Remember Tuskegee: Public Health Student Knowledge of the Ethical Significance of the Tuskegee Syphilis Study

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The ethical problems that surrounded the Tuskegee Syphilis Study prompted widespread public criticism when they first surfaced in 1972; the Tuskegee Study remains an important case in bioethics. We recently examined public health student knowledge of the ethical significance of the Tuskegee Study as part of an ethics curriculum needs assessment at Tulane University. A brief questionnaire was administered to 236 graduate students currently enrolled in seven epidemiology courses. Basic demographic information was obtained along with information about degree program. A series of questions was then asked to assess student knowledge of bioethics including the ethical significance of the Tuskegee Study. Only 19% (46 of 236) of the students demonstrated knowledge of the ethical significance of the Tuskegee Study. Knowledge of the Tuskegee Study's ethical significance was higher among students who were from the United States and those who were enrolled in the epidemiology program ($P < .05$). The ethical problems that surrounded the Tuskegee Study have rarely been encountered in public health. However, this important case stands as an exemplar of the potential for ethical abuses in human subjects research. Such cases ought to be highlighted in public health curricula. Medical Subject Headings (MeSH): blacks, African Americans, educational curriculum, epidemiology, ethics, public health, racism. [Am J Prev Med 1996;12:242–6]

The Tuskegee Syphilis Study was first brought to public attention by the news media in July 1972.[1,2] The disturbing accounts of poor African-American men in the southern United States who were denied access to potentially lifesaving therapy by Public Health Service (PHS) researchers prompted widespread public criticism and condemnation.[1] Senator John Sparkman of Alabama, for instance, denounced the Tuskegee Study as "absolutely appalling" and "a disgrace to the American concept of justice and humanity."[1] As James Jones recounted in *Bad Blood*, "Not since the Nuremberg trials of Nazi scientists had the American people been confronted with a medical cause célèbre that captured so many headlines and sparked so much discussion."[1]

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To many, the ultimate lesson of the Tuskegee Study was the need to protect vulnerable persons in society—including those who are socioeconomically disadvantaged—from scientific pursuits that ignore human values.[1] As the editor of the *Atlanta Constitution* put it at the time of the initial press reports, the important lesson for medical researchers was that "moral judgment should always be a part of any human endeavor [including] the dispassionate scientific search for knowledge."[3]

The response of many PHS officials to the initial swirl of controversy was to decline comment and to distance themselves from the study. To them, "the Tuskegee Study was an embarrassment, a relic of the past they preferred not to have mentioned and had just as soon see forgotten."[1] Some physicians attempted to defend the Tuskegee Study in letters and commentaries that appeared in newspapers across the country and in an editorial in the *Southern Medical Journal*.[1,4] As James Jones observed, "the medical establishment in the United States made little effort to come to grips with the Tuskegee Study."[1] Medical and public discussions of the Tuskegee Study dropped off sharply within a few weeks of the initial press reports.[1]

The Tuskegee Study, however, has continuing importance to public health, bioethics, and African-American studies.[2,5–7] Social scientists, for example, have argued that the Tuskegee Study has

contributed to the legitimate discontent of many African Americans with the public health system and has helped to lay the foundation for a pervasive sense of distrust among African Americans of public health authorities today.[7] This unfortunate legacy of the Tuskegee Study hampers efforts to control AIDS and other contemporary public health problems in African-American communities.[1,7] The Tuskegee Study also stands as an exemplar of the potential for ethical abuses in public health and human subjects research and of the need for vigilance in protecting the welfare and rights of research subjects.[2,8] This important case, including its impact on improvements in regulatory safeguards for the participants in human subjects research in recent decades, is cited in many texts on bioethics.[2,9]

In view of the importance of the Tuskegee case in public health ethics, we recently surveyed public health graduate students at Tulane University about their knowledge of the ethical significance of the Tuskegee Syphilis Study as part of an ethics curriculum needs assessment. The overall objective was to assess student knowledge of bioethics and to further guide the development of curriculum in ethics, epidemiology, and public health.

METHODS

We developed a brief questionnaire for the ethics curriculum needs assessment. The survey was administered to graduate students currently enrolled in seven epidemiology courses offered by the Department of Biostatistics and Epidemiology during the fall semester. The epidemiology courses included electives and introductory, intermediate, and advanced courses taken by departmental and nondepartmental master's and doctoral students, including students enrolled in the MD-MPH joint degree program. The questionnaire was administered in the classrooms over a three-day period in October 1994. Care was taken to avoid interviewing a student more than once. The students were told that an "educational curriculum needs assessment" was being carried out that was completely voluntary and anonymous. They were not told in advance that the survey was about ethics curriculum. Basic demographic information was obtained in a self-administered fashion along with information about department, degree program, semesters enrolled at Tulane, and expected graduation date. A series of questions was then shown to the students one at a time using an overhead projector to assess their knowledge of bioethics. They were asked not to go back to earlier questions to change or add to their earlier responses. The following questions were asked in sequence: (1) What is the significance of the Tuskegee Syphilis Study to public health and epidemiology? (2) What country was the Tuskegee Syphilis Study carried out in? (3) What decade or approximate year did the Tuskegee Syphilis Study come to public attention?

The students were also asked to name the four commonly cited principles of biomedical ethics (nonmaleficence, beneficence, justice, and respect for the autonomy of persons), whether they had ever read any of these proposed ethics guidelines for epidemiologists, and whether they had ever taken a course on ethics. In addition, they were asked to name the document drafted by a military tribunal following World War II that set forth principles of medical ethics including the requirement for *voluntary* consent.

At the end of the survey, the students were asked to avoid discussing the survey with their classmates until the following week to avoid biasing the responses of students who would be interviewed in the next day or two. In our analysis of the results of the survey, the students were considered to have been knowledgeable about the significance of the Tuskegee Syphilis Study only if they mentioned some ethical concern such as lack of informed consent, failure to offer antibiotic therapy following the introduction of penicillin, or racism. Chi-square tests were applied to determine statistical significance along with logistic regression techniques.

RESULTS

A total of 236 students were surveyed from all five departments at the Tulane School of Public Health and Tropical Medicine. Only six students declined to take part in this voluntary survey. The respondents ranged in age from 21 to 47 years; 56% (131 of 234) of the students were women. Sixty-nine percent (162 of 234) were U.S. citizens. About 21% (48 of 232) were in the epidemiology program in the Department of Biostatistics and Epidemiology. About 84% (189 of 224) of the students were enrolled in a master's program (MPH, MPH&TM, or MSPH); the remainder were primarily doctoral students (PhD, DrPH, or DSc; 14%) or joint degree students (MD, MPH; 1%). About 14% (29 of 210) of the students expected to graduate in December 1994; an additional 17% (36 of 210) expected to receive their degrees by May 1995.

Table 1 shows the students' bioethics knowledge by selected characteristics. Only about 19% (46 of 236) demonstrated knowledge of the ethical significance of the Tuskegee Study to public health and epidemiology. Knowledge of the Tuskegee Study's ethical significance was higher among younger students, those who were African American, and those who were from the United States (Table 1). About 46% (22 of 48) of the students enrolled in the epidemiology program demonstrated knowledge of the Tuskegee Study's ethical significance. Contrary to expectation, students who were raised in the southern United States were less likely to be knowledgeable about the Tuskegee Study's ethical significance than other students who were U.S. citizens. Students who expected to graduate in December 1994 were somewhat more likely to be knowledgeable about the Tuskegee Study's ethical significance than continuing students (24% versus 18%). None of the 236 students surveyed was able to name the four commonly cited principles of biomedical ethics. Few had read any of the proposed ethics guidelines for epidemiologists (Table 1). Less than 8% (18 of 236) of the students were able to name the Nuremberg Code (results not shown).

In multivariable analysis of the data using logistic regression, student knowledge of the ethical significance of the Tuskegee Study was positively associated with being in the epidemiology program, being in a doctoral program, and having been raised in a region of the United States other than the South (results not shown). The association with African-American race was of borderline significance in multivariable analysis ($P < .10$).

DISCUSSION

Our survey was designed to obtain information about student knowledge of bioethics in a diverse sample of public health students. It did not assess the ability of students to identify and

Table 1. Student knowledge of the Tuskegee Syphilis Study, Tulane University School of Public Health and Tropical Medicine, fall 1994

	Knew ethical significance of Tuskegee Syphilis Study			Knew country Tuskegee Study carried out in			Knew decade Tuskegee Study came to public attention		
	Yes (%)	No (%)	*P* value	Yes (%)	No (%)	*P* value	Yes (%)	No (%)	*P* value
Age (years)									
21–29	37 (22.8)	125 (77.2)		87 (53.7)	75 (46.3)		26 (16.1)	136 (83.9)	
30–39	8 (13.1)	53 (86.9)		19 (31.2)	42 (68.8)		8 (13.1)	53 (86.9)	
40–47	1 (7.7)	12 (92.3)	.14	3 (23.1)	10 (76.9)	.002	0 (0.0)	13 (100)	.27
Gender									
Male	15 (14.6)	88 (85.4)		39 (37.9)	64 (62.1)		7 (6.8)	96 (93.2)	
Female	31 (23.7)	100 (76.3)	.08	70 (53.4)	61 (46.6)	.02	27 (20.6)	104 (79.4)	.003
Race/ethnicity									
Caucasian	26 (21.0)	98 (79.0)		71 (57.3)	53 (42.7)		18 (14.5)	106 (85.5)	
African American	10 (28.6)	25 (71.4)		24 (68.6)	11 (31.4)		10 (28.6)	25 (71.4)	
Hispanic	2 (12.5)	14 (87.5)		2 (12.5)	14 (87.5)		1 (6.3)	15 (93.7)	
Asian	3 (6.8)	41 (93.2)	.07	5 (11.4)	39 (88.6)	<.001	4 (9.1)	40 (90.9)	.07
Citizenship									
U.S./Canada[a]	44 (27.0)	119 (73.0)		99 (60.7)	64 (39.3)		31 (19.0)	132 (81.0)	
Latin America[b]	1 (7.7)	12 (92.3)		1 (7.7)	12 (92.3)		1 (7.7)	12 (92.3)	
Europe[c]	0 (0.0)	4 (100)		0 (0.0)	4 (100)		0 (0.0)	4 (100)	
Africa[d]	0 (0.0)	12 (100)		3 (25.0)	9 (75.0)		0 (0.0)	12 (100)	
Asia[e]	0 (0.0)	33 (100)	<.001	2 (6.1)	31 (93.9)	<.001	1 (3.0)	32 (97.0)	.06
Grew up in which region of United States									
North	10 (33.3)	20 (66.7)		22 (73.3)	8 (26.7)		9 (30.0)	21 (70.0)	
East	12 (40.0)	18 (60.0)		22 (73.3)	8 (26.7)		7 (23.3)	23 (76.7)	
South	11 (19.0)	47 (81.0)		32 (55.2)	26 (44.8)		8 (13.8)	50 (86.2)	
West	8 (20.0)	32 (80.0)	.11	20 (50.0)	20 (50.0)	.08	7 (17.5)	33 (82.5)	.29
Department/Program									
Biostatistics and Epidemiology	23 (37.1)	39 (62.9)		28 (45.2)	34 (54.8)		12 (19.4)	50 (80.6)	
Biostatistics	1 (7.1)	13 (92.9)		2 (14.3)	12 (85.7)		0 (0.0)	14 (100)	
Epidemiology	22 (45.8)	26 (54.2)		26 (54.2)	22 (45.8)		12 (25.0)	36 (75.0)	
Applied Health Science	5 (13.5)	32 (86.5)		17 (46.0)	20 (54.0)		6 (16.2)	31 (83.8)	
International Health and Development	10 (16.1)	52 (83.9)		28 (45.2)	34 (54.8)		8 (12.9)	54 (87.1)	
Tropical Medicine	3 (12.5)	21 (87.5)		12 (50.0)	12 (50.0)		2 (8.3)	22 (91.7)	
Environmental Health	1 (3.2)	30 (96.8)		11 (35.5)	20 (64.5)		4 (12.9)	27 (87.1)	
Health Systems Management	4 (25.0)	12 (75.0)	.002	11 (68.8)	5 (31.3)	.43	2 (12.5)	14 (87.5)	.86
Degree sought									
PhD/DrPH/DSc	11 (35.5)	20 (64.5)		16 (51.6)	15 (48.4)		6 (19.4)	25 (80.6)	
MPH/MPHTM/MSPH	31 (16.4)	158 (83.6)		85 (45.0)	104 (55.0)		25 (13.2)	164 (86.8)	
MD, MPH	1 (33.3)	2 (66.7)		2 (66.7)	1 (33.3)		0 (0.0)	3 (100)	
Nondegree student	0 (0.0)	1 (100)	.06	0 (0.0)	1 (100)	.69	0 (0.0)	1 (100)	.67
Ever taken a course on ethics									
Yes	20 (25.0)	60 (75.0)		43 (53.7)	37 (46.3)		16 (20.0)	64 (80.0)	
No	26 (16.7)	130 (83.3)	.13	66 (42.3)	90 (57.7)	.09	18 (11.5)	138 (88.5)	.08
Able to name four principles of biomedical ethics									
Yes	0	0		0	0		0	0	
No	46 (19.5)	190 (80.5)		109 (46.2)	127 (53.8)		34 (14.4)	202 (85.6)	
Ever read draft ethics guidelines for epidemiologists									
Yes	5 (27.8)	13 (72.2)		9 (50.0)	9 (50.0)		4 (22.2)	14 (77.8)	
No	41 (18.8)	177 (81.2)	.36	100 (45.9)	118 (54.1)	.74	30 (13.8)	188 (86.2)	.30

[a]United States (n = 162), Canada (n = 1).
[b]Jamaica (n = 1), Mexico (n = 4), Honduras (n = 3), Nicaragua (n = 1), Brazil (n = 1), Ecuador (n = 1), Bolivia (n = 1), Columbia (n = 1).
[c]Germany (n = 1), United Kingdom (n = 2), France (n = 1).
[d]Nigeria (n = 1), Guinea (n = 1), Ethiopia (n = 2), Zambia (n = 1), Egypt (n = 2), Niger (n = 1), Tanzania (n = 1), Kenya (n = 1).
[e]Bangladesh (n = 3), Taiwan (n = 19), Thailand (n = 1), Sri Lanka (n = 2), India (n = 1), Saudi Arabia (n = 1), Japan (n = 2), Pakistan (n = 1), Indonesia (n = 1), China (n = 1).

resolve ethical dilemmas through ethical reasoning, or the ability of students to analyze or evaluate ethical problems in public health. Nevertheless, the results of this survey indicate substantial gaps in the bioethics knowledge of these public health students and ignorance of the ethical significance of the Tuskegee Syphilis Study. Few of the students were able to identify important developments or concepts in bioethics such as the Tuskegee Study or the principles of beneficence, nonmaleficence, justice, and respect for the autonomy of persons.[9]

The Tuskegee Study has been of considerable interest to contemporary historians, bioethicists, and those who are concerned about the experience of African Americans in the twentieth century, including their treatment by U.S. government officials and medical researchers.[1,5–7] An article by Allan Brandt about the Tuskegee Study brought to light disturbing historical facts that the Department of Health, Education, and Welfare's Tuskegee Syphilis Study Ad Hoc Advisory Panel had overlooked.[5,10] Although Brandt emphasized racism in his analysis of the ethical problems that surrounded the Tuskegee Study,[5] other historians have downplayed this explanation and argued instead that the mindsets of the research scientists and their large stake in this project played the greater role.[6] David Rothman argued that "social deprivation ought not to become the occasion for conducting a seemingly natural experiment, for researchers place themselves in an ethically untenable position."[6] In Rothman's analysis, researchers become accomplices to the problem in such situations, not simply observers of it.[6]

In recent years, professional ethics has moved to the forefront in public health as shown by recent ethics workshops and symposiums at national and international meetings,[11–13] numerous publications on ethics topics of interest to public health professionals,[14–23] and the development of proposed ethics guidelines for epidemiologists.[24–26] Standing ethics committees have also been established by many professional associations in public health since the late 1980s.[2]

In conjunction with continuing professional education for practicing public health professionals, there has been increasing interest in incorporating ethics curriculum into public health training programs in the United States and other countries.[8,27,28] At the recent WHO-ISEE International Workshop on Ethical and Philosophical Issues in Environmental Epidemiology in North Carolina, attended by epidemiologists and moral philosophers from Europe and North America, participants strongly recommended that professional organizations and institutions invest in programs for environmental epidemiologists to facilitate their ongoing improvement in ethics knowledge and practice.[13]

In recent decades, training in medical ethics has become standard in medical and nursing education in the United States and many other countries.[8,29,30] Many medical specialty boards have also formally endorsed ethics teaching and evaluation for residents.[31,32] Bioethics curricula developed for physicians-in-training do not directly meet the needs of public health students, however.[8] Ethics in public health involves an interplay between protecting the welfare of the individual, as in medicine and nursing, and the public health model of protecting the public welfare.[8,9]

As innovative curricula on ethics are developed for public health students, there will be a need to compile and disseminate case studies on public health ethics for instructional purposes. Group discussion of ethics case studies is an important instructional method in bioethics.[28] The Tuskegee Study and more recent developments, such as disclosures about radiation experiments sponsored by the U.S. government, stand as important cases in bioethics that ought to be highlighted in public health curricula. In the words of George Silver, "not to remember [Tuskegee] is to forget, and to forget is a disservice to those who suffered the indignities."[33]

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