



Using a Popular Science Nonfiction Book to Introduce Biomedical Research Ethics in a Biology Majors Course †

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Although bioethics is an important topic in modern society, it is not a required part of the curriculum for many biology degree programs in the United States. Students in our program are exposed to biologically relevant ethical issues informally in many classes, but we do not have a requirement for a separate bioethics course. *The Immortal Life of Henrietta Lacks* is a recent nonfiction book that describes the life of the woman whose cervical cancer biopsy gave rise to the HeLa cell line, as well as discussing relevant medical, societal, and ethical issues surrounding human tissue use for research. Weekly reading assignments from the book with discussion questions and a final paper were used to engage students in learning about the ethics of human subjects and human tissues research. Students were surveyed for qualitative feedback on the usefulness of including this book as part of the course. This book has been a successful platform for increasing student knowledge and interest in ethics related to biomedical and biological research.

INTRODUCTION

A wide variety of ethical issues in the biological sciences are continuously debated by both scientists and the public. Headlines regarding vaccines, evolution, genetically modified organisms, and many other related topics are frequently found in the media. This underscores the importance of exposing undergraduate science students to bioethics, since these students will become either professionals contributing to the headlines or members of the public responding to them. However, bioethics is not a required course in the biology curriculum for many colleges and universities in the United States, although several publications in the past decade support the importance of including ethics in undergraduate biology education in some form (1, 2). At Missouri Western State University, there is no formal requirement for students to take an ethics course, although they may opt to take a general studies ethics course as part of their general studies requirements. However, our students are informally exposed to many relevant issues in bioethics in various courses as well as independent research experiences and internships.

One topic of particular relevance to the students in our health science concentration, most of whom are interested in professional or graduate school programs and careers involving patient care or health-related research,

is the ethical guidelines for the use of human subjects in research. The goal of this project was to guide students through an overview of major events that led to the current United States federal guidelines for human subjects research using a popular nonfiction book, *The Immortal Life of Henrietta Lacks* (4). This book describes the woman whose cervical tumor biopsy gave rise to the widely used HeLa cell line and the lives of her family after her death. It also discusses several infamous events that led to the creation of guidelines for human subjects research. Additionally, it introduces the question of what rights a patient has to his or her cells and DNA once removed from his or her body. These topics can all be covered in a more traditional lecture-style format or a stand-alone assignment, but the aim of this project was to use the human backstory to pique the students' interest and increase their investment in learning about these topics.

PROCEDURE

Students were required to purchase the book as part of the requirements for an upper division Molecular Basis of Disease course, which is an elective in our health science concentration. They were given eight weekly reading assignments of 30 to 40 pages and assigned a question related to the reading, with a 150- to 250- minimum word count requirement (Appendix 1). Questions were about either a relevant science topic or the student's reactions to events described within the assigned reading. Responses to these questions were submitted via the online course management system and graded based on accuracy, length, and any writing issues such as grammatical errors or lack of clarity. In certain assignments, questions also required students to comment

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†Supplemental materials available at <http://jmbe.asm.org>

briefly on ethical issues relevant to the topics covered in that section of the book. In many chapters, Ms. Skloot includes a description of the prevalent medical practices and gives the historical context for these practices (for an example, see Chapter 3, p. 29, beginning with: “Like many doctors of his era, TeLinde often used patients from the public wards for research...”) (4). These descriptions are usually brief, but serve to introduce students to the concept that determining what is ethical can vary depending on cultural views at the time. In addition, the book frequently mentions patient consent, a cornerstone of ethical treatment of human subjects in research, and notes that it was not commonly viewed as necessary in the 1950s and 1960s, when many of the events in the book take place.

After the book was completed, students were assigned a short follow-up writing assignment that required them to summarize the current United States guidelines in place for research on human subjects and human tissues, as well as the major world events that led to the development of these guidelines. Students were expected to identify major events referred to in the Skloot book, such as the Nuremberg trials and Tuskegee syphilis study, but also to other events described in more detail by many readily available and reputable sources such as the Belmont Report (3). Students were also directed specifically to the afterword of the Skloot book, which includes an excellent summary of the ethical issues and status of laws related to human tissues research. The combined total of the weekly assignments plus the short paper was worth 50 points out of 800 to 900 points available for the course. Students in three different semester offerings of Molecular Basis of Disease participated in this assignment. In the most recent semester, students were surveyed at the end of the course for their opinions on the usefulness and value of reading this book as part of the class.

This study was approved by the Missouri Western State University Institutional Research Board (protocol #783). A total of 19 students completed the survey out of 20 enrolled in the course.

CONCLUSION

Student responses to weekly reading assignment questions varied greatly in depth and thoughtfulness, as expected. One unanticipated but positive outcome was that this type of assignment, which is atypical in our department’s upper division biology majors courses, gave some quiet students an opportunity to show their writing ability and express surprisingly thoughtful answers. Both informal feedback from students over three semesters and formal survey-based feedback from students in the most recent semester offering of this course were quite positive overall. As shown in Table I, students felt that the book was an enjoyable read, and that they learned new information about ethics and the history of science from reading it. Open-ended comments included generally positive statements such as “It was not hard to stay focused, and since it was such a good read it didn’t feel like homework” and “I thought it was very insightful because I never put much thought into the ethics of human tissue usage.”

In summary, this book has been a useful and well-liked assignment in a rigorous, upper-division Biology majors course, and it provides an avenue for discussion of ethics related to this course topic. Using this or other relevant popular nonfiction books may be a successful way to add an ethics component to a content-based biology course.

SUPPLEMENTAL MATERIALS

Appendix I: Reading assignment questions for *The Immortal Life of Henrietta Lacks*

TABLE I.
Student survey data.

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
I had extensive knowledge of the ethics guidelines for human subjects and human tissues research before taking this class.	16%	5%	21%	47%	11%
I enjoyed reading <i>The Immortal Life of Henrietta Lacks</i> .	53%	42%	5%	0%	0%
The author of <i>The Immortal Life of Henrietta Lacks</i> made the history of cell culture and the related science interesting.	58%	42%	0%	0%	0%
I learned a lot of new information about the ethics guidelines for human subjects and human tissues research from reading this book and completing the assignments.	58%	32%	11%	0%	0%
Reading this book made me appreciate the human side of science research more than I had before.	42%	53%	5%	0%	0%
Reading <i>The Immortal Life of Henrietta Lacks</i> was not a good use of my time for this class.	0%	0%	11%	53%	37%

Students from the spring 2014 course offering were surveyed at the end of the semester for their subjective responses to the usefulness of reading this book and completing the assignments using a Likert scale-based instrument ($n = 19$).

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