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CASE STUDIES IN BIOETHICS can enrich high school classes across the curriculum. A story like the one presented here about Baby K cannot help but fire the imaginations of students. Whose right is it to make decisions for a helpless infant? What does it mean to be born without a brain? Should medical considerations trump legal, religious, ethical, financial, and cultural ones in a situation like this? With the wisdom of hindsight, what ought to have been done for Baby K?

"This case is one of six in a curriculum unit called "Babies" that was developed for high schools at the Kennedy Institute of Ethics at Georgetown University. The full curriculum includes four units, each using a number of cases to illustrate a single bioethics theme. Unit 1 features cases about babies born at risk or injured early in life. Unit 2 addresses organ trans-

plantation. Unit 3 focusses on research involving human subjects. Unit 4 is about eugenics.

Each case is true; each raises tough questions; few, if any, have single "right" answers. Through analyzing the cases, identifying the ethical conundrums they present, and clarifying what aspects of each case are medical, legal, personal, and cultural, students can gain an appreciation for the complexity of the decision making involved in them.

Bioethical dilemmas, once rare, are now commonplace, in part because new medical technologies have outpaced our ability to understand their implications. For example, American society has yet to develop policies and, where appropriate, laws to deal with the consequences of "halfway technologies"—those that keep people alive but not sentient. Every individual bumps up against bioethical dilemmas sooner or later. Our motivation for developing these units was to give students

experience in thinking about complex questions and developing strategies for coping with them both intellectually and emotionally.

In our experience, most students come to the discussions of these cases with pre-formed opinions about what ought to happen. In presenting these cases, teachers need to emphasize the importance of keeping discourse civil, listening respectfully to the opinions of others, weighing competing factors, and entertaining diverse and divergent perspectives.

The story of Baby K, like the other stories in the three units, raises fascinating and troubling questions. Some teachers have found that the richest discussions arise when they teach collaboratively with colleagues from other departments. Such cross-disciplinary discussions show students that, although the school day may be compartmentalized, problems in life are not. While the questions raised in difference courses provide varying springboards for discussion, we find

Bioethics Cases and Issues: Enrichment for Social Science, Humanities, and Science Courses

that students eventually get around to discussing the same wide-ranging issues.

In economics classes, teachers have embarked on classroom discussions about Baby K by asking whether allocating half a million dollars on a futile medical treatment for one baby who was "born dying" is an appropriate use of the limited resources available for health care. What, for example, did this large expenditure of money do to the premiums of other members of Baby K's HMO and to the medical services that were available to them? Or, backing away from financial considerations, at what point is it even appropriate to make medical decisions on the basis of dollars?

The case gives U.S. history students an excellent opportunity to examine the bearing of the First and Fourteenth Amendments on contemporary medical ethics. Did the courts fail to uphold the wall of separation between church and state when they agreed to support Baby K with federal money?

Ethics teachers have triggered their discussions by considering whether Baby K's dignity was compromised by allowing her to be a "slave to technology." Students have consid-



LINK

The website of the High School Bioethics Curriculum Project can be found at bioethics.georgetown.edu/hsbioethics

The Story of Baby K

Baby K was born at Fairfax Hospital in Northern Virginia on October 13, 1992. Although her face was beautiful, the top of her head was flat. She had no brain.

The baby's mother knew from the 16th week of her pregnancy that Baby K's brain had not developed. Baby K had no cerebrum and no cerebellum, but she did have a normal brain stem. The mother was told that babies with "anencephaly"—from the Greek words for negative (*an*) and brain (*enkephalos*)—cannot see, hear, or feel anything no matter how long they live. Baby K would have no thoughts, and she would never achieve "personhood." If she were born alive, her brain stem would prompt her heart to beat and her lungs to pump air in and out of her body.

Baby K, like other babies with anencephaly, would be "born dying" but would not be technically brain dead. Anencephaly is one condition, perhaps the only one, that all doctors agree is futile to treat. The general consensus among medical, legal, and other experts is that heroic measures should not be used to keep such babies alive.

ered the concept of "personhood" and what actually would have been the fairest treatment for the baby. Some of the nurses who cared for Baby K in the NICU felt that she was objectified and that a more humane reaction to her plight would have been to let her die. Was the professional autonomy of the nurses and the doctors violated by interventions by the courts?

In anthropology and psychology classes, the focus may initially be on how different cultures and different individuals react to and handle similar situations. The story of another anencephalic baby, Baby Theresa, has figured in some class discussions. Baby Theresa was also born in 1992; her parents wanted her to be declared dead, because they desperately wanted to donate her tiny organs to a needy baby—a baby born with a bad heart or failing kidneys or lungs. They felt that, if they could save another baby's life, the pregnancy and Baby Theresa's short life would not have been for naught. Baby Theresa's parents fought in the courts for the right to have their born-dying baby declared dead while her heart and lungs were still pumping blood and oxygen through her body. Their case went all the way to the Florida Supreme Court, but Baby Theresa died before any decision was reached. The day Baby Theresa died, her parents appeared on the Phil Donahue Show to talk about the need to change the law. Their use of publicity raises the interesting issue of the role of the media in medical decision making, especially in circumstances where the coverage is sensationalistic.

A completely different set of questions can animate students in biology classes. What errors in fetal development result in anencephaly? What are the medical criteria for death? What are the technical challenges to organ transplantation? What distinguishes killing and letting die? What benefits and problems do prenatal tests and other new technologies create?

But Baby K's mother balked. She wanted to keep her baby alive no matter what the cost. She was motivated by a strong and sincerely held religious belief that "all life is precious" and that God, rather than herself or the doctors or the law, should decide how long her baby would live.

Baby K held on (most babies with anencephaly die within the first few days of their lives) and finally left the hospital when she was seven weeks old. No neonatal intensive care unit (NICU) would accept her, so she went to a nursing home. She lived for 2.5 years, attached to a respirator the whole time. Every time Baby K stopped breathing, her mother would rush her back to Fairfax Hospital to be resuscitated. The hospital asked the courts to allow them to "pull the plug" of the respirator and let the baby die, but both the local and the appeals courts said "no." Baby K's medical bills ran up to \$500,000; her death was attributed to a heart attack.

In all classes, students learn about the power and deceptiveness of language. For example, do euphemisms like "harvesting organs" and "donations" mask the fact that one person is dying to save another? Does replacing "patient" with "client" or "customer" further erode relationships that once were based on caring? That is, as a society, have we gained or lost more by converting the medical marketplace to one that resembles every other marketplace? More generally, students examine their own use of language in preparing to argue their positions persuasively.

As we try to show students how to evaluate the content and the structure of their ideas, how to work together toward solving problems, and how to think both broadly and deeply, we hope to help them along the path to becoming thoughtful individuals, responsible citizens, and caring members of society. ■

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The High School Bioethics Curriculum Project started in 1997. Each summer, teachers from the social sciences, the sciences, and the humanities come to the Kennedy Institute of Ethics (on the Georgetown University campus in Washington, D.C.) for a three-day workshop to learn about the curriculum units, study the pillars of bioethics, and explore and develop classroom activities to accompany the case studies. All expense and a small honorarium are paid by the Kennedy Institute of Ethics. If you are interested in attending a summer workshop or would like more information about the project, please contact Ruth Guyer at (telephone) 202-687-8099, (fax) 202-687-8089, (e-mail) HSBioethics@gunet.georgetown.edu



Classroom Activity for U.S. History

The Aim/Objective

Students will understand how the religion clause of the First Amendment and the citizenship, equal protection, and personal liberty clauses of the Fourteenth Amendment of the U.S. Constitution apply to contemporary medical ethics.

The Activity

Foster classroom discussion with the following questions:

- 1 1 Is the term “citizen” synonymous with “person?” What are the characteristics of a citizen? Does Baby K have these characteristics?
- 1 1 The Fourteenth Amendment guarantees all citizens equal protection of the law. In the United States, what limits, if any, have been placed on that protection? Must/should social worth be considered when the Amendment is applied? How does our society determine social worth?
- 1 1 Why did the courts refuse to grant Baby Theresa the status of a “nonperson” so that she could be declared dead? Assess the legal reasoning of the courts, the moral issues associated with the cases, and the possible benefits that could/might have been gained by recipients of the organs. Which position has the most weight? Explain.

- 1 1 Consider the “free exercise” clause of the First Amendment. To what extent, if any, should society protect the religious rights of individuals? Is spending \$500,000 for one child who is “born dying” appropriate in view of the needs of other children whose lives have potential?

The Assessment

- 1 1 Investigate/research the Americans with Disabilities Act (ADA). What was its original intent? What groups lobbied for its passage? Would Baby K and Baby Theresa be protected by the ADA? Explain why they would/would not be covered.
- 1 1 The Fourteenth Amendment guarantees the equal protection of the law to all citizens. People with handicapping conditions have gone to court to retain their place in society when faced with discrimination. What constitutes a handicapping condition? What about characteristics like obesity and height? Analyze litigation of the past five years and propose a thorough, thoughtful definition of disability. Explain how and why the Fourteenth Amendment should be used to protect people whom you have identified in terms of discrimination in employment, access to public accommodation, etc.

Notes from the Classroom: U. S. History

The stories of Baby K and Baby Theresa have fostered the most passionate discussions I’ve witnessed in almost 30 years of teaching. They force students to think about what constitutes the essence of humanity. The most telling moment came when several students were focused on the expenditure of money for Baby K. The students began to talk about who “deserves” money, and they went further into the issue of “who pays.” One student, Nelly, then tentatively raised her hand and, choking back tears, said, “I want to speak.” She told the class that, when her mother was pregnant with her, the doctor suggested terminating the pregnancy because of “problems.” But, Nelly said, her mother loved her even before she saw her. At birth, Nelly was partially paralyzed. Her family was poor, so they had to resort to public assistance. As the years went on, her health improved. By 9th grade, she could walk with a marked limp and use one of her hands. She was in the lowest academic track. By 10th grade, she moved up one level academically. In 11th grade, she was in a regents-level program. And the group that she told her story to were in an honors-level class.

Most of us were near tears. Nelly’s account of her story illustrated far more meaningfully than could most teachers the flaws in policies that, while ostensibly preventing suffering, instead create an ethical “slippery slope.”

—M. L. D.

Classroom Activity: 10th and 11th Grade Ethics

The Aim/Objective

Students will

- ↳ gain exposure to a range of viewpoints
- ↳ gain awareness of the process of decision making and appreciate the difficulty in making decisions related to bioethics
- ↳ learn about biological, medical, legal, and moral factors that affected the Baby K case
- ↳ understand the challenges that anencephaly poses to the concepts of “personhood” and human dignity
- ↳ use the videotape of the presentation as a teaching tool for related classes

The Activity

Preparation

Students discuss and identify the stakeholders in the Baby K case. Students are then assigned various roles, including family members, medical staff a bioethicist, a Supreme Court Judge, a journalist, and an onlooker. One student will be the moderator. Each student researches the issues raised by the case in the context of her/his assigned position. Each prepares a position paper with “talking points” and an annotated bibliography. The moderator prepares a summary of the case and a series of questions to facilitate the discussion; these questions cover opin-

ions and ideas of all those involved, To locate resource materials, students work with the school librarian and with librarians at the National Reference Center for Bioethics Literature (1-800-med-ethx).

Classroom Presentation

Students arrange themselves around a seminar table. The moderator presents an overview of the case. The moderator then describes the format of the discussion, giving each stakeholder 2-3 minutes to outline her/his position. When all have spoken once, the question period begins. The moderator and others on the panel can ask questions. The moderator makes sure that all players are questioned about the same amount These questions allow stakeholders to elaborate on their positions and to incorporate information and ideas from others into their presentations.

The Assessment

As a follow-up activity, students write a reflection paper on the position of one other stakeholder whose perspective, they felt, added to their overall understanding of the case. The reflection and position papers are collected.

Notes from the Classroom: 10th and 11th Grade Ethics

“This case makes me uneasy; there are too many murky moral issues to sort through,” said a student in my Ethics class on reading the story of Baby K. Another student concurred: “My head tells me one thing but my heart says another. Why does this have to be so tough?”

The toughness is exactly why the Baby K case is such an important component of my Ethics class. I introduced the case when the students needed an example of the complexities involved in an ethical dilemma. The class had been focusing on the foundations of moral philosophy more abstractly, through theory, history, and values. The time had come to move our study into a contemporary and personal context.

I asked the students to come up with a process for working through ethical aspects of the Baby K case. They decided that they needed to consider human dignity, family rights, cultural values systems, religious freedom, the legal system, physician autonomy, technological advances, and resource allocation. When they tried to prioritize or at least consider all these elements, there was intense lobbying by various individuals. Students quickly discovered that their own experiences influenced how they viewed the case. One student, whose father is a physician, argued that the doctor should make all the decisions. Another student, who had lost a sibling, thought it was a family issue. And a student who thought “we spend too much money on futile medical cases” spoke out for resource allocation. Quickly, many in the class rallied around the latter position. This led into a discussion of HMOs and the class was headed toward resolving the issue on the basis of dollars when one girl spoke up: Wait a minute,” she said. What is the bottom line here—a human life or money? How much is a human life worth?” Everyone’s energy then refocused onto the mother and the child.

When the bell rang, I was surrounded by students telling me not to plan anything for the next day. We haven’t even begun to discuss this!” they said.

I wish every subject generated so much enthusiasm.

—L. A.

Classroom Activity for Anatomy and Physiology

The Aims/Objectives

Students will

- ↳ ↳ understand normal brain development
- ↳ ↳ understand how anencephaly is diagnosed and treated
- ↳ ↳ learn about the characteristics of and prognosis for anencephalic infants
- ↳ ↳ evaluate the current definition of brain death
- ↳ ↳ examine the cost of extended newborn care and the role of medical insurers
- ↳ ↳ explore the physiological and legal suitability of organ donation from anencephalic infants

The Activity

Students work in groups of four or five. Each group is assigned a topic from the list below. Students use class time to collect information from texts and online sources.

Group 1: Legal Research

- ↳ ↳ Patients' rights (treatment, care, insurance)
- ↳ ↳ Parents' rights
- ↳ ↳ Laws addressing the treatment of anencephalics
- ↳ ↳ Amendments to the Constitution that apply to the case

Group 2: Anatomy and Physiology

- ↳ ↳ Normal brain development
- ↳ ↳ Characteristics of anencephaly
- ↳ ↳ Responses of healthy newborns
- ↳ ↳ Responses of anencephalics
- ↳ ↳ Definition of the "quality of life"

Group 3: Organ Transplantation

- ↳ ↳ Laws affecting transplants
- ↳ ↳ Organs from anencephalic donors
- ↳ ↳ Who decides if an infant's organs can be used
- ↳ ↳ Transplantation Act of 1984

Group 4: Insurance Issues

- ↳ ↳ Cost of care for a normal newborn
- ↳ ↳ Cost for a typical stay in a NICU
- ↳ ↳ Extended coverage for newborns
- ↳ ↳ Options for babies who can't go home
- ↳ ↳ Insurance plans and what they offer
- ↳ ↳ Allocation of health care dollars

Group 5: Other Issues

- ↳ ↳ Definitions of death
- ↳ ↳ Understanding "living" in relation to anencephaly
- ↳ ↳ Diagnosis of prenatal defects
- ↳ ↳ Prognosis for anencephalic infants
- ↳ ↳ Societal and religious values that pertain to the Baby K case

The Assessment

Each group analyzes and synthesizes its information. Groups describe their findings and conclusions in writing. All papers are then distributed to everyone in the class. Each group also makes an oral presentation with visuals. After all materials have been studied by all students, the class discusses the case in an open-class format.

Notes from the Classroom: Anatomy and Physiology

Biology classes provide a rich but largely untapped resource for discussions of bioethics. Genetics, the environment, and reproduction naturally generate controversial discussions of ethics, morals, and choice. Many science teachers hesitate to embark on these issues, fearful of encroaching on the foreign territory of ethics.

I've found that bioethics case studies are comfortable and safe resources for both teachers and students. In my Anatomy and Physiology class and in my course on Health and Disease, the Baby K case brought students to a sophisticated understanding of ethical and emotional factors that affect biomedicine. Students fired off a range of questions about anencephaly: What is it? Do the babies feel? Can they smile or interact? Do people name them? Do they name the ones who are stillborn? What sorts of burial ceremonies do the families have for these babies! How do they cope with this tragedy? What do these babies look like? How does it happen? Other discussions center around personhood, parental rights, insurance coverage, organ donation, and the definition of brain death.

In my experience, case studies convert students from being passive learners to being active ones.

—L. S.