lump; I was scared; I was diagnosed with breast cancer. I fought and never gave up. I survived breast cancer, and now I'm a better person." A couple of things give me pause about that narrative. One is that it is repeated so often that it has become naturalized and expected, and so it has come to suppress other illness narratives. It does this despite the fact that many women with the disease find their experience poorly represented by the triumphal story.[59]

More pertinent to medical education is the second thing that gives me pause about this generic story: that it is almost invariably a *personal* story, an account of one struggle and one survivor at a time. The very conventions of the personal narrative persuade us that breast cancer is a disease of individuals—indeed individual heroes—even if a new story begins about 270,000 times every year in North America. While people with breast cancer experience their disease personally, there are social consequences of seeing cancer as a struggle for one person at a time, to be approached with one low-fat diet, one yoga class, one positive attitude, at a time. A lot is left out of the standard breast cancer story: the causes of cancer and its epidemiology are left out, for example. The focus on individuals makes it harder to focus on systems.

We find some of the same individualist (indeed, humanist) thinking in medical education. The question "What would you teach medical students in order to make them more human, more compassionate, more empathic?" conflates humanity, humanism, and the humanities—and, with that conflation, aims, in an inconsistently theorized way, to produce one good doctor at a time. Medical school, however, is not a project of human improvement. Humanism is a philosophy, focusing on individuals, their potential, their will, and their power; and most scholars working now in the humanities are not humanists. Humanities scholars think about human beings not, in the first instance, as individuals, with individual potential for greatness, but as actors in social and cultural contexts, living within systems, using language, under constraints. Medical humanities should use the resources of the humanities, the work that humanities scholars actually do, to help doctors become more critical participants in the systems in which they work. That is one way to prepare them to provide care.

It is difficult to know how to integrate humanities into the medical-school curriculum, especially as we have noted that such instruction is not always well received. Yet the medical curriculum ought to be revised to help doctors see their work as *centrally* more than mechanical, technical, scientific—to help them understand the ways that serious illness flings whole people about and tosses them around and, if it puts them down again, leaves them not exactly in the same place.

No single course or humanities-specific slate of courses can teach that, especially if such courses are the soft curriculum hived off from the hard curriculum that includes pathology, immunology, pharmacology, anatomy, human genetics, and so on. I propose that the humanities (not to be confused with the arts) not be taken up in designated medical humanities courses but rather distributed throughout the curriculum.

Humanities across the Curriculum might include, for example, on the pathology syllabus, a selection of cancer narratives and an essay that considers the effect of those narratives on the cancer experience. It might include on the immunology syllabus an essay on the politics of HIV testing;[60] on the pharmacology syllabus, a reading on the history of prescription regulation, moral panic, and social stigma;[61] on the anatomy syllabus, an essay on the social uses to which testicle transplantation was put in the 1920s;[62] on the human genetics syllabus, an article on gene metaphors and how publics understand genes.[63] These readings would help medical students to consider their own assumptions, see their work in its contexts of history, theory, and practice, and, finally, see more clearly both the lives of people who come to them ill and in need of care and the system in which that care can be offered.

An objection to my proposal might be that anatomy professors and immunology professors are typically not equipped to teach such readings. If that is the case, then we may want to think about an ideal professor of medicine, who is educated himself or herself in a different curricular world. For now, however, medical faculty need only some advice on what to assign, and then they need to take these readings seriously, engage with them, create conditions under which they can be discussed, and put questions about them on their exams. In Humanities across the Curriculum, a specialist in medical humanities is not someone who can be charged with teaching a stand-alone course or two, but rather someone who can work with medical faculty across departments to help them develop courses that take into account the doctor, the patient, and the system within which they encounter each other.

Ethics and the Care of a Good Doctor

The rhetoric of care includes a set of considerations inside an ethics of care. I have maintained that care properly requires an understanding of the patient as agent. I have suggested one means by which some people—doctors, especially, although not only doctors, for these are the people patients see least in the course of a hospital stay—might be trained to be more considerate of other people who, as they are met, are in need of looking after.

While ethics is multifarious, a dominant trope is part of much of the discussion of it, both in scholarly and in popular discourse. Moreover, because ethical questions—about the beginning of life and the end of it, about reproductive technologies and predictive testing—are so pressing for so many, scholarly and popular discourse often overlap. The trope is that technology is moving so fast that ethics cannot keep up with it. That is, there is a technology train that is going very fast on its track, and another train, an ethics train, running on a parallel track and going much more slowly. Indeed, Michael Sandel writes, "When science moves faster than moral understanding, as it does today, men and women struggle to articulate their unease."[64]

On questions of patient care in a biotechnological future, the double-train-track version of ethics is of little help. Our medical future, rather, characterized by biotechnological advances that have presented us with our current ethical predicaments, is made of the same cultural material as ethics itself. We are not, for example, cyborg beings, on the one hand, and beings with the capacity to come to terms with ourselves as cyborg beings (more slowly), on the other. The ability to imagine ourselves as such beings is what has enabled us to constitute ourselves as such beings in the first place. There is only one train, moving uncomfortably fast: technology and ethics are produced together, messily. The feeding tube, when it was invented, did not come with instructions on when to use it, but it came from the same medical culture that must participate in the adjudication of its use.

The challenge we face in a biotechnological future, as we think about ethics and care is to see if we can make views on autonomy and empowerment jibe with the facts of clinical practice, so that we can tell the truth about patient experience and then consider what sort of medical education might be aimed at improving that patient experience—for, indeed, even *homo biologicus* will one day find himself in need of a good doctor. Entralgo again:

> Doctor and patient, each influenced by his own motives, are about to meet. The characters have taken their places on the stage and the curtain is going up. What comedy or drama will result from such a meeting? How will the basis of this mutual relationship—"medical philia" in the most favourable circumstances—express itself in examination, diagnosis and treatment? Let us see.[65]

NOTES

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Chapter 3. Lessl: The "Warfare" of Science and Religion

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Chapter 5. Ceccarelli: Crossing Frontiers of Science

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2 *Webster's New World College Dictionary*, 3rd ed., ed. Victoria Neufeldt (New York: Macmillan, 1997), s.v. "frontier," 542.

3 For more on the history of this term, see my forthcoming book: Leah Ceccarelli, *On the Frontier of Science: An American Rhetoric of Exploration and Exploitation* (East Lansing: Michigan State University Press, in press).

4 He made these comments in a commencement address at the University of

Indiana, reprinted as a chapter in Frederick Jackson Turner, *The Frontier in American History* (New York: Henry Holt, 1920), 281, 284.

5 Vannevar Bush, *Science: The Endless Frontier* (Washington, D.C.: Government Printing Office, 1945), 6.

6 John Dewey, "The American Intellectual Frontier," *New Republic* 30, no. 388 (May 10, 1922): 303.

7 Dewey, "American Intellectual Frontier," 303–4.

8 At the end of the Clinton administration, government officials had developed an interpretation of existing law that would have allowed federal funding of research using human embryonic stem cell lines that were derived at any point in time, as long as their derivation met certain ethical guidelines. However, after Bush took office, but before any funding could be granted by the National Institutes of Health, the review of applications for such funding was indefinitely suspended by the new administration. Bush's subsequent decision to allow federal funding of research on only those cell lines that existed on August 9, 2001, was thus a restriction when compared to the previous administration's policy. For more on this history, see American Association for the Advancement of Science, "AAAS Policy Brief: Stem Cell Research," August 12, 2011, http://www.aaas.org/spp/cstc/briefs/stemcells/#ban.

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10 John Lynch, *What Are Stem Cells? Definitions at the Intersection of Science and Politics* (Tuscaloosa: University of Alabama Press, 2011), 120–24.

11 For more on this, see my reading of Bush's speech in the sixth chapter of *On the Frontier of Science*.

12 An extended argument for embryonic stem cell research from a religious perspective can be found in Ted Peters, Karen Lebacqz, and Gaymon Bennett, *Sacred Cells? Why Christians Should Support Stem Cell Research* (Lanham, Md.: Rowman & Littlefield, 2008). Supporting arguments from ethicists that would have been available to the Bush administration prior to his speech include George J. Annas, Arthur Caplan, and Sherman Elias, "The Politics of Human-Embryo Research—Avoiding Ethical Gridlock," *New Engl. J. of Med.* 334, no. 20 (1996): 1329–32; Geron Ethics Advisory Board, "Research with Human Embryonic Stem Cells: Ethical Considerations," *Hastings Center Report* 29, no. 2 (1999): 31–36; and National Bioethics Advisory Commission, *Ethical Issues in Human Stem Cell Research: Executive Summary,* September 1999, http://bioethics.georgetown.edu/nbac/execsumm.pdf. Religious organizations that had made statements in support of stem cell research before Bush's policy was announced include the United Church of Christ and the Presbyterian Church (USA); these statements are reproduced in appendices to Brent Waters and

Ronald Cole Turner, eds., *God and the Embryo: Religious Voices on Stem Cells and Cloning* (Washington, D.C.: Georgetown University Press, 2003).

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14 Jay P. Lefkowitz, "Stem Cells and the President: An Inside Account," *Commentary* 125, no. 1 (2008): 22.

15 George W. Bush, "Remarks on Signing the Fetus Farming Prohibition Act and Returning Without Approval to the House of Representatives the 'Stem Cell Research Enhancement Act of 2005,'" July 19, 2006, American Presidency Project, http://www.presidency.ucsb.edu/ws/?pid=349. All citations to this speech are by paragraph number in the text.

16 George W. Bush, "Remarks on Returning Without Approval to the Senate the 'Stem Cell Research Enhancement Act of 2007,'" June 20, 2007, American Presidency Project, http://www.presidency.ucsb.edu/ws/?pid=75462. All citations to this speech are by paragraph number in the text.

17 Compare the Clinton-era National Bioethics Advisory Commission, Ethical Issues in Human Stem Cell Research cited above to the report produced five years later by the Bush administration bioethics commission, Leon R. Kass et al., *Monitoring Stem Cell Research: A Report of the President's Council on Bioethics* (Washington, D.C., 2004), http://bioethics.georgetown.edu/pcbe/reports/stemcell/pcbe_final_version_monitoring_stem_cell_research.pdf.

18 See, e.g., the statement of the Presbyterian Church (USA) reproduced in Waters and Turner, *God and the Embryo*.

19 J. Arthur Harris, "Frontiers," *Scientific Monthly* 30, no. 1 (1930): 19, 30–32. The "edge of cultivation" and "beyond the ranges" lines used by Harris are quotes from Kipling's poem "The Explorer." The allusion to Roosevelt's rhetoric in this summary of Harris' argument is mine, not his. See Theodore Roosevelt, "The Strenuous Life," April 10, 1899, Voices of Democracy: The U.S. Oratory Project, http://voicesofdemocracy.umd.edu/roosevelt-strenuous-life-1899-speech-text/.

20 "Remarks by the President, Prime Minister Tony Blair of England (via Satellite), Dr. Francis Collins, Director of the National Human Genome Research Institute, and Dr. Craig Venter, President and Chief Scientific Officer, Celera Genomics Corporation, on the Completion of the First Survey of the Entire Human Genome Project," June 26, 2000, White House Office of the Press Secretary, National Human Genome Research Institute, http://www.genome.gov/10001356. All citations to the speeches at this ceremony are by paragraph number in the text.

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Project Was Revealed to the Public," *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine* 6, no. 4 (2002): 450.

22 For more on these entailments for the frontier metaphor in this speech and others, see Ceccarelli, *On the Frontier of Science*.

23 Francis Collins, *The Language of God: A Scientist Presents Evidence for Belief* (New York: Free Press, 2006): 2–3.

24 Collins, *Language of God*, 3.

25 Francis Collins, *The Language of Life: DNA and the Revolution in Personalized Medicine* (New York: HarperCollins, 2010), 1–2.

26 Collins, *Language of God*, 118–19.

27 Collins, *Language of God*, 123–24.

28 Collins, *Language of Life*, 2.

29 Leah Ceccarelli, "Neither Confusing Cacophony nor Culinary Complements: A Case Study of Mixed Metaphors for Genomic Science," *Written Communication* 21, no. 1 (2004): 92–105. In that article, I looked at these White House ceremony speeches to understand the merger of map and blueprint vehicles for genomic science and the merger of text and code vehicles for genomic science. In the current essay, I examine the same speeches to understand the merger of frontier territory and divine text vehicles for the human genome.

30 Collins, *Language of God*, 86, 88.

31 Collins, *Language of God*, 107.

32 Collins, *Language of God*, 62–63. The word awe appears at least sixteen times in this book, almost always in reference to a scientific discovery that points to the existence of the divine.

33 Collins, *Language of God*, 62–63, 67, 219.

34 Collins, *Language of God*, 199.

35 Hub Zwart, review of *The Language of God*, by Francis Collins, in *Genomics, Society and Policy* 2, no. 3 (2006): 138.

36 Jonathan Witt, "Random Acts of Design: Francis Collins Sees Evidence That God Made the Cosmos—But Life Is Another Matter," *Touchstone: A Journal of Mere Christianity* 19, no. 8 (2006): 32; Logan Paul Gage, "Best Explanations," review of *The Language of God*, by Francis Collins, in *American Spectator* 39, no. 8 (2006): 74. They are critical of his book though for its explicit arguments against contemporary "intelligent design" arguments concerning biological evolution.

37 Michael Potemra, "God Is in the DNA," review of *The Language of God*, by Francis Collins, in *National Review* 58, no. 17 (2006): 53; Bill Williams, "Worshiping the God of the Genome," review of *The Language of God*, by Francis Collins, in *National Catholic Reporter* 42, no. 43 (2006): 2a; Ken Mickleson, review of *The Language of God*, by Francis Collins, in *Stimulus: The New Zealand*

Journal of Christian Thought & Practice 15, no. 3 (2007): 41. In contrast, a review of the book for a skeptical audience completely skips over these arguments by Collins, focusing only on his "superb demolition of intelligent design pretensions"; see Paul R. Gross, "Mammoth in the Garden: Why Harmonizing Science and Religion Is a Strong Human Need," review of *The Creationism Debate*, by Arthur McCalla, in *Creatures of Accident*, by Wallace Arthur, and *The Language of God*, by Francis Collins, *Skeptic* 13, no. 2 (2007): 70–71.

38 Pat Fosarelli, "Science and Belief," review of *The Language of God*, by Francis Collins, in *Journal of the American Medical Association* 296, no. 13 (2006): 1659.

39 As Collins puts in *The Language of God*, "If God is outside of nature then He is outside of space and time. In that context, God could in the moment of creation of the universe also know every detail of the future. That could include . . . the evolution of humans, right to the moment of your reading this book—and beyond. In that context, evolution could appear to us to be driven by chance, but from God's perspective the outcome would be entirely specified. Thus, God could be completely and intimately involved in the creation of all species, while from our perspective, limited as it is by the tyranny of linear time, this would appear a random and undirected process" (205).

40 For an argument approving of it, see Stephen M. Barr, "The Form of Speaking," review of *The Language of God*, by Francis Collins, in *First Things: A Monthly Journal of Religion & Public Life* 168 (2006): 43; for an argument opposing it, see Robert K. Eberle, "If God Could Talk What Would He Say?," review of *The Language of God*, by Francis Collins, in *Skeptic* 13, no. 1 (2007): 79.

41 Collins, *Language of God*, 211.

42 Collins, *Language of God*, 158, 230.

43 Thomas M. Lessl, *Rhetorical Darwinism: Religion, Evolution, and the Scientific Identity* (Waco, Tex.: Baylor University Press, 2012), xvii.

44 For a summary of opinion polls demonstrating that an overwhelming majority of Americans, despite their purportedly evangelical frontier fear, hold science in high regard, see Jon D. Miller, "Public Understanding of, and Attitudes toward, Scientific Research: What We Know and What We Need to Know," *Public Understanding of Science* 13, no. 3 (2004): 284–87; and National Science Board, *Science and Engineering Indicators 2012* (Arlington, Va.: National Science Foundation, 2012), 7.27–7.36.

Chapter 6. Chambers: The Angels and Devils of Representing Prozac

1 See Ryan Bloom, "Lost in Translation: What the First Line of 'The Stranger' Should Be," *New Yorker*, http://www.newyorker.com/online/blogs/books/2012/05/camus-translation.html.

2 Carl Elliott, *Better Than Well: American Medicine Meets the American Dream* (New York: Norton, 2003). 74.

3 Cited in Elliott, *Better Than Well.*
4 Elliott, *Better Than Well.*
5 Philip K. Dick, *Do Androids Dream of Electric Sheep?* (New York: Del Rey, 1996), 5.
6 Dick, *Do Androids Dream?*, 5–6.
7 Peter D. Kramer, *Listening to Prozac* (New York: Viking, 1993). 87.
8 Erik Parens, "Kramer's Anxiety," in *Prozac as a Way of Life*, ed. Carl Elliott and Tod Chambers (Chapel Hill: University of North Carolina Press, 2004), 23.
9 Carl Elliott, *A Philosophical Disease: Bioethics, Culture, and Identity, Reflective Bioethics* (New York: Routledge, 1999). 29.
10 James C. Edwards, "Passion, Activity, and the Care of the Self: Foucault and Heidegger in the Precincts of Prozac," in Elliott and Chambers, *Prozac as a Way of Life*, 61.
11 Edwards, "Passion, Activity," 61–62.
12 Edwards, "Passion, Activity," 62.
13 Parens, "Kramer's Anxiety," 29.
14 Joseph R. Gusfield, "Introduction," in *On Symbols and Society*, ed. Joseph R. Gusfield (Chicago: University of Chicago Press, 1989), 14.
15 Kenneth Burke, *A Grammar of Motives* (Berkeley: University of California Press, 1969), 127.
16 Gusfield, "Introduction," 11.
17 Kenneth Burke, *Permanence and Change: An Anatomy of Purpose*, 3rd ed. (Berkeley: University of California Press, 1984). 35.
18 Joseph R. Gusfield, *The Culture of Public Problems: Drinking-Driving and the Symbolic Order* (Chicago: University of Chicago Press, 1981).
19 Burke, *Grammar of Motives*, 56.
20 Burke, *Grammar of Motives*, 28.
21 Sonja K. Foss, "Pentadic Criticism," in *Rhetorical Criticism: Exploration and Practice*, ed. Sonja K. Foss (Long Grove, Ill.: Waveland Press, 1989), 342.
22 Donald A. Schön and Martin Rein, *Frame Reflection: Toward the Resolution of Intractable Policy Controversies* (New York: Basic Books, 1994), 26.
23 David A. Ling, "A Pentadic Analysis of Senator Edward Kennedy's Address to the People of Massachusetts, July 25, 1969," *Communication Studies* 21, no. 2 (1970): 82.
24 Ling, "Pentadic Analysis," 82.
25 Ling, "Pentadic Analysis."
26 Elliott, *Better Than Well*, 59.
27 Elliott, *Better Than Well*, 70.
28 Carl Elliott, "Pursued by Happiness and Beaten Senseless: Prozac and the American Dream," in Elliott and Chambers, *Prozac as a Way of Life*, 136.

29 Mary Douglas, "The Effects of Modernization on Religious Change," *Daedalus* 111, no. 1 (1982): 1–19.
30 Gallup, "Religion," September 8, 2012, http://www.gallup.com/poll/1690/religion.aspx.
31 Elliott, *Better Than Well*, 53.
32 See Paul David Numrich, *Old Wisdom in the New World: Americanization in Two Immigrant Theravada Buddhist Temples* (Knoxville: University of Tennessee Press, 1996); Charles S. Prebish, *Luminous Passage: The Practice and Study of Buddhism in America* (Berkeley: University of California Press, 1999).
33 David F. Colvard and William P. Wilson, "On a Pill and a Prayer," *Christian Counseling Today* (Fall 2004): 15.
34 Clark E. Barshinger, Lojan E. LaRowe, and André Tapia, "The Gospel According to Prozac," *Christianity Today*, August 1, 1995, 37.
35 Barshinger, LaRowe, and Tapia, "Gospel According to Prozac," 35.
36 Barshinger, LaRowe, and Tapia, "Gospel According to Prozac."
37 Kramer, *Listening to Prozac*, x.
38 Kramer, *Listening to Prozac*.
39 Kramer, *Listening to Prozac*, xi.
40 Kramer, *Listening to Prozac*.
41 Barshinger, LaRowe, and Tapia, "Gospel According to Prozac," 35.
42 Barshinger, LaRowe, and Tapia, "Gospel According to Prozac," 36.
43 Barshinger, LaRowe, and Tapia, "Gospel According to Prozac," 36.
44 Barshinger, LaRowe, and Tapia, "Gospel According to Prozac," 37.
45 Michael J. Boivin, "Finding God in Prozac or Finding Prozac in God: Preserving a Christian View of the Person Amidst a Biopsychological Revolution," *Christian Scholars Review* 32, no. 2 (2003): 165.
46 Boivin, "Finding God," 170.
47 Boivin, "Finding God," 175–76.
48 Burke, *Grammar of Motives*, 287–88; emphasis original.
49 D. Gareth Jones, "Neuroscience and the Modification of Human Beings," in *Future Perfect? God, Medicine and Human Identity*, ed. Celia Deane-Drummon and Peter Manley Scott (London: T&T Clark, 2010), 88
50 Gareth Jones, "Neuroscience and the Modification of Human Beings," 89.
51 Jones, "Neuroscience," 98.
52 Mark Epstein, "Awakening with Prozac: Pharmaceuticals and Practice," *Tricycle: The Buddhist Journal*, http://buddhism.lib.ntu.edu.tw/BDLM/toModule.do?prefix=/search&page=/search_detail.jsp?seq=281732.
53 Epstein, "Awakening with Prozac."
54 Epstein, "Awakening with Prozac."
55 Judith Hooper, "Prozac and Enlightened Mind," *Tricycle: The Buddhist Journal* (1999), http://www.tricycle.com/feature/prozac-enlightened-mind.

56 Philip Martin, *The Zen Path through Depression* (San Francisco: Harper, 1999), 4.

57 See Tod Chambers, "Prozac for the Sick Soul," in Elliott and Chambers, *Prozac as a Way of Life*.

58 See Pema Chödrön, *Working with the Different Levels of Shenpa: The Doorway to Freedom* (n.d., audio CD).

59 Burke, *Grammar of Motives*, 171.

60 Epstein, "Awakening with Prozac."

Chapter 7. Leonard: "Leave Your Medicine Outside"

1 Rev. Gene Sherbert, snake handler, cited in http://yeltsin.tripod.com/Punkin/punkin.html.

2 Fred Brown and Jeanne McDonald, *The Serpent Handlers: Three Families and Their Faith* (Winston-Salem, N.C.: John F. Blair, 2000), 29.

3 Brown and McDonald, *Serpent Handlers*, 30; emphasis original.

4 Brown and McDonald, *Serpent Handlers*, 30–31; emphasis added.

5 Footnotes to the New Revised Standard Version reflect on the long ending of Mark's gospel (16:9-20), suggesting, "Nothing is certainly known either about how this Gospel originally ended or about the origin of vv. 9-20, which, because of the textual evidence as well as stylistic differences from the rest of the Gospel, cannot have been part of the original text of Mark. . . . Many witnesses, some ancient, end the Gospel with vv. 9-20, thus showing that from early Christian times these verses have been accepted traditionally and generally as part of the canonical Gospel of Mark. . . . The longer ending may have been compiled early in the second century as a didactic summary of grounds for belief in Jesus' resurrection, being appended to the Gospel by the middle of the second century." See Bruce M. Metzger and Roland E. Murphy, eds., *The New Oxford Annotated Bible* (New York: Oxford University Press, 1990), 74NT.

6 A 1969 study administered the Minnesota Multiphasic Personality Inventory (MMPI) to members of the Scrabble Creek (Holiness) church and a control group in a local Methodist congregation. The study showed comparable health between members of the two churches, with serpent handlers somewhat healthier in some categories. See Ralph W. Hood Jr., and W. Paul Williamson, *Them That Believe: The Power and Meaning of the Christian Serpent-Handling Tradition* (Berkeley: University of California Press, 2008), 217. Other researchers have used EEG and blood samples to explore the physiological and neurological nature of the "anointing" that empowers individuals to take up serpents. See Scott W. Schwartz, *Faith, Serpents, and Fire* (Jackson: University Press of Mississippi, 1999), 60–66.

7 See http://www.aboutbioscience.org/topics/bioethics.

8 Lisa Sowle Cahill, *Theological Bioethics: Participation, Justice, Change* (Washington, D.C.: Georgetown University Press, 2005), 16.
9 Cahill, *Theological Bioethics*, 16.
10 Cahill, *Theological Bioethics*, 16.
11 Cahill, *Theological Bioethics*.
12 Ralph W. Hood Jr., "When the Spirit Maims and Kills: Social Psychological Considerations of the History of Serpent Handling Sects and the Narrative of Handlers," *International Journal for the Psychology of Religion* 8, no. 2 (1998): 71.
13 Hood, "When the Spirit Maims and Kills," 73–74.
14 Deborah Vansau McCauley, *Appalachian Mountain Religion: A History* (Urbana: University of Illinois Press, 1995), 75. McCauley elaborates on this rhetorical style on 75–79; emphasis original.
15 Elder John Rogers, *The Biography of Eld. Barton Warren Stone* (Cincinnati: J. A. & U. P. James, 1847), 72–75, 81–93.
16 David Tracy, *Plurality and Ambiguity: Hermeneutics, Religion and Hope* (San Francisco: Harper & Row, 1987), 15.
17 Eleanor Dickinson, *Revival!* (San Francisco: Harper & Row, 1974), 127–28; Bill J. Leonard, "The Bible and Serpent-Handling," in *Perspectives on American Religion and Culture*, ed. Peter W. Williams (Oxford: Blackwell, 1999), 228; and Hood, "When the Spirit Maims and Kills," 78.
18 Bill J. Leonard, videotape, serpent handling, Berea, Ky., June 1990.
19 Leonard, videotape, serpent handling.
20 Leonard, videotape, serpent handling.
21 Mary Lee Daugherty, "Serpent-Handling as Sacrament," *Theology Today*, October 1976, 234; Thomas Burton, *Serpent-Handling Believers* (Knoxville: University of Tennessee Press, 1993), 134; and Leonard, "Bible and Serpent-Handling," 238–39.
22 Lisa Alther, "They Shall Take Up Serpents," *New York Times Magazine*, June 6, 1976.
23 Robert W. Pelton and Karen W. Carden, *Snake Handlers: God-Fearers? Or, Fanatics?* (Nashville: Thomas Nelson, 1974), 30. Other serpent handlers believe they can take up serpents "by faith" without dramatic anointing.
24 Leonard, "Bible and Serpent-Handling," 238.
25 Robert Hariman and John Louis Lucaites, *No Caption Needed: Iconic Photographs, Public Culture, and Liberal Democracy* (Chicago: University of Chicago Press, 2007), 4–5.
26 Hariman and Lucaites, *No Caption Needed*, 8.
27 Brown and McDonald, *Serpent Handlers*, 209.
28 Darrel W. Amundsen, *Medicine, Society, and Faith in the Ancient and Medieval Worlds* (Baltimore: Johns Hopkins University Press, 1996), 82. Amundsen

notes that the great theologian Origen "as a youth whose father was about to be martyred, wished to present himself to the magistrates for martyrdom. His plans were thwarted by his Christian mother, who hid his clothes to keep him home until the crisis passed" (79). He concludes, "Likely the majority of those who wished to quit life held the position most commonly encountered in the [early Christian] literature, namely that seeking martyrdom was wrong" (82).

29 Hood and Williamson, *Them That Believe*, 12.

30 Hood and Williamson, *Them That Believe*, 13–36.

31 Grant Wacker, *Heaven Below: Early Pentecostals and American Culture* (Cambridge, Mass.: Harvard University Press, 2001), 12; and Hood and Williamson, *Them That Believe*, 12.

32 McCauley, *Appalachian Mountain Religion*, 7.

33 McCauley, *Appalachian Mountain Religion*, 6.

34 McCauley, *Appalachian Mountain Religion*, 17.

35 Burton, *Serpent-Handling Believers*, 20–21.

36 McCauley, *Appalachian Mountain Religion*, 18. McCauley's work gives primary focus to mountain Pentecostals (non–serpent handling) and such mountain Baptist groups as the Primitive and Old Regular Baptists.

37 David Kimbrough, *Taking Up Serpents: Snake Handlers of Eastern Kentucky* (Chapel Hill: University of North Carolina Press, 1995), 32–33. Kimbrough notes that serpent handlers also make exceptions, as when they seem to look beyond founder George Hensley's four divorces.

38 Kimbrough, *Taking Up Serpents*, 32. Not every church member follows these regulations. I was present at a serpent handling service in 1991 when Arnold Saylor preached against the dress and makeup worn by three young women who were family members.

39 Jimmy Morrow, with Ralph W. Hood Jr., ed., *Handling Serpents: Pastor Jimmy Morrow's Narrative History of His Appalachian Jesus' Name Tradition* (Macon, Ga.: Mercer University Press, 2005), 164–65.

40 Kimbrough, *Taking Up Serpents*, 33–34.

41 Mary Lee Daugherty, "Serpent Handlers: When the Sacrament Comes Alive," in *Christianity in Appalachia: Profiles in Regional Pluralism*, ed. Bill J. Leonard (Knoxville: University of Tennessee Press, 1999), 143–44.

42 Brown and McDonald, *Serpent Handlers*, 208.

43 Brown and McDonald, *Serpent Handlers*, 187.

44 Bishop Kelly Williams, interviewed in *The Saga of the Serpent Handlers*, documentary film, produced by Mary Lee Daugherty, Charleston, W. Va., 1981.

45 Alther, "They Shall Take Up Serpents."

46 Lauren Pond, "Why I Watched a Snake-Handling Pastor Die for His Faith," *Washington Post*, May 31, 2012, http://www.washingtonpost.com/lifestyle/

style/why-i-watched-a-snake-handling-pastor-die-for-his-faith/2012/05/31/gJQA3fRP5U_story.html?hpid=z1.

47 Pond, "Why I Watched a Snake-Handling Pastor Die."

48 Pond, "Why I Watched a Snake-Handling Pastor Die."

49 Pond, "Why I Watched a Snake-Handling Pastor Die"; emphasis added.

50 Roger S. Gottlieb, *A Spirituality of Resistance* (New York: Crossroad, 1999), 13–15. For Gottlieb, the spirituality of resistance requires a response to ecological issues in an increasingly endangered global environment.

Chapter 8. Frank: Biovaluable Stories and a Narrative Ethics

1 Quoted in Edward S. Golub, *The Limits of Medicine: How Science Shapes Our Hope for the Cure* (Chicago: University of Chicago Press, 1997), 114; emphasis added by Golub.

2 Catherine Waldby, "Stem Cells, Tissue Cultures and the Production of Biovalue," *Health: An Interdisciplinary Journal for the Social Study of Health, Illness, and Medicine* 6, no. 3 (2002): 305–23.

3 Waldby, "Stem Cells," 310.

4 Rebecca Skloot, *The Immortal Life of Henrietta Lacks* (New York: Crown, 2010).

5 For example, see Karla F. C. Holloway, *Private Bodies, Public Texts: Race, Gender, and a Cultural Bioethics* (Durham, N.C.: Duke University Press, 2011).

6 J. L. Austin, *How to Do Things with Words* (Cambridge, Mass.: Harvard University Press, 1975).

7 My emphasis is on understanding stories by their distinct capacities—what a story is able to do that other speech genres (e.g., the factual narratives found in medical charts) cannot do, rather than trying to define stories. The extended rationale for this approach is Arthur W. Frank, *Letting Stories Breathe: A Socio-narratology* (Chicago: University of Chicago Press, 2010). My usage of speech genres is derived from Mikhail Bakhtin, *Speech Genres and Other Late Essays* (Austin: University of Texas Press, 1986). Genre refers less to literary genres (tragedy, comedy, etc.) and more to ways of speaking that are characteristic of types of speakers and speech contexts; in medicine, the diagnostic interview is a speech genre, with particular expectations including relevance of content, turn taking, appropriateness of specialized usage, and so forth. In such situations, people expect certain ways of speaking, and by speaking certain ways, people know where they are and who plays what role.

8 Margaret Atwood, *In Other Worlds: SF and the Human Imagination* (New York: Random House, 2011), 185.

9 Margaret Atwood's three novels of what she prefers to call "speculative fiction" are *The Handmaid's Tale*, *Oryx and Crake*, and *The Year of the Flood*. The latter two involve biotechnologies.

10 Nikolas Rose, *The Politics of Life Itself* (Princeton, N.J.: Princeton University Press, 2006), 11.

11 Rose, *Politics of Life Itself*, 11.

12 I use the term *actor* here as actors are discussed in actor-network theory; that is, as whatever—human or nonhuman—acts, thus making the presence and activity of other actors possible, with the sum of actors constituting the network. Actors are whatever enables action; the diagnostic scanner makes it possible for the physician to order the test, the medical equipment company that designed the scanner to represent bodies in a particular way, and so forth. Many studies employ this approach; see especially Annemarie Mol, *The Body Multiple: Ontology in Medical Practice* (Durham, N.C.: Duke University Press, 2002) and Nik Brown and Andrew Webster, *New Medical Technologies and Society: Reordering Life* (Cambridge: Polity, 2004).

13 Waldby, "Stem Cells," 308.

14 Waldby, "Stem Cells," 318. Holloway, without reference to Waldby, argues that in the case of the Lacks cell line, "there had been a decided effort and specific intent to attach narrative elements to this unusual medical story, despite the fact that the Lacks family was never told that her cells were available to medical researchers. . . . The vocabulary that described the HeLa cell line as 'vigorous,' 'aggressive,' and 'difficult to control' was not detached from the body that produced them" (*Private Bodies, Public Texts*, 5). For Holloway, the difference between the narrative personification of the Lacks cell line and the non-narrative utilization of Moore's cells reflects a racial divide and the vulnerability of women and ethnic minorities to privacy violation. Both Waldby, writing of biovalue generally, and Holloway, writing specifically about the Lacks case, can be correct. The greater the number of variations on the Lacks story that become told, the more ways become available for understanding what happened and continues to happen.

15 Cover text, Skloot, *Immortal Life of Henrietta Lacks*; emphasis original.

16 Skloot, *Immortal Life of Henrietta Lacks*, 328.

17 Skloot, *Immortal Life of Henrietta Lacks*, 325.

18 Skloot, *Immortal Life of Henrietta Lacks*, 205.

19 Rose, *Politics of Life Itself*, 4.

20 Skloot, *Immortal Life of Henrietta Lacks*, 315.

21 Norbert Elias, *The Civilizing Process* (Oxford: Blackwell, 1994).

22 Elias, *Civilizing Process*, 59.

23 Atwood, *In Other Worlds*, 202.

24 Atwood, *In Other Worlds*, 196, 200, 201.

25 Atwood, *In Other Worlds*, 209, 150.

26 Terry Pratchett, *Witches Abroad* (London: Corgi Books, 1992), 8. For my own arguments about stories taking on lives of their own, see Frank, *Letting Stories*

Breathe. Like Pratchett, I believe humans follow paths etched by stories—and then tell stories they claim as their own.

27 Pratchett, *Witches Abroad*, 192–93.

28 Atwood, *In Other Worlds*, 131.

29 "In Their Own Words: 'Study Drugs,'" *The New York Times*, June 9, 2012, accessed June 9, 2012, http://www.nytimes.com/interactive/2012/06/10/education/stimulants-student-voices.html#/.

30 Frank, *Letting Stories Breathe*, 35.

31 Frank, *Letting Stories Breathe*, 36

32 Rose, *Politics of Life Itself*, 187ff. Rose anticipates the study-drugs story perfectly when he writes, "Individuals themselves and their authorities—general practitioners, nurses, teachers, parents—are beginning to recode variations in moods, emotions, desires, and thoughts in terms of the functioning of their brain chemicals, and to act upon themselves in light of this belief." He proceeds to note the "wider shift in which such drugs are becoming central to the ways in which our conduct is governed, by others, and by ourselves" (223). In the study-drugs stories, students are clear that they made decisions to take the drugs, but the stories are densely populated with other authorities to whom students are responding. Finally, Rose anticipates the blurred lines between drugs as treatments for diagnosed conditions (in these stories, primarily ADHD) and drugs as enhancement.

33 Rose, *Politics of Life Itself*, 216ff.

34 Waldby, "Stem Cells," 314.

35 Michael Hauskeller, "Reinventing Cockaigne: Utopian Themes in Transhumanist Thought," *Hastings Center Report* 42, no. 2 (2012): 39–47, 39.

36 Nick Bostrom, "The Fable of the Dragon Tyrant," *Journal of Medical Ethics* 31 (2005): 273–77.

37 Bostrom, "Fable of the Dragon Tyrant," 273–74.

38 Bostrom, "Fable of the Dragon Tyrant," 274–75.

39 Bostrom, "Fable of the Dragon Tyrant," 276.

40 Transhumanist thinking invariably depends upon this argument that accelerated progress, specifically in computing power, makes possible what was previously considered fantastic. The trope for this acceleration is "singularity," a not-too-distant moment when "the pace of technological change will be so rapid, its impact so deep, that human life will be irreversibly transformed." Ray Kurzweil, *The Singularity Is Near: When Humans Transcend Biology* (New York: Viking, 2005), 7. The paradox of talking about the singularity, or "Singularity," is that because the extent of change will be so extensive, we cannot imagine it well enough to talk about it. But it will be beneficial, and refusal is not an option.

41 Bostrom, "Fable of the Dragon Tyrant," 276–77.

42 Atwood, *In Other Worlds*, 200.
43 Atwood, *In Other Worlds*, 200–201.
44 This form of argument is typically modern. In 1848 Marx claimed that the proletarian revolution would succeed where previous worker revolts had failed because now capitalism has prepared the means of production necessary to support a socialist state; technology trumps precedent. Karl Marx and Friedrich Engels, *The Communist Manifesto* (1848; repr., Oxford: Oxford University Press, 1992).
45 Hauskeller, “Reinventing Cockaigne,” 40.
46 Hauskeller, “Reinventing Cockaigne,” 45.
47 Bostrom, “Fable of the Dragon Tyrant,” 277.
48 Philip Smith, *Why War? The Cultural Logic of Iraq, the Gulf War, and Suez* (Chicago: University of Chicago Press, 2005), 28.
49 Smith, *Why War?*, 28–29.
50 Atwood, *In Other Worlds*, 66.
51 Atwood, *In Other Worlds*, 66.
52 With respect to this latter capacity to tell stories, I object not to Bostrom writing his argument as a fable, but only to the particular fable he tells. However, fables are a questionable genre for bioethics storytelling because they seek to tell universal truths and thus devalue local particulars. The characters in fables tend toward caricature, and chance plays too little part.
53 For early versions of narrative ethics, including my own, see Hilde Lindemann Nelson, ed., *Stories and Their Limits: Narrative Approaches to Bioethics* (New York: Routledge, 1997). For a more recent summation, see Howard Brody, *Stories of Sickness*, 2nd ed. (New York: Oxford, 2003), esp. chaps. 11–15. On situating ethics within a project of human flourishing, my Aristotelianism follows Jonathan Lear, *Radical Hope: Ethics in the Face of Cultural Devastation* (Cambridge, Mass.: Harvard University Press, 2006). Hauskeller, “Reinventing Cockaigne,” 42, 45, identifies problems with what he calls “crypto-Aristotelian” thinking in transhumanist thought. I agree and seek to be a noncrypto neo-Aristotelian.
54 I follow the line of argument expressed by the philosopher whom I consider the godmother of narrative ethics, Iris Murdoch, *The Sovereignty of Good* (London: Routledge & Kegan Paul, 1970).
55 I summarize an argument made in more detail in the closing chapter of Frank, *Letting Stories Breathe*.
56 Waldby, “Stem Cells,” 319.
57 Frank, *Letting Stories Breathe*. In my earlier work, storytellers are crucially dependent on narrative resources that cultures and institutions do or do not make available to them. Again, consciousness is decentered, if never

determined. Arthur W. Frank, *The Wounded Storyteller: Body, Illness, and Ethics* (Chicago: University of Chicago Press, 1995).

58 Cf. Rose: “I am wary of epochal claims. . . . Yet, from the point of view of the present, a threshold has been crossed.” *Politics of Life Itself*, 7.

59 Waldby, “Stem Cells,” 319.

60 For a useful overview, see Donna J. Haraway, *The Haraway Reader* (New York: Routledge, 2004). Most recently, Donna J. Haraway, *When Species Meet* (Minneapolis: University of Minnesota Press, 2008).

61 Quoted above, Waldby, “Stem Cells,” 319.

Chapter 9. Griffith: Blacks and the Language of Their Biotechnological Future

1 Robert Sellers, Mia Smith, J. Nicole Shelton, Stephanie Rowley, and Tabbye Chavous, “Multidimensional Model of Racial Identity: A Reconceptualization of African American Racial Identity,” *Personality and Social Psychology Review* 2, no. 1 (1998): 18–39.

2 Orlando Patterson, “Being and Blackness,” *The New York Times*, January 8, 2006, sec. 7.

3 Kenneth Chang, “Black Scientists Less Likely to Win Federal Research Grants, Study Reports,” *The New York Times*, August 19, 2011, sec. A, 16.

4 Alan Feuer, “Under Pressure to Diversify,” *The New York Times*, August 28, 2011, Metropolitan sec., 1, 6.

5 Deborah Sontag, “Global Failures on a Haitian Epidemic,” *The New York Times*, April 1, 2012, sec. A., 1, 14–15.

6 Dorothy E. Roberts, “Is Race-Based Medicine Good for Us? African American Approaches to Race, Biomedicine, and Equality,” *Journal of Law, Medicine & Ethics* 36 (2008): 537–45.

7 See, e.g., William Cross Jr., *Shades of Black: Diversity in African-American Identity* (Philadelphia: Temple University Press, 1991); Sellers et al., “Multidimensional Model.”

8 Jane Sheldon, Toby Jayaratne, Merle Feldbaum, Courtney DiNardo, and Elizabeth Petty, “Applications and Implications of Advances in Human Genetics: Perspectives from a Group of Black Americans,” *Community Genetics* 10 (2007): 82–92.

9 Risa Lavizzo-Mourey and James Knickman, “Racial Disparities—The Need for Research and Action,” *New England Journal of Medicine* 349, no. 14 (2003): 1379–80.

10 Troy Duster, “Race and Reification in Science,” *Science* 307 (2005): 1050–51.

11 Robert Temple and Norman Stockbridge, “BiDil for Heart Failure in Black Patients: The U.S. Food and Drug Administration Perspective,” *Annals of Internal Medicine* 146, no. 1 (2007), 57–62.

12 Temple and Stockbridge, “BiDil for Heart Failure.”

13 Kirsten Bibbins-Domingo and Alicia Fernandez, “BiDil for Heart Failure in Black Patients: Implications of the U.S. Food and Drug Administration Approval,” *Annals of Internal Medicine* 146, no. 1 (2007): 52–56; Jay Cohn, “The Use of Race and Ethnicity in Medicine: Lessons from the African-American Heart Failure Trial,” *Journal of Law, Medicine & Ethics* 34 (2006): 552–54.

14 See, e.g., Esteban Burchard, Elad Ziv, Natasha Coyle, Scarlett Gomez, Hua Tang, Andrew Karter, Joanna Mountain, Eliseo Perez-Stable, Dean Sheppard, and Neil Risch, “The Importance of Race and Ethnic Background in Biomedical Research and Clinical Practice,” *New England Journal of Medicine* 348, no. 12 (2003): 1170–75; see also Michael Root, “The Use of Race in Medicine as a Proxy for Genetic Differences,” *Philosophy of Science* 70 (2003): 1173–83. Root concludes there are no biological races.

15 See, e.g., Cohn, “Use of Race and Ethnicity.”

16 Root, “Use of Race in Medicine,” 1175.

17 See Luke 10:30-37.

18 See Sheldon et al., “Applications and Implications.”

19 For consideration of the importance, barriers, and solutions concerning such participation, see Richard D. Branson, Kenneth Davis Jr., and Karyn L. Butler, “African Americans’ Participation in Clinical Research: Importance, Barriers, and Solutions,” *American Journal of Surgery* 193 (2007): 32–39.

20 Joseph Washington Jr., *The Politics of God: The Future of the Black Churches* (Boston: Beacon, 1967).

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22 Ezra E. H. Griffith, *Ye Shall Dream: Patriarch Granville Williams and the Barbados Spiritual Baptists* (Kingston, Jamaica: University of the West Indies Press, 2010).

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Chapter 10. Brody: Bioethics, Economism, and the Rhetoric of Technological Innovation

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Chapter 11. Keränen: Technologies of the Self at the End of Life

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1 The Patient Self-Determination Act (PSDA) of 1990 required U.S. hospitals, nursing homes, and HMOs receiving Medicare and Medicaid funding to generate written policies regarding advance directives and to educate staff about their use. PSDA also required these institutions to inquire if patients possessed an advance directive upon admission and to provide educational materials about their right to have one. See Charles P. Sabatino, "The Evolution of Health Advance Care Planning Law and Policy," *Milbank Quarterly* 88 (2010): 211–39; and Edward J. Larson and Thomas A. Eaton, "The Limits of Advance Directives: A History and Assessment of the Patient Self-Determination Act," *Wake Forest Law Review* 32 (1997): 249–93.

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7 I find the term *patient* problematic because of its implied subordinate relation to medical authority. However, I find the term that is often substituted, *client*, equally problematic because it embeds health care in a language of consumer choice. And finally, *care-receiver* strikes me as subordinate. I therefore use the term *patient* but acknowledge its limits.

8 See Mitchell, "Analysis of Common Arguments"; Bruce Jennings, Gregory E. Kaebnick, and Thomas H. Murray, eds., "Improving End of Life Care: Why Has It Been So Difficult?" *Hastings Center Report* 35 (2005): S1–60, accessed June 10, 2012, http://www.thehastingscenter.org/Publications/SpecialReports/Detail.aspx?id=1344; and Perkins, "Controlling Death."

9 Jennings et al., "Improving End of Life Care."

10 Interviews were conducted in the spring and early summer of 2011 with leading Colorado-based palliative care experts, which means that these interviewees likely have more knowledge of the inner workings of these forms than health care practitioners representing other specialties. The interview transcripts are not intended to be generalizable. In addition, this research is informed by my previous participation in medical ethics committees and consultation services and as part of a volunteer community palliative care initiative. See also Paul K. J. Han, Lisa B. Keränen, Dianne A. Lescisin, and Robert M. Arnold, "The Palliative Care Clinical Evaluation Exercise (CEX): An Experience-Based Intervention for Teaching End-of-Life Communication Skills," *Academic Medicine* 80 (2005): 669–76.

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of advance directives. See Jacobson and Kasworm, "May I Take Your Order"; DePalo, Iacobucci, and Crausman, "Do-Not-Resuscitate"; and Veatch, "Do Not Resuscitate." See my analysis of one of these forms in Keränen, " 'Cause Someday We All Die."

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63 Foucault, "Subject and Power," 784. Foucault here explains that pastoral power "has been commuted to a salvation in this life (health, wellbeing, security, etc.)."

64 Foucault, "Subject and Power," 784.

65 Foucault, "Subject and Power," 784. Foucault notes that in the eighteenth century, pastoral power began to be exercised by "complex structures such as medicine, which included private initiatives with the sale of services on market economy principles, but which also included public institutions, such as hospitals" (794).

66 Thomas F. Tierney, "Foucault on the Case: The Pastoral and Juridical Foundation of Medical Power," *Journal of Medical Humanities* 25 (2004): 290.

67 Teghtsoonian, "Depression and Mental Health," 28.

68 Foucault, "Subject and Power," 783.

69 Aging with Dignity, accessed June 13, 2012, http://www.agingwithdignity.org/.

70 Peter Conrad, *The Medicalization of Society* (Baltimore: Johns Hopkins University Press, 2007).

71 Foucault, "Technologies of the Self," 18.

72 Aging with Dignity, "Five Wishes," 2; emphasis added.

73 Aging with Dignity, "Five Wishes," 11.

74 Ken Y., April 20, 2009 (12:23 p.m.), comment on Paula Span, "Why Do We Avoid Advance Directives?," The New Old Age: Caring and Coping Blog, *The New York Times*, April 20, 2009, accessed June 13, 2012, http://newoldage.blogs.nytimes.com/author/paula-span/.

75 Kd, April 20, 2009 (4:44 p.m.), comment on Paula Span, "Why Do We Avoid Advance Directives?"

76 Pat, April 21, 2009 (6:51 a.m.), comment on Span, "Why Do We Avoid Advance Directives?"

77 Pat, April 21, 2009 (6:51 a.m.), comment on Span, "Why Do We Avoid Advance Directives?"

78 Clif G., April 20, 2009 (3:41 p.m.), comment on Span, "Why Do We Avoid Advance Directives?"

79 Please note that oral speech, by contrast to its written counterpart, is messy and fragmented. In order to preserve natural speech patterns, I did not edit the oral speech of my interviews to make it resemble written text, except that I eliminated vocal fillers and lightly edited disfluencies.

80 Foucault, "Subject and Power," 784.

81 One of my interviewees stressed that research suggests that Five Wishes is not geared toward low-literacy and low-health-literacy patients.

82 Aging with Dignity, "Five Wishes," 4; emphasis original.

83 Aging with Dignity, accessed June 13, 2012, http://www.agingwithdignity.org/.

84 Aging with Dignity, "Five Wishes," 2.

85 Rabinow and Rose, "Biopower Today," 197. See also Nikolas Rose and Carlos Novas, "Biological Citizenship," in *Global Assemblages: Technology, Politics, and Ethics as Anthropological Problems*, ed. Aihwa Ong and Stephen J. Collier (Malden, Mass.: Blackwell, 2004), 439–63; Michel Foucault, "The Right of Death and Power over Life," in *The Foucault Reader*, ed. Paul Rabinow (New York: Pantheon Books, 1984), 258–72; and *The Birth of Biopolitics: Lectures at the College De France, 1978–1979*, ed. Michel Senellart and Francois Ewald, trans. Graham Burchell (New York: Palgrave Macmillan, 2010).

86 Rose, *Politics of Life Itself*, 134.

87 Rose, *Politics of Life Itself*, 63.

88 Amy K., April 20, 2009 (4:11 p.m.), comment on Span, "Why Do We Avoid Advance Directives?"

89 Andrew S. Epstein, Angelo E. Volandes, and Eileen M. O'Reilly, "Building on Individual, State, and Federal Initiatives for Advance Care Planning, an

Integral Component of Palliative and End-of-Life Cancer Care," *Journal of Oncology Practice* 7 (2011): 356.

90 Rebecca L. Sudore, "Redefining the 'Planning' in Advance Care Planning: Preparing for End-of Life Decision Making," *Annals of Internal Medicine* 153 (2010): 256–61, 259.

91 Sudore, "Redefining," 259.

92 Sudore, "Redefining," 259.

93 Angela E. Volandes et al., "Augmenting Advance Care Planning in Poor Prognosis Cancer with a Video Decision Aid: A Preintervention-Postintervention Study." *Cancer* 118 (2012): 1–8. These authors note that more than five hundred decision tools for advance care planning have been developed; twelve of these include video components. See also Ben Daitz, "With Poem, Broaching the Topic of Death," *The New York Times*, January 24, 2011, accessed June 18, 2012, http://www.nytimes.com/2011/01/25/health/25navajo.htm.

94 Another concern a lot of practitioners shared during my interviews was that they are not able to bill for the long time it takes to have palliative care conversations, which serves as a disincentive.

95 For recent research on POLST/MOST, see Bernard J. Hammes, Brenda L. Rooney, Jacob D. Gundrum, Susan E. Hickman, and Nickijo Hager, "The POLST Program: A Retrospective Review of the Demographics of Use and Outcomes in One Community where Advance Directives Are Prevalent," *Journal of Palliative Medicine* 15 (2012): 77–85. For POLST/MOST configured as a "major advance," see Janet L. Abrahm, "Advances in Palliative Medicine and End-of-Life Care," *Annual Review of Medicine* 62 (2011): 187–99.

96 Ballentine, "New Tool."

97 Rose, *Politics of Life Itself*, 134.

98 Jennings et al., "Improving End of Life Care."

99 For some speculative comments on the intersections between health and security, see Lisa Keränen, "Addressing the Epidemic of Epidemics: Germs, Security, and a Call for Biocriticism (Review Essay)," *Quarterly Journal of Speech* 72 (2011): 224–44; and Keränen, "Concocting Viral Apocalypse."

100 Bernard Lo and Robert Steinbrook, "Resuscitating Advance Directives," *Archives of Internal Medicine* 164 (2004): 1501–6.

101 Tierney, "Foucault on the Case," 290.

Chapter 12. Segal: Suffering and the Rhetoric of Care

1 Quoted in Pedro Lain Entralgo, *Doctor and Patient* (New York: McGraw-Hill, 1969), 243.

2 Entralgo, *Doctor and Patient*, 244.

3 There is the image, and then there is the interpretation of the image. For one

account of their relation, see Joseph Dumit, *Picturing Personhood: Brain Scans and Biomedical Identity* (Princeton, N.J.: Princeton University Press, 2004); for another, see Annemarie Mol, *The Body Multiple: Ontology in Medical Practice* (Durham, N.C.: Duke University Press, 2002).

4 For ethics of care, see, e.g., Virginia Held, *The Ethics of Care: Personal, Political, Global* (Oxford: Oxford University Press, 2006). For logic of care, see Annemarie Mol, *The Logic of Care: Health and the Problem of Patient Choice* (London: Routledge, 2008), 8. Mol posits a "logic of care" against a "logic of choice," and argues that the latter, much as it is promoted in many circles, "does not offer a way of living superior to the life that may be led in a world infused by a . . . logic of care." Mol concerns herself with what patients do in a logic of care ("inject their own insulin, measure their own blood sugar levels, count the carbohydrates they eat"); patient agency is not, then, associated only with a "logic of choice."

5 Kenneth Burke, *A Rhetoric of Motives* (1950; repr., Berkeley: University of California Press, 1969), 42.

6 Kenneth Burke, *A Grammar of Motives* (1945; repr., Berkeley: University of California Press, 1969), 105.

7 See Robert G. Evans and Gregory L. Stoddart, "Producing Health, Consuming Health Care," *Social Science and Medicine* 31 (1990): 1347–63.

8 See my *Health and the Rhetoric of Medicine* (Carbondale: Southern Illinois University Press, 2005), 130–31.

9 See, e.g., David John Doukas and Michael Aristides Doukas, "Turning from 'Cure' to 'Care,'" *Hastings Center Report* 31, no. 5 (2001): 11. The shift described is from aggressive cancer therapies to palliative care. The very idea of the shift, however, entails that the cancer treatment itself was uncontaminated by care.

10 Margaret Mohrmann says that the spiritual care of the ill and dying is not and should not be the special province of hospital chaplains: it is "within the domain of good nurses and good doctors." "Ethical Grounding for a Profession of Hospital Chaplaincy," *Hastings Center Report* 38, no. 6 (2008): 18–23, 18.

11 See Vincanne Adams, Michelle Murphy, and Adele E. Clarke, "Anticipation: Technoscience, Life, Affect, Temporality," *Subjectivity* 28 (2009): 246–65.

12 S. Lochlann Jain, "Living in Prognosis: Towards an Elegaic Politics," *Representations* 98, no. 1 (2007): 77–92.

13 B. E. Willard, "Feminist Interventions in Biomedical Discourse: An Analysis of the Rhetoric of Integrative Medicine," *Women's Studies in Communication* 28, no. 1 (2005): 115–48.

14 Thomas A. Hutchison, ed., *Whole Person Care: A New Paradigm for the 21st Century* (New York: Springer, 2011).

15 Joanna Goodrich and Jocelyn Cornwell, *Seeing the Person in the Patient: The Point of Care Review Paper* (London: The King's Fund, 2008).

16 *Patient* is itself a problematic term, not least because of its association with passivity. It can be contrasted with *client* or *consumer* (see Rob Irvine, "Fabricating 'Health Consumers' in Health Care Politics," in *Consuming Health: The Commodification of Health Care,* ed. Sara Henderson and Alan Petersen [New York: Routledge, 2002], 31–47) or with *laypeople* (see Rebecca Kukla, "How Do Patients Know?" *Hastings Center Report* 37, no. 5 [2007]: 27–35). I use *patient* here, despite its problems, because we can agree on whom it represents, and because I wish to conjure that seemingly paradoxical figure: the patient as agent.

17 Anna B. Reisman, "Helping Patients Become 'Competent Inquirers,'" *Hastings Center Report* 37, no. 5 (2007): 3.

18 Reisman, "Helping Patients."

19 See also my "'Compliance' to 'Concordance': A Critical View," *Journal of Medical Humanities* 28 (2007): 81–96.

20 Richard Gwyn, *Communicating Health and Illness* (London: Sage, 2009), 90.

21 Robert Klitzman, *When Doctors Become Patients* (Oxford: Oxford University Press, 2008), 259.

22 Klitzman, *When Doctors Become Patients*, 271.

23 Klitzman, *When Doctors Become Patients*, 281.

24 A 2009 initiative in New Zealand seeks to guarantee patients the legal right "to have services provided with compassion, including a prompt and human response to suffering." See Ron Paterson, "Can We Mandate Compassion?" *Hastings Center Report* 41, no. 2 (2011): 20–23, 20.

25 Jenny Firth-Cozens and Jocelyn Cornwell, *The Point of Care: Enabling Compassionate Care in Acute Hospital Settings* (London: The King's Fund, April 2009).

26 For an explanation of conviction as a function of the faculty of understanding, and persuasion as a function of the faculty of the will, see, e.g., George Campbell's 1776 *Philosophy of Rhetoric* (repr., Carbondale: Southern Illinois University Press, 1963).

27 Klitzman, *When Doctors Become Patients*, 274.

28 Kathryn Montgomery, *How Doctors Think* (Oxford: Oxford University Press, 2006), 162.

29 Goodrich and Cornwell, *Seeing the Person*, vii.

30 Stephen Liben, "Empathy, Compassion, and the Goals of Medicine," in *Whole Person Care*, ed. Thomas A. Hutchinson (New York: Springer, 2011), 66.

31 See, e.g., Chris Feudtner and Dimitri A. Christakis, "Making the Rounds: The Ethical Development of Medical Students in the Context of Clinical Rotations," *Hastings Center Report* 24 (1994): 6–12. See also Helen McNamara

and Donald Boudreau, "Teaching Whole Person Care in Medical School," in Hutchison, *Whole Person Care*, 183–200.

32 Paterson, "Can We Mandate Compassion?," 22.

33 Robert Klitzman, keynote address at Fragmentation of Care Conference (Simon Fraser University, Vancouver, April 20, 2012).

34 Michael W. Kahn, "Etiquette-Based Medicine," *New England Journal of Medicine* 358, no. 19 (2008): 1988–89.

35 The generic patient is gendered female for several reasons; some of them are detailed in my *Health and the Rhetoric of Medicine* (see esp. 176–77, n. 6). My discussion here pertains to male patients as well as female ones.

36 See Karen Kopelson, "Writing Patients' Wrongs: The Rhetoric and Reality of Information Age Medicine," *Journal of Advanced Composition* 29, nos. 1–2 (2009): 352–404. See also my "Internet Health and the 21st-Century Patient," *Written Communication* 26, no. 4 (2009), 351–69.

37 On "lifeworld," see Elliot G. Mishler, *Discourse of Medicine: Dialectics of Medical Interviews* (Norwood, N.J.: Ablex, 1984).

38 For an analysis of this view of two knowledges, see Miriam Solomon, "Epistemological Reflections on the Art of Medicine and Narrative Medicine," *Perspectives in Biology and Medicine* 51 (2008): 406–17.

39 See Anita Ho, " 'They Just Don't Get It': When Family Disagrees with Expert Opinion," *Journal of Medical Ethics* 35 (2009): 497–501.

40 Rita Charon, *Narrative Medicine: Honoring the Stories of Illness* (Oxford: Oxford University Press, 2006).

41 My account of the patient experience is quite negative. Some patients, of course, report positive hospital experiences. Pediatric and palliative units in many hospitals are especially well known for superior care. My general description does not exceed the literature I cite in this essay, my own direct observation, or the firsthand reports of patients.

42 For more on the language of the hospital and on what patients are credited with doing in that language, see Abraham Fuks, "Healing, Wounding, and the Language of Medicine," in Hutchinson, *Whole Person Care*, 83–96.

43 Fuks quotes this statement, heard at a conference: "the patient perforated her uterus during the procedure." "Healing, Wounding, and the Language of Medicine," 93.

44 This is a firsthand patient report.

45 Sholom Glouberman, *My Operation* (Toronto: Health and Everything Publications, 2010), 4.

46 Robert K. Merton, "Sociological Ambivalence," in *Sociological Ambivalence and Other Essays* (New York: Free Press, 1976), 3–31.

47 See, e.g., Renée R. Anspach, "Notes on the Sociology of Medical Discourse:

The Language of the Case Presentation," *Journal of Health and Social Behavior* 29 (1988), 368–69.

48 Rita Charon, "Narrative and Medicine," *New England Journal of Medicine* 286, no. 15 (2004): 862.

49 See Joan Leach, "How Do You Talk to a Patient?," in *Rhetorical Questions of Health and Medicine*, ed. Joan Leach and Deborah Dysart-Gale (Lanham, Md.: Lexington, 2011), 181–94.

50 See, e.g., essays published in *Journal of Medical Humanities*, *Medical Humanities*, *Literature and Medicine*, *Academic Medicine*, *Hastings Center Report*, and other journals of bioethics.

51 Rafael Campo, "Why Should Medical Students Be Writing Poems?" *Journal of Medical Humanities* 27 (2006): 253–54.

52 See, e.g., Martha C. Nussbaum, *Poetic Justice: The Literary Imagination and Public Life* (Boston: Beacon, 1995).

53 Byron J. Good, *Medicine, Rationality, and Experience: An Anthropological Perspective* (New York: Cambridge, University Press, 1994), 78.

54 Wear cites William Pinar for the term *hidden curriculum*—the "ideological and subliminal message[s] presented within the overt curriculum, as well as a by-product of what is not offered—the null curriculum." William F. Pinar, William M. Reynolds, Patrick Slattery, and Peter M. Taubman, *Understanding Curriculum: An Introduction to the Study of Historical and Contemporary Curriculum Discourses* (New York: Peter Lang, 1995), 27. See also Frederick W. Hafferty and Ronald Franks, "The Hidden Curriciulum, Ethics Teaching, and the Structure of Medical Education," *Academic Medicine* 69 (1994): 861–71.

55 Delese Wear, "Respect for Patients," in *Professionalism in Medicine: Critical Perspectives*, ed. Delese Wear and Julie M. Aultman (New York: Springer, 2006), 92.

56 See Jakob Ousager and Helle Johannessen, "Humanities in Undergraduate Medical Education: A Literature Review," *Academic Medicine* 85 (2010): 988–98. For a reply to Ousager and Johannessen, see Catherine Belling, "Sharper Instruments: On Defending the Humanities in Undergraduate Medical Education," *Academic Medicine* 85 (2010): 938–40.

57 Igor J. Polianski and Heiner Fangerau, "Toward 'Harder' Medical Humanities: Moving beyond the 'Two Cultures' Dichotomy," *Academic Medicine* 87, no. 1 (2012): 122. See also Tod Chambers, "Manifesto for Medicine Studies," *Atrium* 7 (2009): 4–5.

58 See *Health and the Rhetoric of Medicine* and "Breast Cancer Narratives as Public Rhetoric: Genre Itself and the Maintenance of Ignorance," *Linguistics and the Human Sciences* 3, no. 1 (2007): 3–23.

59 See, e.g., Christina Sinding and Ross Gray, "Active Aging—Spunky Survivorship? Discourses and Experiences of the Years beyond Breast Cancer," *Journal*

of Aging Studies 19 (2005): 147–61, and the film, *Pink Ribbons, Inc.*, directed by Léa Pool (Montreal: National Film Board of Canada, 2011).

60 See J. Blake Scott, *Risky Rhetoric: AIDS and the Cultural Practices of HIV Testing* (Carbondale: Southern Illinois University Press, 2003).

61 See Nicolas Rasmussen, "Goofball Panic: Barbiturates, 'Dangerous' and Addictive Drugs, and the Regulation of Medicine in Postwar America," in *Prescribed: Writing, Filling, Using, and Abusing the Prescription in Modern America*, ed. Jeremy A. Green and Elizabeth Siegel Watkins (Baltimore: Johns Hopkins University Press, 2012), 23–45.

62 See Thomas Schlich, "Rejuvenating Men: Testicle Transplants," in *The Origins of Organ Transplantation: Surgery and Laboratory Science, 1880–1930* (Rochester, N.Y.: University of Rochester Press, 2010), 99–115.

63 See Leah Ceccarelli, "Neither Confusing Cacophony nor Culinary Complements: A Case Study of Mixed Metaphors for Genomic Science," *Written Communication* 21 (2004): 92–105.

64 Michael J. Sandel, *The Case against Perfection: Ethics in the Age of Genetic Engineering* (Cambridge, Mass.: Harvard University Press, 2007), 9.

65 Entralgo, *Doctor and Patient*, 176.

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INDEX