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Introduction

The social issues related to medical science are often intimate and spark passionate debate. The primary sources contained in *Medicine, Health, and Bioethics* demonstrate the development, diversity, and nexus of science and ethics as embodied in medical advances, social policy, and law. Most importantly, the articles selected show a complex range of views on topics such as abortion, cloning, and stem cell research that are not always easily characterized as “for” or “against.” The intent is not to present the reader with all facets of a topic but rather to provoke critical thinking while providing both a foundation and desire to investigate topics increasingly important in social and political discourse.

The link between science and social issue is well forged. Significant sums of public money go toward biomedical research, and how much is spent on what type of research can engender fractious political and social debate. The fruits of that research bring new temptations and possibilities that beckon some and frighten others.

Since the 1950s, studies of the molecular biology of the gene have provided answers to fundamental questions about the mechanism of inheritance and the relationship between genes and disease. In addition to the articulation of the human genome sequence, the metabolic basis of several hundred inherited disorders is now known and many defective genes resulting in such disorders have already been isolated.

The pace of advance in genetics is daunting, however, and challenges both scientists and non-scientists who must form rational opinions on the social issues related to genetics that seem to arise with equal rapidity. For example, geneticists have developed tools that

allow scientists to recreate steps in the evolution of organisms within a laboratory environment. These tools provide the means to carry out experiments that nature alone is incapable of performing. With the techniques of recombinant DNA technology, geneticists have also learned how to transplant genes from one organism to another, thus reshuffling genetic material in ways never experienced in the evolution of life on Earth. Such genetic advances and other research into developmental biology easily leap from the laboratory into the crucible of public discourse regarding “life as we know it” versus “life as we make it.”

In turn, issues that were once purely social or ethical issues, such as sexuality or alcoholism, are now understood to be aspects of human behavior and personality, at least in some part, influenced by genetics.

Many of the great successes for medical science are also important social milestones for humanity, especially with regard to the prevention and treatment of infectious disease. Throughout history, microorganisms have spread deadly diseases and caused widespread epidemics that threatened and altered human civilization. In the modern era, civic sanitation, water purification, immunization, and antibiotics have dramatically reduced the overall morbidity and the mortality of disease in advanced nations. Yet, much of the world is still ravaged by disease and epidemics, and new threats constantly appear to challenge the most advanced medical and public health systems.

Without question, advances such as the global eradication of smallpox is a profound achievement in human history. Also, an emphasis on wellness and preventative health measures has allowed physicians to fight a two-front war on disease while returning

primary responsibility for health and well-being to the individual.

Regardless, social issues can still arise out of even the most effective and seemingly well-intended of medical advances. For example, although childhood diseases such as measles, mumps, whooping cough, and diphtheria have been effectively controlled by childhood vaccinations, some parents resist or reject vaccinating their own children because they feel that the small personal risk is not mitigated by the larger social benefit of disease control. By opting out of the system by relying on the immunizations of others to reduce the risk of disease, they rely upon the acts of the social group to offer their children personal protection.

The interplay of complex ethical and social considerations is also evident when considering the general rise of infectious diseases that sometimes occurs as an unintended side effect of the otherwise beneficial use of medications. Nearly half the world's population, for example, is infected with the bacterium causing tuberculosis (TB) (although for most people the infection is inactive) yet the organism causing some new cases of TB is evolving toward a greater resistance to the antibiotics that were once effective in treating TB. Such statistics also take on added social dimension when considering that TB disproportionately impacts certain social groups such as the elderly, minorities, and people infected with HIV.

Globalization and the increased contact between societies also raises new biomedical concerns about the potential spread of disease, and sparks social debate

regarding the nature and extent of medical cooperation across a varied political landscape. A shrinking global village, beneficial in many cultural and economic aspects, increases the possibility that the terrible loss of life associated with the plagues of the Middle Ages or with the pandemic influenza outbreak of 1918 and 1919 might once again threaten humanity on a worldwide scale.

Lastly, as if the challenges of nature and disease were not sufficient, the political realities at the dawn of the twenty-first century point toward a probability that, within the first half of the century, biological weapons will surpass nuclear and chemical weapons in terms of potential threat to civilization. In such a world, solutions to scientific and public health challenges will spawn new and urgent debate than will span traditional geographic and political boundaries to become truly global social issues.

Because an understanding of the historical development of medical science and the social issues that arise from its advance is increasingly vital, *Medicine, Health, and Bioethics* takes a sweeping view of events over the last 200 years. The articles presented in this volume are designed to be readable and to instruct, challenge, and excite a range of student and reader interests while, at the same time, providing a solid foundation and reference for more advanced study.

**K. Lee Lerner and Brenda Wilmoth Lerner,
editors**

*London, U.K.
March, 2006*

About the Entry

The primary source is the centerpiece and main focus of each entry in *Medicine, Health, and Bioethics: Essential Primary Sources*. In keeping with the philosophy that much of the benefit from using primary sources derives from the reader's own process of inquiry, the contextual material surrounding each entry provides access and ease of use, as well as giving the reader a springboard for delving into the primary source. Rubrics identify each section and enable the reader to navigate entries with ease.

ENTRY STRUCTURE

- Primary Source/Entry Title, Subtitle, Primary Source Type
- Key Facts—essential information about the primary source, including creator, date, source citation, and notes about the creator.
- Introduction—historical background and contributing factors for the primary source.
- Primary Source—in text, text facsimile, or image format; full or excerpted.
- Significance—importance and impact of the primary source related events.
- Further Resources—books, periodicals, Web sites, and audio and visual material.

NAVIGATING AN ENTRY

Entry elements are numbered and reproduced here, with an explanation of the data contained in these elements explained immediately thereafter according to the corresponding numeral.

Primary Source/Entry Title, Subtitle, Primary Source Type

[1] **Screening Creates Disease Free Baby**

[2] Genetic Selection, Ethical Issues

[3] **News article**

[1] **Primary Source/Entry Title:** The entry title is usually the primary source title. In some cases where long titles must be shortened, or more generalized topic titles are needed for clarity primary source titles are generally depicted as subtitles. Entry titles appear as catchwords at the top outer margin of each page.

[2] **Subtitle:** Some entries contain subtitles.

[3] **Primary Source Type:** The type of primary source is listed just below the title. When assigning source types, great weight was given to how the author of the primary source categorized the source.

Key Facts

[4] **Author:** Anonymous

[5] **Date:** February 22, 2002

[6] **Source:** BBC News. "Screening Creates Disease Free Baby." February 22, 2002. <<http://news.bbc.co.uk/1/hi/health/1842932.stm>> (accessed December 28, 2005).

[7] **About the Organization:** This news article was written by an unattributed author for the British Broadcasting System (BBC), the United Kingdom's public news service. The BBC provides interactive TV channels, radio networks, and an online news site, all providing local and national news and commentary.

[4] **Author, Artist, or Organization:** The name of the author, artist, or organization responsible for the creation of the primary source begins the Key Facts section.

[5] **Date of Origin:** The date of origin of the primary source appears in this field, and may differ from the date of publication in the source citation below it; for example, speeches are often delivered before they are published.

[6] **Source Citation:** The source citation is a full bibliographic citation, giving original publication data as well as reprint and/or online availability.

[7] **About the Author:** A brief bio of the author or originator of the primary source gives birth and death dates and a quick overview of the person's work. This rubric has been customized in some cases. If the primary source written document, the term "author" appears; however, if the primary source is a work of art, the term "artist" is used, showing the person's direct relationship to the primary source. For primary sources created by a group, "organization" may have been used instead of "author." Other terms may also be used to describe the creator or originator of the primary source. If an author is anonymous or unknown, a brief "About the Publication" sketch may appear.

Introduction Essay

[8] INTRODUCTION

Genetics is one of the most rapidly growing specialties in medicine. Since 1980, research in genetics has added immeasurably to the understanding of the etiology of many diseases by identifying biologically important genes and disease-causing mutations. These data have generated large numbers of new clinical diagnostic assays, the majority of which are performed on peripheral blood or bone marrow of children or adults. The information obtained is used to make a specific diagnosis that leads to appropriate treatment for the patient. But when testing is done prenatally, other choices are possible. If the fetus is affected or potentially affected with a debilitating or life-threatening disease, pregnancy termination is an option. Although it is not yet possible to create a "designer" baby (a baby with characters chosen by the parents), it is possible to perform prenatal testing for one or more defined characters. This raises concerns about when, and if, it is appropriate to select or deselect a fetus based on certain "desired" criteria.

[8] **Introduction:** The introduction is a brief essay on the contributing factors and historical context of the primary source. Intended to promote understanding and equip the reader with essential facts to understand the context of the primary source.

To maintain ease of reference to the primary source, spellings of names and places are used in accord with their use in the primary source. According names and places may have different spellings in different articles. Whenever possible, alternative spellings are provided to provide clarity.

PRIMARY SOURCE

[9] A woman has chosen to have a genetically selected baby to ensure it does not develop early onset Alzheimer's disease which runs in the family.

The woman, who is thirty and has not been identified, may be unable to recognize or care for her daughter within ten years.

She and her family carry a mutation which causes the onset of Alzheimer's disease before the age of forty.

However, the child, who is now about eighteen months old, did not inherit the tendency to develop the disease.

Early onset Alzheimer's, a very rare condition, is defined as Alzheimer's—a form of dementia—that strikes before the age of sixty-five.

Researchers at the Reproductive Genetics Institute of Chicago said the baby's birth marked the first time preimplantation genetic diagnosis, as the technique is called, has been used to weed out embryos carrying the defect that causes early onset Alzheimer's.

The little girl is thriving, said Yuri Verlinsky, chief author of the report in this week's *Journal of the American Medical Association*.

Verlinsky said genetic screening has been used more than three thousand times and is often employed to avoid inherited disorders like sickle cell anemia.

His clinic was involved in a case last year where an embryo was chosen to provide stem cells to assist a sibling of the unborn child.

Ethical debate While the child's mother is still healthy, her sister developed early onset Alzheimer's at the age of thirty-eight, her father died at forty-two after suffering psychological and memory problems and one of her brothers began having short-term memory problems at thirty-five.

He said: "I can't speak for the public, but it's a decision of the family and not the public."

In a commentary published in the same journal, Dena Towner and Roberta Springer Loewy of the University of California said the study raised ethical questions.

They said: “Much like her sister, the woman in the report . . . most likely will not be able to care for or even recognize her child in a few years.”

The two doctors said the mother acted responsibly by ensuring that her child will not have to live with the threat of developing early onset Alzheimer’s.

However, they took issue with defining her ethical responsibility “solely in terms of disease prevention” without considering that she may not be able to care for her child.

“The differences between these two interpretations of ethical responsibility are stark, but both rest on assumptions made about reproduction—is it a privilege or it is an unquestionable and inalienable right?” they asked.

[9] Primary Source: The majority of primary sources are reproduced as plain text. The primary source may appear excerpted or in full, and may appear as text, text facsimile (photographic reproduction of the original text), image, or graphic display (such as a table, chart, or graph).

The font and leading of the primary sources are distinct from that of the context—to provide a visual clue to the change, as well as to facilitate ease of reading. As needed, the original formatting of the text is preserved in order to more accurately represent the original (screenplays, for example). In order to respect the integrity of the primary sources, content some readers may consider sensitive (for example, the use of slang, ethnic or racial slurs, etc.) is retained when deemed to be integral to understanding the source and the context of its creation.

Primary source images (whether photographs, text facsimiles, or graphic displays) are bordered with a distinctive double rule. Images have brief captions.

The term “narrative break” appears where there is a significant amount of elided (omitted) material with the text provided (for example, excerpts from a work’s first and fifth chapters, selections from a journal article abstract and summary, or dialogue from two acts of a play).

Significance Essay

[10] SIGNIFICANCE

Ethical issues arise in all areas of medicine, but special attention focuses on genetics, probably because this field explores the transmission of genes within families. In particular, issues associated with prenatal diagnosis seem to be problematic.

Prenatal genetic diagnosis can identify a large number of diseases by evaluation of placental and/or fetal cells. The studies are usually performed between ten and twenty weeks gestation, and the type of study used is based on the parents’ age, medical history, and ethnicity. When a known disease or major malformation is identified, the parents have the option of terminating the pregnancy. For a more limited group of diseases, preimplantation genetic diagnosis can be performed. With this technology, eggs removed from the mother are fertilized *in vitro* by sperm from the father, and the resultant zygotes are cultured to the eight to sixteen cell stage. One cell from each is removed and tested, and only “normal” embryos are implanted in the mother’s uterus. This technology eliminates the need for termination of an ongoing pregnancy and, thus, is more acceptable to many individuals. Either technique has the effect of selecting a fetus based on specific criteria.

Under what circumstances is this type of selection acceptable? Geneticists use the technology to obtain relevant clinical information on a patient. If the data shows the fetus has a lethal or severely debilitating disorder, termination of pregnancy is considered an acceptable option. Therefore, parents may be offered a choice between continuing or terminating a pregnancy with a confirmed diagnosis of terminal conditions such as anencephaly or trisomy thirteen, or an incapacitating disease such as Tay Sachs, sickle cell disease, or Duchenne muscular dystrophy.

A different dilemma is posed by diseases such as Alzheimer’s disease, Huntington’s disease, and breast cancer. These are classified as late onset diseases since affected individuals show no signs or symptoms until they are adults. Genetics professionals discourage the use of prenatal diagnosis to select against embryos or fetuses at risk for such disorders since most affected individuals can live a productive life before the disease strikes. However, these diseases are usually progressive, and watching a loved one slowly deteriorate can be devastating for families. Thus, some will chose prenatal diagnosis rather than bringing a child into the world knowing that he or she would have that fate.

An area of genetic selection that is considered unethical by genetics professionals is elective termination of a pregnancy solely because the sex of the fetus is not what the parents desire. This abuse of the system can occur since most prenatal testing provides the sex of the fetus as a courtesy to the parents.

Decisions on what testing to request and how to use the results are often difficult. Geneticists provide counseling, but the final choice rests with the patient. It is critical that all relevant factors be considered before a

decision is made. For example, in the case cited above, a question was raised if the mother acted ethically in having a child whom she could take care of for only a few years. But, this should not be an issue if the woman has a partner or family member who participated in the decision to have the child and who will be able to raise the child after the mother becomes incapacitated.

As of January 2006, there are few rules governing genetic selection via prenatal diagnosis, creating a challenge for potential parents and geneticists alike.

[10] **Significance:** The significance discusses the importance and impact of the primary source and the event it describes.

Further Resources

Books

Magill, Gerard, ed. *Genetics and Ethics: An Interdisciplinary Study*. New York: Fordham University Press, 2003.

Verlinsky, Yury, and Anver Kuliev. *Practical Preimplantation Genetic Diagnosis*. New York: Springer, 2005.

Web sites

ADEAR. *Alzheimer's Disease Education and Referral Center. National Institute on Aging*. <<http://www.alzheimers.org/generalinfo.htm>> (accessed January 23, 2006).

Genetics and Public Policy Center. <<http://dnapolicy.org/index.jhtml.html>> (accessed January 23, 2006).

Human Genetics in the Public Interest. The Center for Genetics and Society. <<http://www.genetics-and-society.org>> (accessed January 26, 2006).

PGD: *Preimplantation Genetic Diagnosis*. "Discussion by the Genetics and Public Policy Center." <http://dnapolicy.org/downloads/pdfs/policy_pgd.pdf> (accessed January 23, 2006).

[11] **Further Resources:** A brief list of resources categorized as Books, Periodicals, Web sites, and Audio and Visual Media provides a stepping stone to further study.

SECONDARY SOURCE CITATION FORMATS (HOW TO CITE ARTICLES AND SOURCES)

Alternative forms of citations exist and examples of how to cite articles from this book are provided below:

APA Style

Books: Kübler-Ross, Elisabeth. (1969) *On Death and Dying*. New York: Macmillan. Excerpted in K. Lee Lerner and Brenda Wilmoth Lerner, eds. (2006) *Medicine, Health, and Bioethics: Essential Primary Sources*, Farmington Hills, Mich.: Thomson Gale.

Periodicals: Venter, J. Craig, et al. (2001, February 16). "The Sequence of the Human Genome." *Science*, vol. 291, no. 5507, pp. 1304–51. Excerpted in K.

Lee Lerner and Brenda Wilmoth Lerner, eds. (2006) *Medicine, Health, and Bioethics: Essential Primary Sources*, Farmington Hills, Mich.: Thomson Gale.

Web sites: Johns Hopkins Hospital and Health System. "Patient Rights and Responsibilities." Retrieved January 14, 2006 from http://www.hopkinsmedicine.org/patients/JHH/patient_rights.html. Excerpted in K. Lee Lerner and Brenda Wilmoth Lerner, eds. (2006) *Medicine, Health, and Bioethics: Essential Primary Sources*, Farmington Hills, Mich.: Thomson Gale.

Chicago Style

Books: Kübler-Ross, Elisabeth. *On Death and Dying*. New York: Macmillan, 1969. Excerpted in K. Lee Lerner and Brenda Wilmoth Lerner, eds. *Medicine, Health, and Bioethics: Essential Primary Sources*, Farmington Hills, Mich.: Thomson Gale, 2006.

Periodicals: Venter, J. Craig, et al. "The Sequence of the Human Genome." *Science* (2001): 291, 5507, 1304–1351. Excerpted in K. Lee Lerner and Brenda Wilmoth Lerner, eds. *Medicine, Health, and Bioethics: Essential Primary Sources*, Farmington Hills, Mich.: Thomson Gale, 2006.

Web sites: *Johns Hopkins Hospital and Health System*. "Patient Rights and Responsibilities." <http://www.hopkinsmedicine.org/patients/JHH/patient_rights.html> (accessed January 14, 2006). Excerpted in K. Lee Lerner and Brenda Wilmoth Lerner, eds. *Medicine, Health, and Bioethics: Essential Primary Sources*, Farmington Hills, Mich.: Thomson Gale, 2006.

MLA Style

Books: Kübler-Ross, Elisabeth. *On Death and Dying*. New York: Macmillan, 1969. Excerpted in K. Lee Lerner and Brenda Wilmoth Lerner, eds. *Medicine, Health, and Bioethics: Essential Primary Sources*, Farmington Hills, Mich.: Thomson Gale, 2006.

Periodicals: Venter, J. Craig, et al. "The Sequence of the Human Genome." *Science*, 291 (16 February 2001): 5507, 1304–51. Excerpted in K. Lee Lerner and Brenda Wilmoth Lerner, eds. *Medicine, Health, and Bioethics: Essential Primary Sources*, Farmington Hills, Mich.: Thomson Gale, 2006.

Web sites: "Patient's Rights and Responsibilities." Johns Hopkins Hospital and Health System. 14 January 2006. <http://www.hopkinsmedicine.org/patients/JHH/patient_rights.html> Excerpted in K. Lee Lerner and Brenda Wilmoth Lerner, eds.

Using Primary Sources

The definition of what constitutes a primary source is often the subject of scholarly debate and interpretation. Although primary sources come from a wide spectrum of resources, they are united by the fact that they individually provide insight into the historical context and environment during which they were produced. Primary sources include materials such as newspaper articles, press dispatches, autobiographies, essays, letters, diaries, speeches, song lyrics, posters, works of art—and in the twenty-first century, Web logs—that offer direct, first-hand insight or witness to events of their day.

Categories of primary sources include:

- Documents containing firsthand accounts of historic events by witnesses and participants. This category includes diary or journal entries, letters, email, newspaper articles, interviews, memoirs, and testimony in legal proceedings.
- Documents or works representing the official views of government leaders. These include primary sources such as policy statements, speeches, interviews, press releases, government reports, and legislation.
- Works of art, including (but certainly not limited to) photographs, poems, and songs, including advertisements and reviews of those works that help establish an understanding of the cultural environment with regard to attitudes and perceptions of events.
- Secondary sources. In some cases, secondary sources or tertiary sources may be treated as primary sources. For example, the article “Implementation of the Program” discusses the evolution of the Red Cross blood donation program across a time span of

more than twenty years, from World War II (1938–1945) through the Vietnam War in 1964. The primary source includes recollections of communications exchanged between the U.S. Army and the Red Cross about the need for obtaining large quantities of human blood plasma for use in treating injured soldiers. Ordinarily, an historical retrospective such as this excerpt, published two decades after the initial event, might not be considered a primary source. The fact that the retrospective was written by the general responsible for the Army blood program during World War II, a participant in the initial effort, makes it an illuminating primary source.

ANALYSIS OF PRIMARY SOURCES

The material collected in this volume is not intended to provide a comprehensive overview of a topic or event. Rather, the primary sources are intended to generate interest and lay a foundation for further inquiry and study.

In order to properly analyze a primary source, readers should remain skeptical and develop probing questions about the source. As in reading a chemistry or algebra textbook, historical documents require readers to analyze them carefully and extract specific information. However, readers must also read “beyond the text” to garner larger clues about the social impact of the primary source.

In addition to providing information about their topics, primary sources may also supply a wealth of insight into their creator’s viewpoint. For example, when reading a news article about an outbreak of disease, consider whether the reporter’s words also

indicate something about his or her origin, bias (an irrational disposition in favor of someone or something), prejudices (an irrational disposition against someone or something), or intended audience.

Students should remember that primary sources often contain information later proven to be false, or contain viewpoints and terms unacceptable to future generations. It is important to view the primary source within the historical and social context existing at its creation. If for example, a newspaper article is written within hours or days of an event, later developments may reveal some assertions in the original article as false or misleading.

TEST NEW CONCLUSIONS AND IDEAS

Whatever opinion or working hypothesis the reader forms, it is critical that they then test that hypothesis against other facts and sources related to the incident. For example, it might be wrong to conclude that factual mistakes are deliberate unless evidence can be produced of a pattern and practice of such mistakes with an intent to promote a false idea.

The difference between sound reasoning and posterous conspiracy theories (or the birth of urban legends) lies in the willingness to test new ideas against other sources, rather than rest on one piece of evidence such as a single primary source that may contain errors. Sound reasoning requires that arguments and assertions guard against argument fallacies that utilize the following:

- false dilemmas (only two choices are given when in fact there are three or more options)
- arguments from ignorance (*argumentum ad ignorantiam*; because something is not known to be true, it is assumed to be false)

- possibilist fallacies (a favorite among conspiracy theorists who attempt to demonstrate that a factual statement is true or false by establishing the possibility of its truth or falsity. An argument where “it could be” is usually followed by an unearned “therefore, it is.”)
- slippery slope arguments or fallacies (a series of increasingly dramatic consequences is drawn from an initial fact or idea)
- begging the question (the truth of the conclusion is assumed by the premises)
- straw man arguments (the arguer mischaracterizes an argument or theory and then attacks the merits of their own false representations)
- appeals to pity or force (the argument attempts to persuade people to agree by sympathy or force)
- prejudicial language (values or moral goodness good and bad are attached to certain arguments or facts)
- personal attacks (*ad hominem*; an attack on a person’s character or circumstances)
- anecdotal or testimonial evidence (stories that are unsupported by impartial or unreproducible data)
- *post hoc* (after the fact) fallacies (because one thing follows another, it is held to cause the other)
- the fallacy of the appeal to authority (the argument rests upon the credentials of a person, not the evidence)

Despite the fact that some primary sources can contain false information or lead readers to false conclusions based on the “facts” presented, they remain an invaluable resource regarding past events. Primary sources allow readers and researchers to come as close as possible to understanding the perceptions and context of events and, thus, to more fully appreciate how and why misconceptions occur.