

Using *Bad Blood* as a Teaching Tool in a Pharmacy Ethics Class

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ABSTRACT. This paper describes the experience of two instructors who used James Jone's *Bad Blood: The Tuskegee Syphilis Experiment* as a required textbook in a pharmacy law and ethics class. All students were required to read the book and write a four- to six-page reaction paper that discussed what ethical principles were violated in the experiment and how reading the book would influence their practice of pharmacy. The paper includes student reflections on how the principles of beneficence, nonmaleficence, veracity, fidelity, and justice were broken in the experiment. Over 85% of the students stated that reading the book would influence their future practice of pharmacy. [Article copies available for a fee from The Haworth Document Delivery Service: 1-800-342-9678. E-mail address: getinfo@haworthpressinc.com]

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BACKGROUND

The purpose of this paper is to discuss the importance of using James Jones's *Bad Blood: The Tuskegee Syphilis Experiment* when teaching ethics

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to pharmacy students and other health-care professionals (1). The book provides students with a real-world example of how ethical principles can be violated by health-care professionals when providing patient care. It also illustrates the importance of health-care professionals understanding and respecting a patient's ethnic and social background when providing patient care.

Pharmacy ethics did not become an essential element of many pharmacy schools' curricula until the 1990s. Several national and state pharmaceutical organizations have had codes of ethics since the 1800s, but pharmacy education placed little emphasis on teaching ethics in the early twentieth century. In the 1990s, several new pharmacy ethics textbooks have been published (2-5). Ethics and ethical decision-making is becoming an increasingly important element of pharmacy practice as pharmacists become more involved with dispensing medications that are used for abortion, assisted suicide, and clinical trials research.

James Jones's *Bad Blood: The Tuskegee Syphilis Experiment* can be used by pharmacy and other health-care professional educators as a supplement to required pharmacy or bioethics textbooks. Using narratives to teach bioethics is becoming more widespread in professional schools (6-10). Montello notes "a growing number of medical educators who use literary and personal narratives to teach bioethics consistently observe that narrative explorations provide a highly effective method for teaching moral reasoning in medicine" (10). *Bad Blood* provides students with a real-life example of how ethical principles can be violated when providing patient care and how discrimination against patients of certain backgrounds can occur. As Kathryn Hunter stated, "literature adds to ethics teaching because it stimulates moral imagination and requires readers to engage in the retrospective construction of a situated, subjective account of events" (6).

Patricia King adds that the Tuskegee experiment "provided a basis for the exploration of many ethical and social issues in medicine, including professional ethics, the limitations of informed consent as a means of protecting subjects, and the motives and methods used to justify the exploitation of persons who live in conditions of severe economic and social disadvantage" (11). Having pharmacy students read about the Tuskegee experiment gives them the opportunity to better understand how ethical issues can arise not only at the patient level but also at a local, state, or federal level, for as Gillon points out, "the understanding of cases can in part be gained through clinical experience but can be enhanced by reading good poems, good novels, by seeing plays" (12).

All the Tuskegee events are tainted fundamentally because they occurred in the absence of informed patient consent. Indeed, it can be said that all health care in the United States is based on the concept of a person, after

being made aware of all relevant information, consenting to treatment ranging from surgery to pharmaceuticals to physical therapy. The doctrine of informed consent has developed legally and morally (13). In fact, while the Tuskegee experiment was being conducted, ethics and medical experimentation was being discussed at a national as well as international level, resulting in the formulation of the Nuremberg Code in 1949, the Declaration of Helsinki in 1964, and the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research in 1974. However, all too often informed consent is addressed, particularly in institutions, by a signature on a document. Our increasing population with English as a second language only serves to exacerbate this issue (14).

In January 1996, the Tuskegee Syphilis Study Legacy committee was created as a result of a workshop at Tuskegee University that explored ways to increase minority representation in medical research (15). Another way to increase minority representation in medical research might be to better educate health-care professionals about important historical events such as the Tuskegee experiment so that health-care professionals can attempt to regain the trust of patients who remember this event.

On May 16, 1997, President Clinton made the first official government apology for the Tuskegee experiment. "We commit to strengthen researchers' training in bioethics," President Clinton stated. "We are constantly working on making breakthroughs in protecting the health of our people and in vanquishing disease," he continued:

But all people must be assured that their rights and dignity will be respected as new drugs, treatments, and therapies are tested and used. So I am directing Secretary Shalala to work in partnership with higher education to prepare training materials for medical researchers . . . they will help researchers build on core ethical principles of respect for individuals, justice, and informed consent, and advise them on to how use these principles effectively in diverse populations (16).

It is important that all health-care professionals, not just medical researchers, better understand and apply these principles in their daily practices. President Clinton also addressed the need to improve trust between researchers and patients when he added, "We commit to increased community involvement so that we may begin restoring lost trust. The study at Tuskegee served to sow distrust of our medical institutions, especially where research is involved" (16). The restoration of trust will most likely occur within the health-care professional-patient relationship. Therefore, all health-care professionals need to be educated about this important historical event. The purpose of this paper is to describe the results of a teaching exercise used in a

pharmacy ethics class that required the students to read *Bad Blood* and write a reaction paper.

METHODS

All pharmacy students in a required one-credit pharmacy ethics course were required to read James Jones's *Bad Blood: The Tuskegee Syphilis Experiment* in the fall of 1996 (1). The university where the course was taught has a semester system. Each student was required to read the book and write a four- to six-page reaction paper. Students were required to respond to the following questions: 1. What did you find the most interesting about the book? 2. What didn't you like about the book? 3. What ethical principles, if any, were violated in the Tuskegee experiment? 4. Do you think the legend of the Tuskegee experiment will influence your practice of pharmacy in any way? It was stressed to the students that they would not be graded on their opinions, but they would be graded on if they addressed the four questions listed above and if they wrote a clear and well-organized paper. Students handed their papers in before the Tuskegee experiment was discussed in class. A total of 48 students completed papers for the class. All agreed to having their papers analyzed by faculty after their identifiers had been removed. The major themes and issues were then subjected to content analysis.

RESULTS

Table 1 illustrates what students stated that they liked and disliked about *Bad Blood*. Seventy-seven percent of the students commented that they enjoyed the historical context of the book. As one student stated, "One of the most interesting aspects about the book *Bad Blood* is its detailed description of how the Tuskegee experiment evolved and survived—for forty years!" Almost 17 percent of the students commented that they enjoyed reading Nurse Rivers's story, possibly because they related to her as being a health-care professional like themselves:

The most interesting aspect of *Bad Blood* to me was Nurse Rivers's relationships to the physicians and the men . . . Nurse Rivers was a complicated woman. I do not understand how a black woman could participate in a project so dehumanizing and discriminating against her own race. Maybe it was because for her as a black female to be in such an "important" position in the eyes of the white males was an exceptional accomplishment at that time in America. I believe that in Nurse Rivers's eyes, she was doing her job to the best of her ability.

What interested me the most while reading *Bad Blood* was the constant theme of Nurse Rivers throughout the book. She herself was probably most responsible for making sure that these men did not receive treatment. I suppose this came from the mentality of the time that nurses did exactly what the doctors told them and did not make clinical decisions on their own.

It is also interesting that 6 percent of the students stated that they would have liked the book better if more had been written about Nurse Rivers. Future pharmacists, like Nurse Rivers, face the possible ethical dilemma of wanting to do what is best for the patient even if it may contravene physicians' orders. The authors believe that *Bad Blood* is an excellent way to illustrate to students that they may not fill medications as ordered, and there is sometimes the need to question the prescriber on what is right for the patient.

TABLE 1. What Pharmacy Students Liked and Disliked About *Bad Blood* ($n = 48$).

What Students Liked and Did Not Like	Percent (n)*
What They Liked	
Historical context	77.0 (37)
Nurse Rivers's story	16.7 (8)
Causes one to think	12.5 (6)
Facts and details	10.4 (5)
Unbiased	10.4 (5)
Pictures of people involved	4.2 (2)
Increased awareness of race	4.2 (2)
Does not overly emphasize race	2.1 (1)
The quotes that were used	2.1 (1)
What They Did Not Like	
Too few patient interviews	14.6 (7)
Digresses/unorganized	12.5 (6)
Biased	12.5 (6)
What reaction of the health professions were	12.5 (6)
Wanted more information on Nurse Rivers	6.3 (3)
Too long	6.3 (3)
Too many names	6.3 (3)
Too many quotes	6.3 (3)
Repetitive	4.2 (2)

*Multiple response were sometimes given.

Ten percent of the students said they liked the book because they felt that it was unbiased. As one student stated, "The author James H. Jones must be given credit for providing an unbiased depiction of the study. The book's focus is to explain the rationale of the researchers, not to criticize them. This enables the reader to better understand the details of the study and to make his own judgment." However, 12 percent of the students stated that they did not like the book because they felt it was biased. Many students also disliked the book because they felt that it contained too few patient interviews. Students really wanted a better understanding of how the patients felt about participating in the Tuskegee experiment.

All of the students mentioned that they believed that the principles of patient autonomy and informed consent had been violated during the Tuskegee experiment. As one student stated, "One principle that was violated in the study was autonomy or self-determination. While the men involved did decide for themselves whether to participate in the study, they did so under false pretenses. To keep them coming back for observations, the physicians lied to the men by giving them aspirin and iron tonic, and placing them under the impression that this was treatment for 'bad blood.'"

However, at the same time, several students acknowledged that whether the experiment was "okay" depended on the time period that was examined. One student reflected:

In evaluating the experiment and thinking about why and how it developed, it becomes clear that this case was simply a reflection of the ethical and moral codes of that time period. There were surprisingly no objections made to the idea of such an experiment nor were there any during the years in which it operated. This anomaly raises the question of why. Why was this idea that is considered shocking and cruel today accepted by everyone without a second thought 65 years ago? Again, the ethical and moral codes were much different than the ones that exist for the majority of people today.

One of the main principles that the authors attempt to teach pharmacy students is that professional codes of ethics change over time. What was ethically acceptable for pharmacists, physicians, or nurses to do in the 1930s might be very different from what is ethically appropriate for pharmacists to do in the 1990s. Buerki and Vottero's textbook *Ethical Responsibility in Pharmacy Practice* provides an excellent discussion of various codes of ethics (3). It has an appendix with codes of ethics from different time periods to illustrate changing expectations in pharmacy and medical practice. Challenging students to recognize this evolution will help them as they prepare to enter professional life with colleagues, some of whom have ethical templates formed dozens of years ago.

Seventy-seven percent of the students discussed how the experiment violated the principles of beneficence and nonmaleficence from the Hippocratic Oath. The students had learned about the American Pharmaceutical Association's Code of Ethics and the Hippocratic Oath in the pharmacy ethics class (3). However, many of the students probably chose to cite the principles of beneficence and nonmaleficence as originating from the Hippocratic Oath rather than the American Pharmaceutical Association's Code of Ethics for Pharmacists because they had been taught the historical evolution of medical and pharmacy codes of ethics. Listed below are a few excerpts from student papers.

The principle of beneficence, acting for the good of the patient, was also clearly violated. Certainly the good of the patient was not considered in the study which left untreated a deadly disease for which treatment was available. In fact, even the most basic of ethical principles, to do no harm, was violated. Surely, these patients were harmed by their enrollment in the study. Though the doctors insisted that salvarsan treatment posed greater risks than the disease itself, clearly this was a convenient excuse for the doctors to justify the premise of the experiment. After the discovery of penicillin as a much safer and more effective treatment for syphilis, the patients still remained untreated.

The principle of nonmaleficence was violated in the Tuskegee experiment. The patients in the study were harmed by not receiving adequate treatment. This was especially true after penicillin became available to treat syphilis. Before penicillin, treatment was risky with adverse side effects. However, penicillin proved to be a much better and safer option. Therefore, no excuse exists for not giving the men this medication. In addition, the investigators put the men under certain procedures that were not always necessary, such as spinal taps. This procedure was painful to most of the men.

Bad Blood sparks and holds the interest of pharmacy students because it centers around providing or not providing drug treatment to patients enrolled in research studies. Although pharmacists are not mentioned in the book, providing or withholding drug therapy is an issue they clearly understand. This point is further illustrated by the student comments listed below.

Reading the story will prompt me to be more cautious of studies that involve human patients. Modern day pharmacists can learn from the Tuskegee syphilis experiment. First, like a public member of a research review committee, the pharmacist is supposed to look out for the patient's best interest. He should scrutinize not only prescriptions, but also

policies and procedures concerning any experimental or store policies concerning a patient's well-being. Second, one should not just accept policies and procedures because the prior pharmacist did. After all, the Tuskegee experiment became an accepted part of the Public Health Service after a period of time. Thus, just because something has been around a long time, does not mean it is ethical or right. Each pharmacist should evaluate each individual situation and policy himself.

Thirty-seven percent of the students felt that the experiment violated the principle of veracity and 27 percent believed that the experiment violated the principle of fidelity. Presented below are student discussions of how the principles of veracity and fidelity were violated in the Tuskegee experiment.

. . . the researchers failed to demonstrate faithfulness in their relationships with the subjects. They did not maintain fidelity . . . however since the men were viewed as "subjects," rather than "patients," it can be seen why the researchers failed to observe this principle. This however, did not excuse them from their professional obligations. As a result of the lack of fidelity, the researchers also failed to demonstrate veracity toward the subjects. The researchers took advantage of the lack of education of their subjects.

The researchers used deceit to achieve their goals. By telling the men that they were receiving treatment when all they were receiving was tonic and aspirin is an example of some of the deceit used in this study.

Thirty-five percent of the students stated that the experiment violated the principle of justice. As one student commented, "The racial aspect of the Tuskegee study clearly violates the principle of justice as applied to health care. This principle implies that all patients should be treated equally, without regard to social, economic, religious, or other issues. It is no coincidence that the Tuskegee study was carried out on poor, illiterate blacks of the rural South."

Table 2 presents what students said about how reading *Bad Blood* would or would not influence their practice of pharmacy. Fifteen percent stated that reading the book would not influence their future practice of pharmacy. As one student explained, "I do not think that *Bad Blood* will influence the way I practice pharmacy because I try on an every day basis to provide the best possible care I can to each and every patient regardless of race, age, or gender."

Eighty-five percent of the students stated that reading the book would influence their future practice of pharmacy. Almost 30 percent of the students felt that reading the book would influence how they approached patient

TABLE 2. How Students Thought Reading the Book *Bad Blood* Would Influence Their Practice of Pharmacy ($n = 48$).

How Students Thought the Book Would Influence Their Practice	Percent (n)*
Will Influence Their Practice	85.4 (41)
Patient education	29.2 (14)
More conscious of ethics	20.8 (10)
Will think about racism	20.8 (10)
Need to question authority when patients' rights are being violated	16.7 (8)
Patient trust	14.6 (7)
Put patient welfare first	14.6 (7)
Treat patients as people	12.5 (6)
Keep a more critical eye of clinical trials	12.5 (6)
Treat everyone fairly	8.3 (4)
Provide the best possible care	4.2 (2)
Will Not Influence Their Practice	14.6 (7)

*Multiple response were sometimes given.

education about medications. Displayed below are student descriptions of how reading the book affected how they will approach counseling patients about their medications in the future.

I will probably offer more explanations about therapeutic risks versus benefits (e.g., estrogen replacement therapy versus no therapy) to patients—giving them more autonomy and corresponding responsibility for drug outcomes.

Studying the Tuskegee experiment makes me more aware of the need for well understood communication between the health care provider and the patient. I will pay more attention to the educational level of my patients. I will give information in such a way for patients to understand their medical problems, their medications, and possible side effects so that as long as they are capable of making decisions they will know enough to be involved in their care.

. . . reading *Bad Blood* has reminded me that there are still today many people who do not have the benefit of even basic education, much less more specialized health education. This makes it very important for me to make every effort to teach my patients about the condition they have and the way it will be treated.

I have a renewed commitment to support and work towards a health care system in this country that will one day make health care available to all people regardless of economic status or educational background. I believe that the primary reason that the patients in the Tuskegee study were susceptible to the ongoing deception of the study is that they were in need of, and had such a great desire for health care. These people were, as many people in 1996 are, desperate for any sort of medical attention. I believe that reading this book has encouraged me to be an active supporter of health care reform in the United States.

Finally, listed below is a student statement that illustrates how *Bad Blood* can help students view patients from a much more holistic approach.

I do believe that the legend of the Tuskegee experiment will influence my practice of pharmacy. First, the book heightened my awareness of the importance of treating patients foremost as people. I have become aware of the strong temptation to regard people as “cases” or “subjects.” For example, in pharmacy school classes, all patients have been simulations. I have grown accustomed to studying the symptoms, analyzing the possible methods of treatment, and recommending therapy, all without much thought to the real purpose: improving the life of a person. Health care professionals are trained to be so detail-oriented, that unfortunately, it takes events like the Tuskegee experiment to remind us to look at the bigger picture—the person as a whole.

DISCUSSION

We now require all pharmacy students to read *Bad Blood* in a required pharmacy law and ethics course that is usually taken by 120 students a year. We are convinced that requiring students and health care professionals to read *Bad Blood* really opens their eyes to an important historical event that must be understood if they are going to regain the trust of patients from diverse backgrounds. We were especially surprised when a group of students in one of our classes stopped at Tuskegee University on their way to a spring break destination and took pictures of the area. This certainly signified how reading the book had an important impact on some students. The following student comment clearly illustrates why all pharmacy and other health professionals should be encouraged to read *Bad Blood* during their professional education: “The Tuskegee experiment has opened my eyes to activities that have taken place in the past and ways we can learn from them in order to prevent this course of action. ‘Those who do not remember the past are condemned to repeat it.’”

Some would say that the Tuskegee experiment occurred in a different era and could not happen today with all of the safeguards on research involving human subjects. But one doesn't need to look far for potential problems. It's generally accepted that 20 percent of the American public is functionally illiterate (17). People in this category often have some crude reading skills but cannot reliably understand instructions such as those found on over-the-counter drugs or prescription labels. We believe that the best term for these citizens is "maliterate"; they have some reading comprehension but not enough to function with adequate safety in today's world.

One excellent example of terminal maliteracy is the North Carolina woman who visited a dermatologist for treatment of psoriasis. He prescribed Methotrexate 2.5 mg tablets with the directions for use to "Take two tablets every twelve hours, twice a day for three doses each week." The prescriber intended for her to take two tablets one day in the morning, two more that evening, and two the next morning and stop until repeating the schedule the next week. She read and understood the first half of the directions, "Take two tablets twice a day" and just ignored the rest of the label. Her death certificate listed Methotrexate toxicity which we believe was secondary to maliteracy (18). Therefore, we believe that it is critical for all health-care professionals and students to learn about the ethical issues surrounding the Tuskegee experiment so that optimal patient care can be provided to individuals from all types of backgrounds in the future.

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