1-1-2012

Bioethics at the Beginning, Middle, and End of Life

Elizabeth M. Anderson

Follow this and additional works at: http://scholarship.law.nd.edu/ndjlepp

Recommended Citation
Available at: http://scholarship.law.nd.edu/ndjlepp/vol17/iss1/1
FOREWORD

BIOETHICS AT THE BEGINNING, MIDDLE, AND END OF LIFE

ELIZABETH M. ANDERSON*

INTRODUCTION

Bioethical rhetoric that pervades American discourse today began at a time when the problems associated with technologies such as embryonic stem cell research and cloning were unimaginable. Issues in biological sciences were first spurred in large part by the effort to improve military medicine after World War II. At that time, penicillin, which had been discovered in 1928 and was first applied clinically during the war, had begun to be produced synthetically. The ease and low cost of synthetic production made penicillin the preferred drug for treating pneumonia and other infections. Further developments led to the introduction of cancer treatments, anti-hypertensive drugs, the cardiac pacemaker, and the polio vaccine. With this increased progress of medicine came the development of medical specialties, and with such development came concern regarding the damage these specialties would have on the relationship between patients and the traditional general-practice physician. Thus was born one of the first significant bioethical issues. Nevertheless, this and other growing issues of the time, such as the increasing use of human subjects for medical research and the rising costs of health care, were infrequently discussed with those outside the medical field.

* Editor-in-Chief, Notre Dame Journal of Law, Ethics & Public Policy, 2002–2003; J.D. Candidate, University of Notre Dame Law School, 2003; White Scholar, Thomas J. White Center on Law & Government, 2001–2003; B.S., Civil Engineering, The Ohio State University, 1998. I would like to thank Kevin Gin-gras for his helpful comments.

2. Id.
3. Id.
4. Id. at 12–13.
As medical technology continued to advance, however, so did the scope of the bioethics dialogue. By the 1960s, those outside the medical field began discussing bioethical issues. Both human cloning and embryo research became topics of discussion in many circles after the successful cloning of tadpoles in 1962 and the birth of the first human "test-tube baby" in 1978.\(^5\) While these events became topics of discussion in academic circles, early works discussing bioethics still did not have much impact on the media or on public opinion.\(^6\) Not until years later, when the public began to take a personal stake in decisions regarding abortion, euthanasia, neonatal infanticide, and the refusal of life-prolonging technology, did members of the general public begin to find bioethical issues of interest.

The incredible, and almost unimaginable, technological advances of the past quarter century have brought issues in bioethics to the forefront of public attention. These advances have already provided remarkable enhancements for human life, and they hold the potential for even more improvements. Unfortunately, this accelerated pace of scientific advancement has hindered the ability of our cultural values and laws, in many cases, to deal adequately with the opportunities and dangers such developments present. Science continues to develop at a pace that exceeds the pace of public debate and political action. Consequently, the basic moral questions remain: Are we in some cases treating human life as raw material to be exploited as a natural resource? Have we blurred the line between creation and manufacture? What moral boundaries should researchers observe?\(^7\)

To determine the future direction of the development of biotechnology requires a deep understanding of the ethical issues involved—on the part of both the general public and of members of the legal profession. For the general public, biotechnology, and the bioethics that can govern how we decide to use that technology, affects many aspects of people's lives. Bioethical decisions can affect the way people bear their children, the way they are treated for disease or disability, the way their...

---

6. This can be demonstrated by the way bioethical publications were received in the public. For example, one early leading book in bioethics, Ethics at the Edges of Life: Medical and Legal Intersections, written by Paul Ramsey in 1978, did not have much of an impact on the public. James J. McCartney, Embryonic Stem Cell Research and Respect for Human Life: Philosophical and Legal Reflections, 65 Alb. L. Rev. 597, 597 (2002). One possible reason for this is that, at the time, "many people would have just as soon avoid discussing issues that concern life and death." Id.
7. Kass, supra note 5, at 82.
physical characteristics are used by government officials in crime investigation, and how they spend the last moments of their lives. The ethical concerns regarding biotechnology can affect how these types of actions are regulated when such concerns are relayed to lawmakers. Consequently, a broad understanding of bioethical issues that relate to the regulation of biotechnology can help to ensure that medical advancements are not made in an unethical or immoral manner.

For those in the legal profession, bioethical-related decisions can pervade their professional lives. Unfortunately, however, the area of bioethics is one with which many lawyers, judges, and lawmakers do not often have significant experience or education because it is a relatively new area of study and is one that was not taught in any law school just a few years ago. As the area of biotechnology and law continues to grow, however, a practicing attorney cannot escape facing bioethical issues on a regular basis: Do I defend a husband’s right to have the frozen embryos of his and his widow’s destroyed after her death? Do I defend a prescribing physician who has encouraged a patient to take experimental treatments for which he has received a financial incentive? Do I advocate for a couple to clone their child for “spare parts?” In each of these situations, the benefits of medical advances to a larger population can often persuade others to ignore or lessen the emphasis of the ethical impact of such actions.

Despite its benefits, however, the development of biotechnology has moral limits that conform to specific moral absolutes, as an ethical approach to the development of biotechnology should remain grounded in certain fundamental truths about the human person. First among these truths is “the dignity or value of each human person at every stage and condition.” The revelation of our likeness to and relationship with God affirmatively attests to this truth. Pope John Paul II’s encyclical, Evangelium Vitae, illustrates why the human person is an entity of incomparable dignity. In the encyclical, Pope John

---

11. Id.
Paul notes the threat to the weakest members of the human race—the unborn, the sick, and the dying. Most importantly, his Holiness makes an impassioned plea to all people of goodwill to recognize the dignity and sanctity of human life, to defend it from attacks launched against it, and to love it as a precious gift from God. In this light, acts that manipulate, marginalize, or kill human persons in any phase or condition are grave offenses that should be proscribed by civil law in a civilized society.

While scientific research and development can lead to improving lives by helping scientists to discover cures for diseases and disabilities, these developments often involve the destruction or modification of human life. In this way, such developments can violate the dignity of the human person, thus creating a tension between the need for advancing biotechnology and preserving human dignity. This inherent tension must be resolved in a way that maintains the dignity of every human person while allowing science to improve the quality of lives to whatever extent possible within these limits. Consequently, the developers and utilizers of biotechnology must observe certain moral limits. The moral limits of medical advancement addressed in this symposium concern such bioethical matters that surface at the beginning, middle, and end of life.

I. The Beginning of Life—When the Dignity Requirement Begins

There may be no more pressing area of bioethics than the ethics surrounding the creation of life. Ethical issues surfacing at the beginning of life include those involving human cloning, embryonic stem cell research, and genetic manipulation. To address these issues is to address the eternal question: When does life begin? Many individuals believe that human life begins at conception and others find that a blastocyst, a human in the earliest stage of development, does not become a human being until it looks like a human being and can do some of what human beings do. How one defines the beginning of life has a large impact on how one views the ethics of actions such as abortion and embryonic stem cell research. For instance, if a human being becomes such at the moment of conception, the human

---

13. Id.
14. Id.
15. See Kass, supra note 5, at 88 (arguing that blastocysts are not human beings because they do not look human or act human, though recognizing that the blastocyst is potentially a human being).
embryo that later develops must "be defended in its integrity, tended and cared for, to the extent possible, in the same way as any other human being . . . ."16 Today, "[m]odern science recognizes that the biological identity of a new human individual is already constituted in the zygote resulting from fertilization."17 If one accepts this proposition, then the dignity of a human must be respected from this first moment of existence.

The issue of human dignity as it relates to embryonic stem cell research is addressed in Roger Brownsword's article, *Bioethics Today, Bioethics Tomorrow: Stem Cell Research and the "Dignitarian Alliance."*18 Professor Brownsword notes that the Dignitarian Alliance focuses on the inherent dignity and worth of human beings—a dignity that should not be violated by any scientific or other endeavor. In his article, Professor Brownsword argues that "human dignity is an extremely powerful idea and it is likely to seem even more important as technology races ahead to redefine what we hitherto took to be the limits of human finitude."19 Professor Brownsword argues that the dignitarian approach is vital to give voice to our correct gut reaction toward certain biotechnological pursuits—such as embryonic stem cell research. He then critiques the government policy toward stem cell research in the United Kingdom, arguing that human embryos should be treated with a sort of reverence that is contrary to the government's policy. Because the government, while allowing stem cell research, notes that it ought to be conducted as little as possible and that existing embryos should be used instead of creating new ones, Brownsword questions how the government can recognize in its policy-making that human embryos should be treated differently yet continue to allow embryonic research.

Similarly, Senator Rick Santorum addresses the ethical implications of embryonic stem cell research on human dignity in his essay, *The New Culture of Life: Promoting Responsible and Appropriate Medical Research.*20 Senator Santorum admonishes the use of government funding for scientific research that involves

19. Id.
the destruction of human embryos or that is based on the prior
destruction of human life. The essay notes the history of
instances—including the notable Nuremberg war crime trials—
in which humankind has paused to consider certain ethical
boundaries that should govern scientific research. Noting that
the manufacture and destruction of human embryos for the sole
purpose of scientific inquiry is immoral, the essay encourages
policymakers to reconsider the issue of embryonic stem cell
research and seek a policy framework that will protect and
enhance human dignity.

In addition to embryonic stem cell research, human cloning
is an issue in bioethics that, while it first gained wide attention
several years ago, remains an issue of significant public attention.
From the announcement that the first animal was cloned in 1997
in Edinburgh, Scotland\(^2\) to the declaration in 2001 that
Advanced Cell Technology (ACT), a small biotech firm in Massa-
chusetts, had succeeded in creating the first human embryonic
cloned,\(^2\) developments in cloning and the unresolved ethical
issues surrounding the technology keep the issue in public
debate. As of today, human cloning remains substantially unreg-
ulated despite significant efforts to the contrary, including the
Human Cloning Prohibition Act of 2001,\(^2\) which passed by vote
in the House of Representatives but failed in the Senate in
August of that year.

In an effort to encourage the regulation of human cloning,
Shawn Peterson’s note, *A Comprehensive National Policy to Stop
Human Cloning: An Analysis of the Human Cloning Prohibition Act of
2001 with Recommendations for Federal and State
Legislatures*,\(^2\) proposes that the federal government join other nations in the inter-
national community that have attempted to ban human cloning.
The Human Cloning Prohibition Act of 2001 (HCPA), the note
suggests, would be an effective first step toward such an
endeavor. Nevertheless, Congress should make several amend-
ments to the proposed ban to increase its effectiveness, including
“instilling friendly rules of construction, giving HHS interpretive
authority over the scientific subsections of the statute, creating its

\(^{21}\) Rick Weiss, *Scottish Scientists Clone Adult Sheep; Technique’s Use With

\(^{22}\) Joannie Fischer, *The First Clone*, U.S. NEWS & WORLD REP., Nov. 25,
2001, at 51, 52.


\(^{24}\) Shawn E. Peterson, Note, *A Comprehensive National Policy to Stop Human
Cloning: An Analysis of the Human Cloning Prohibition Act of 2001 with Recommenda-
tions for Federal and State Legislatures*, 17 NOTRE DAME J.L. ETHICS & PUB. POL’Y
own expressed statute of limitations, and adding its own conspirac-
y and solicitation charge.\textsuperscript{25} Despite possible arguments that
the Act could infringe on an individual's right to create a child, 
the note concludes that the HCPA is nevertheless constitutional 
because the United States Supreme Court has not recognized 
such a right. In addition, Mr. Peterson suggests actions for state 
governments including: 1) passing a similar ban on human clon-
ing to allow state officials to enforce the ban and to police clon-
ing in their respective states; and 2) passing acts prohibiting the 
destruction of embryos for research purposes to give further disincentives for researchers to clone embryos within their bor-
ders.\textsuperscript{26} The note concludes that if Congress and its state 
counterparts have the courage to take the steps necessary to 
enact the HCPA and similar state acts, we will be able to stop the 
practice of human cloning in the United States.

Elaborating on the ethical implications of the mistreatment 
of human embryos in his article, \textit{Creating Clones, Kids & Chimera: 
Liberal Democratic Compromise at the Crossroads},\textsuperscript{27} Nathan Adams 
addresses three areas of biotechnology that have ethical implica-
tions surfacing at the beginning of life—human cloning, genetic 
screening, and genetic engineering. Dr. Adams argues that bio-
technology may lead to a more radical transformation of the 
political economy than any previous cluster of innovations 
because biotechnology alone holds the ability to modify the 
human species. The article makes a set of policy recommenda-
tions regarding manipulating the ex vivo living human embryo, 
arguing that “\textit{t}o extend no civil rights to the living human 
embryo, but \textit{t}o treat it as the moral and legal equivalent of a 
thing to be produced, patented, priced, and purchased would 
substantially extend utilitarianism beyond its current foothold in 
medical science.”\textsuperscript{28} Consequently, the article concludes, the best 
solution is to extend the liberal democratic compromise regard-
ing Equal Protection, reproductive rights, the First Amendment, 
human subject experimentation, patent law, and parental rights, 
to ban or monopolize certain biotechnologies and extend sub-
stantial respect to the living human embryo.

\begin{footnotes}
\item 25. \textit{Id.} at 267.
\item 26. \textit{Id.} at 267–68
\item 27. Nathan A. Adams, IV, \textit{Creating Clones, Kids & Chimera: Liberal Demo-
cratic Compromise at the Crossroads}, 17 \textit{Notre Dame J.L. Ethics & Pub. Pol'y} 71 
(2003).
\item 28. \textit{Id.} at 147.
\end{footnotes}
II. DURING LIFE—DIGNITY OF THE HUMAN PERSON

During the course of a human life, several bioethical issues can arise that require attention—including the use of genetic profiling in the criminal justice system, the ability to receive informed consent during human subject research, and the proper method of legislating medical research and in forming public policy regarding biotechnology. In August of 2001, President Bush announced the formation of the President’s Council of Bioethics, chaired by Dr. Leon Kass, to address some of these issues. Members of the Council included scientists, researchers, doctors, ethicists, theologians, and law professors, who were brought together to advise the President regarding bioethical policy-making. Specifically, the Council was formed “to monitor stem cell research, to recommend appropriate guidelines and regulations, and to consider all of the medical and ethical ramifications of biomedical innovation.” Backed by members of the Council, President Bush urged Congress, in April of 2002, to support a ban on human cloning, stating, “Life is a creation, not a commodity.” To conform to this idea that life should not be treated as a commodity, lawmakers should refrain from allowing human beings to be treated as such during their lifetimes through the use of biotechnology. Similarly, scientists should refrain from engaging in acts that abrogate the dignity of a person during his lifetime.

Inherent in the respect for the dignity of a human person is respect for the autonomous choices for other persons. Although “[r]espect for the autonomous choices of other persons runs as deep in common morality as any principle, . . . little agreement exists about its nature and strength or about specific rights of autonomy.” The concept of autonomy has special applications in the area of health care, as a patient’s ability to give informed consent to medical procedures is vital to retaining an individual’s autonomy and likewise, an individual’s inherent dignity. The

30. LEON R. KASS, THE PRESIDENT’S COUNCIL ON BIOETHICS, CHAIRMAN’S VISION, http://www.bioethics.gov/chairman.htm (last visited Jan. 20, 2003) (on file with the Notre Dame Journal of Law, Ethics & Public Policy). The Council was formed to not only advise the President on issues related to advances in biomedical science and technology, but also to provide a national forum for a discussion of these issues. Id.
ethical issues surrounding the act of obtaining informed consent when using human beings as research subjects are addressed in Shannon Benbow's note, *Conflict + Interest: Financial Incentives and Informed Consent in Human Subject Research.* Ms. Benbow introduces the conflict of interest that arises when physicians receive incentives from drug companies to prescribe the companies' drugs to their patients, highlighting this problem in the context of pharmaceutical research. Applying this conflict of interest to the doctrine of informed consent, the note raises the question of whether patients can provide informed consent when treating physicians do not adequately disclose their financial interests in such research. Though financial conflicts may never be fully eliminated, the note concludes that regulatory safeguards and monitoring are necessary to ensure that a physician's conflict does not result in damage to a patient's integrity and autonomy.

Ethical issues in biotechnology involve not only maintaining an individual's dignity during medical treatment, but also respecting an individual's Constitutional rights of privacy and due process. For example, the ethics of a genetics-based criminal justice system is addressed in Lindsy Elkins' note, *Five Foot Two With Eyes of Blue: Physical Profiling and the Prospect of a Genetics-Based Criminal Justice System.* Ms. Elkins explores the current nationwide crisis in the criminal justice system as it relates to existing DNA technology and presents the prosecutorial uses of such technology. The note concludes that while a DNA-based profiling system raises Equal Protection issues, such a system would pass constitutional muster because no group of individuals is singled out for special treatment and no group is penalized because of hostility toward a particular trait or race. Rather, the note suggests, DNA profiling in crime investigations could correct discriminatory tendencies while allowing law enforcement to locate criminal perpetrators.

In the pursuit to determine the best course of biotechnological advancement, many different voices strain to be heard. As discussions regarding the appropriate direction pervade the media, recognizing the appropriate weight that should be given to different sources of opinion remains vital. In their essay, *The

---


**Appropriate Limits of Science in the Formation of Public Policy,**

Maureen and Samuel Condic argue that scientists ought not be thrust into the spotlight and trusted above all others regarding important issues in biotechnology. Dr. and Mr. Condic note that opinions and recommendations of scientific experts often contrast vividly with the opinions of many Americans, and that the utility of scientific opinions depends critically on the nature of the decision at hand and remains limited by the culture of science and the personality traits of scientists.

### III. The End of Life—Maintaining Dignity in the Face of Death

At the end of a human life, ethical considerations become prevalent just as in any other time. Issues developing at the end of life concern the questions—when does, when should, and how should—life end? Furthermore, an important question remains—is a person ever morally justified in causing the death of another? One might say that causing death is morally wrong because the subject of the act loses a part of his autonomy, or “the capacity to plan and choose a future.” Consequently, the question arises—if a person desires death, is another person causing harm to him by causing his death? The answer to this question requires a recognition that the sanctity of human life, even more than a person's autonomy, requires the kind of reverence that prohibits any person from causing the death of another. The Declaration on Euthanasia, promulgated by the Congregation for the Doctrine of the Faith, states, “nothing and no one can in any way permit the killing of an innocent human being, whether a fetus or an embryo, an infant or an adult, an old person or one suffering from an incurable disease, or a person who is dying.” To violate this principle by assisting another's suicide is a violation of divine law and an offence against the dignity of the human person.

Murder could be the most direct assault on the sanctity of human life, but can actions such as assisting suicide, or euthanasia, be morally distinguished from murder? Some distinguish

---


38. KASS, *supra* note 5, at 236.
the acts by specifying that euthanasia allows a person to "die with dignity." Such dignity, however, is not one that can be demanded or claimed, as it is not owed. In his recent Encyclical Letter, Evangelium Vitae, Pope John Paul II accuses contemporary culture of adopting a Promethean attitude, "which leads people to think that they can control life and death by taking the decisions about them into their own hands." Death with dignity, or living dignifiedly in the face of death, is not a matter of pulling the plugs or taking poison. Rather, euthanasia to achieve death with dignity is, at best, paradoxical, for "how can I honor myself by making myself nothing?" To die with dignity is to accept the course that we have been given, to die when our times come to die and not when we have decided that our lives should end.

Although a majority of Americans support physician-assisted suicide, public opinion polls during the last decade have shown a decreasing willingness to sanction assisted suicide both morally and legally. In 1990, when Dr. Jack Kevorkian assisted Janet Adkins' suicide, his action was preceded by a century of controversy over the morality of assisted suicide and euthanasia. Those favoring euthanasia have cited patient autonomy and the importance of relieving suffering as reasons for allowing the

---

39. See, e.g., Washington v. Glucksberg, 521 U.S. 702, 790 (1997) (Breyer, J., concurring) (recognizing that there might "roughly" be a "right to die with dignity" encompassing a right to physician-assisted suicide or euthanasia).
41. Evangelium Vitae, supra note 12.
42. Kass, supra note 5, at 251.
43. Id.
44. Nevertheless, measures may be taken to prevent a person's suffering despite the risk that the action may shorten the patient's life. For example, "it is morally legitimate for health care providers to offer adequate analgesia to patients in deep and unremitting pain so that they are spared profound and unremitting pain, even if this would shorten their lives." Robert L. Barry, The Sanctity of Human Life and Its Protection 140 (2002).
45. A 1993 Harris Poll indicated that 73% were in favor of legalizing physician-assisted suicide; a 1997 poll indicated 68% agreed; in 2001 only 65% thought physician-assisted suicide should be legal. Humphrey Taylor, Harris Interactive, 2-1 Majorities Continue to Support Rights to Both Euthanasia and Doctor-Assisted Suicide, at http://www.harrisinteractive.com/harris_poll/index.asp?PID=278 (Jan. 9, 2002) (on file with the Notre Dame Journal of Law, Ethics & Public Policy).
In contrast, opponents of euthanasia have argued that patient suffering can be relieved without resorting to euthanasia; that legalizing euthanasia would undermine patient trust in physicians; that if euthanasia were legalized, the right to die would become a duty to die; that patients could choose euthanasia in cases when the physician was mistaken about their prognoses; and that euthanasia could cause the disabled to be victimized by those who feel burdened by their care.49

The immorality of physician-assisted suicide, however, does not necessarily prevent the act from being illegal. Therefore, the question remains—who should decide whether causing the death of another in this way is illegal? In 1997, the United States Supreme Court held, in two landmark cases, that individuals do not have a Constitutional right to physician-assisted suicide.50 In his opinion in Glucksberg, Chief Justice Renquist wrote, “Throughout the nation, Americans are engaged in an earnest and profound debate about the morality, legality and practicality of physician-assisted suicide. Our holding permits this debate to continue, as it should in a democratic society.”51 Reflecting the existence of the ongoing debate regarding physician-assisted suicide, one state—Oregon—has differed from all others and passed legislation permitting the act.52 In his article, Physician-Assisted Suicide and Federalism, Brian Bix acknowledges states’ rights to decide whether physician-assisted suicide will be permissible in their respective states.53 Professor Bix finds that the federal government has little power to limit states’ abilities to legalize physician-assisted suicide. Furthermore, Professor Bix notes that while some states might choose to legalize physician-assisted suicide because it reflects the values of the states’ citizens, such allowance is permissible only if the spillover effects of the allowance are minimized. The effect of allowing states to determine their responses to this issue has been that all states, except Oregon, have refrained from legalizing physician-assisted suicide despite the organized effort to legalize it through legislation and the courts.54 Consequently, the practice of physician-

49. See id. at 28–35.
51. Glucksberg, 521 U.S. at 735.
assisted suicide remains, and rightly so, limited by state regulation.

**Conclusion**

Most of the bioethics issues discussed today, and those discussed in this symposium, are not new issues. They are, however, issues that have been, and continue to be, refined through the course of public discussion. As debate continues and technology develops, those who are interested in ethical issues in biotechnology continue to find themselves in new territory. At the beginning of life, difficult issues in bioethics, such as issues in embryonic stem cell research and human cloning, surround the question of when life begins. During a human life, bioethical issues affect how a person is treated medically, as in cases involving informed consent by human research subjects, and extend to how a person is treated by the government, as in the use of genetic profiling to convict criminals. At the end of life, the difficult issues in bioethics, including the regulation of physician-assisted suicide, surround the questions of how a human life should end.

In all phases of human existence, we have a duty to respect the dignity of the human person and to ensure that this dignity is respected by others. Although advances in medical technology can eventually help people to lead longer, and perhaps healthier, lives, these advances should not come at the cost of the lives of others. Nor should advances in medical technology be exercised if such procedures violate the dignity of the person on whom they are exercised. Rather, biotechnology should proceed at a pace that ensures that the inherent dignity of the human person is upheld while allowing science to improve the quality of lives. The moral limits of biological developments addressed in this symposium add important arguments to the public discourse in bioethics—allowing readers to better assess the ethical impacts of advances in biotechnology.

---

55. Finnis, *supra* note 9, at 106.