Effect of Teaching *The Immortal Life of Henrietta Lacks* on Student Beliefs of Health Care, Medical Ethics, and Health Disparities

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Abstract

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Purpose: To explore student perceptions on topics of health care, medical ethics, and disparities both before and after taking a course focused on the biography *The Immortal Life of Henrietta Lacks by Rebecca Skloot*.

Study Design: Quasi-experimental, mixed qualitative study conducted among University of Washington Master of Public Health (MPH) graduate students.

Methods: A survey was developed and administered to MPH graduate students at the University of Washington soliciting their perceptions on the following categories: *health disparities; health access; race, culture, and spirituality; distrust of medicine; ethical medical research; and* *current and future health needs*. The survey was given to students both before and after having received the intervention of an academic course focused on *The Immortal Life of Henrietta Lacks*. Qualitative research methods were used to identify themes common within the discourse generated from the survey among participants with a particular interest in how these themes may have changed following the intervention.

Results: In all categories of interest, new themes emerged post-intervention after students had taken a course covering *The Immortal Life of Henrietta Lacks* . In particular, more race-specific themes, as well as themes highlighting the social determinants of health and the need for open access to health care became more apparent post-intervention.

Conclusions: This study suggests that student perceptions on health care, medical ethics, and health disparities may be influenced by being immersed in an ethics course covering the biography of Henrietta Lacks. The results of this study indicate that this intervention may provide a framework for engaging individuals on difficult discussions of culture, race, and equality within the health care field.

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DEDICATION

I would like to dedicate this thesis to my partner in life Kevin Werner. Your unconditional love, support, and encouragement throughout these past 13 years (let alone these past 2 years) means the world to me. I admire your passion, tenacity, and gusto for life. You make me want to be a better person and I cannot wait to see what the next stage of our lives look like. Just no more school, okay?

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INTRODUCTION

Understanding Health Disparities: definitions and approaches

Health disparities can be defined as differences that exist when groups within a population do not benefit from the same health status as those in other groups (1). The etiologies of health disparities are often multidimensional, involving a broad range of social health determinants such as socioeconomic status, education, community-life, occupational hazards, and race. For example, African Americans show lower utility of general services covered by Medicare (2) as well as different levels of ambulatory care (3). In addition, in 2001 the reported rate of Hepatitis B acute infection was more than twice as high among Asian Americans when compared to Caucasians (4). Although race defines one variable important in the disparities listed above, complexities of decreased health care access, limited availability of interpreter services, lack of social support systems, and distrust of the medical establishment all interplay as confounders that compound these disparities. Therefore a basic understanding of such complexities from healthcare providers and healthcare professionals is essential to combat, minimize, and prevent such inequities. Theories of health behavior posit that social and cultural appropriateness are a requisite for efficient delivery and internalization of health education (5). As such, the flow of information, knowledge, and education from a social and cultural context is essential to any education initiative aimed at teaching about health disparities.

Agencies such as the Institute of Medicine, Department of Health and Human Services, and the Society of General Internal Medicine have agreed on the importance of teaching about health disparities and, as such, each group offers various educational resources aimed at providing such training. These resources sometimes narrowly focus on the disproportions in health care specifically, not placing into context the additional complexities of the social determinants of health (6). Indeed, data in the literature suggest that medical education on health disparities can be enhanced if the education includes a broader context for how social determinants factor into the framework of such differences (6). For example, “life course maps” could be incorporated into health disparities curriculum to demonstrate proximal events that might engage downstream events (6). In addition, Cene and co-workers suggest that key to truly understanding how contextual factors can impact gaps in health care is a thorough understanding of the community in which such health inequities exist in order for learners to place the disparities into a social context (7).

The impact of books and the humanities on mainstream public health issues

Books in the popular media can often bring difficult to broach topics into the mainstream by presenting captivating narratives, transforming complex scientific and moral issues into meaningful everyday discussion. Such narratives can help to illustrate key take-aways, facilitating reader understanding and potential conclusions to be made from the story (12, 13). A best-selling science book can serve to educate and engage its audience, as well as disseminate information through a broader cultural context (11). As such, contextualizing the social determinants of health, through a popular best-selling science book, could facilitate poignant discussions about health disparities and serve as an effective tool in engaging the broader public. Moreover, history, science philosophy, ethics, literature, and art may present opportunities for open discourse and, therefore, the development of one’s perspective, creativity, values, and critical thinking around issues of public health (14).

The Immortal Life of Henrietta Lacks

Named by more than 60 critics as one of the best books of 2010, *The Immortal Life of Henrietta Lacks* by Rebecca Skloot has earned the accolades of popular media and academics alike. Interestingly, Skloot's biography has not only made popular best-seller lists, such as the The New York Times Bestseller List, but *The Immortal Life of Henrietta Lacks* has become incorporated into many college and university campuses across the country as a required "common read" book. Skloot's biography tells the tale of how HeLa cells became infamous both from the perspective of biomedical innovation and medical research, as well as from the perspective of Henrietta Lacks, from whom the cells were originally derived, and of her family who bear the continued legacy of Lacks' story. Skloot's website describes the book: "Her name was Henrietta Lacks, but scientists know her as HeLa. She was a poor black tobacco farmer whose cells—taken without her knowledge in 1951—became one of the most important tools in medicine, vital for developing the polio vaccine, cloning, gene mapping, in vitro fertilization, and more. Henrietta's cells have been bought and sold by the billions, yet she remains virtually unknown, and her family can't afford health insurance" (8). As the quote alludes, Skloot's biography dives into a discussion about Lacks' life story, along the way identifying many complicating components that paved the way for HeLa cells to come to fruition as well as illuminating the complex etiologies of health disparities. Skloot's biography invites discussion across broad interest areas ranging from science to ethics to sociology and by all accounts is easily accessible to the common reader. Given its accessibility, the contextual presentation of social determinants of health, and the vivid images of the communities portrayed in the book, *The Immortal Life of Henrietta Lacks*, may be a model teaching tool useful in facilitating a thorough understanding of health disparities in an educational and/or professional training setting.

Exploring student perceptions before and after learning about Lacks

Here, we explored whether teaching *The Immortal Life of Henrietta Lacks* can impact student pre-conceived beliefs around health care, medical ethics, and the social determinants of health (Figure 1). Although the literature is robust with reviews and interpretations of Skloot's biography, no study to date has tested the effect the biography has on student belief systems and perceptions. We conducted an in-depth exploration of student perceptions at the University of Washington. We were particularly interested in student discourse on health care, medical ethics, and health disparities and how a formal course focused on discussion of *The Immortal Life of Henrietta Lacks* might impact that discourse. To this end, we administered surveys to students at the University of Washington with questions aimed at understanding their awareness in certain topic areas. Moreover, we focused on how participant responses may have been similar, as well as what responses may have newly emerged as a result of having discussed *The Immortal Life of Henrietta Lacks* in the context of having taken a formal course. This approach allowed the participants to offer detailed, unanticipated answers as many of the survey questions were open-ended.

METHODS

Subjects

Our sample consisted of 20 graduate students, all candidates for a Masters degree in Public Health (MPH), at the University of Washington. These graduate students were selected to be in either one of two study cohorts: the intervention arm or the comparator arm (Figure 2). 17 students enrolled in the University of Washington course HSERV 590: Values and Ethics in Public Health were selected to be in the intervention arm, as the basis of this course is content review and discussion of *The Immortal Life of Henrietta Lacks.* These students received a pre-test survey; 14 of the 17 students in this group completed the post-test survey. In contrast, 3 MPH graduate students who had never enrolled in HSERV 590 were selected to be in the comparator arm and received only one survey (which contained the same content as both the pre-test and post-test given to the intervention arm students).

Intervention

HSERV 590: Values and Ethics in Public Health is a 10 week, 1-credit graduate level public health course designed for graduate students interested in how and why ethics emerge in public health practice. The course utilizes *The Immortal Life of Henrietta Lacks* by Rebecca Skloot as the framework for discussions on how values and ethics, race and culture, medicine and scientific discovery intersect from a public health perspective. Students attend two in-person, four hour class sessions, one at the start of and one at the end of the academic quarter. In between the live class meetings, students engage in weekly reading assignments and online discussion postings. Students must submit a paper based on major themes represented in Skloot's biography serves as the final course deliverable.

Survey

We developed a survey of 19 questions based on 6 topic areas or categories: *health disparities; health access; race, culture, and spirituality; distrust of medicine; ethical medical* *research; and current and future health needs*. Each question developed was reflective of a topic contained within the biography *The Immortal Life of Henrietta Lacks*. Questions were designed to evoke student perceptions and core beliefs around the topic area and were intentionally left vague to elicit frank answers. The survey contained both open-ended questions as well as some polar questions requiring a "yes" or "no" answer (Table 1). The survey was administered online via Google. Respondents were emailed a link to the Google survey site and given as much time as they wanted to respond. In the case of the intervention arm, respondents were given classroom time to complete their pre- and post- test surveys which were given before the class discussion began on either the first day of class or on the last day of class respectively. In contrast, the comparator cohort, a group of public health graduate students who reported that they did not take HSERV 590, was sent the survey link and allowed to complete the surveys at their leisure (Table 1). The study was approved by the University of Washington Human Subjects Division as being exempt from Institutional Review Board review in accordance with the federal regulations under 45 CFR 46.101/ 21 CFR 56.104. Students were given a brief backgrounder on the study rationale and goals prior to obtaining informed consent either in person or via email.

Analysis

Interview data was collected through the survey website and independently analyzed by two research investigators (CD and CS). Questions in the survey were grouped according to categories (described in Results section, Categories based on survey areas; Table 2). To ascertain student perceptions per category we took an inductive approach, identifying trends in the data and organizing them into relevant themes (9, 10). The coding process focused on statements, words, terms, quotes, and concepts thought to be reflective of perspectives about health care, medical ethics, and health disparities within the context of race, ethnicity, gender, culture, and class (socioeconomic status). Categories and domains were established from the survey questions; themes were then identified independently by the two investigators to ensure inter-rater reliability. Three polar questions requiring “yes” or “no” answers were reported in a standard histogram format comparing the proportion of answers.

RESULTS

The sample was composed of 20 participants. 17 participants took part in the pre-test survey, 14 in the post-test survey, and 3 participants in the comparator survey (Figure 2). The researchers were blinded to the demographic profile of the participants except for knowing that each was a graduate student in the Master of Public Health program at the University of Washington.

Categories based on survey areas

Six broad categories were developed based on the topic area of the 19 individual survey questions in order to facilitate organization of the data. The following categories were designated: *health disparities* (encompassing questions 1-4); *health access* (encompassing questions 5-6); *race, culture, and spirituality* (encompassing questions 7-10); *distrust of medicine* (encompassing questions 11-13); *ethical medical research* (encompassing questions 14-18); *current and future health needs* (encompassing questions 17-19). Themes were then identified per category as described below (Table 2).

Theme identification: baseline results

Using a lean coding method, data was reduced into shorthand labels, and common themes per category were identified. Several themes, common in the pre-test, post-test, and comparator survey data prominently emerged. Given the similarity of responses across the study arms, we designated these common responses as the students' baseline beliefs and perceptions, regardless of having received the intervention (Table 2). After establishing these baseline themes, any new themes or changed trends in responses were identified from the same categories of interest, in an effort to determine if any differences could be seen in the study arm that received the intervention of *The Immortal Life of Henrietta Lacks* (Figure 3, Table 2).

Discourse on *health disparities* leads to themes of inequality based on socioeconomic status at baseline while new themes focused on race and the social determinants of health emerge post-intervention

Within the category of *health disparities*, it was evident from the responses received, in all study arms, that the students had some previous understanding of what a health disparity was and that some level of inequality was at the center of their "working" definitions. Typical responses seen in the baseline dataset that illustrate themes of inequity included the following definition of health disparities:

> *"Different health outcomes with respect to mortality and morbidity*
> *that are strongly associated with socioeconomic or ethnic status"*

Interestingly, ideas of education, culture, socioeconomic status (SES), and access also dominated many of the responses as additional themes within this category throughout the study groups. Another example from the pre-test study arm that highlight these themes:

> *"Health disparities can be defined as not having the same access*
> *to care and quality of care as those who can afford it. There is also*
> *an aspect of education and culture that are very important"*

Themes surrounding the consequences of one's inherent situation and the lack of essential healthcare options also emerged within the category of health disparities as well. Definitions that help to delineate these included comments such as this:

> *"Differences in the ability to be healthy that are beyond the individual's control"*

Although never explicitly stated, student responses addressed the idea that social determinants of health played a key role in the propagation of health disparities. Interestingly, these social determinants did emerge as more thematically explicit in the post-intervention data (Table 2).

An interesting difference observed within the category of *health disparities* following the intervention was either the shift to use of the terminology "social determinants of health" or a more explicit reference to specific tenets of these social determinants in the student derived examples. For example, a typical response that demonstrates these new themes is captured from the post-test cohort:

> *"Health disparities are those factors as defined by the social determinants of health that disproportionately affect certain populations based on gender, race, age, socioeconomic status, etc."*

Moreover, participants in the post-intervention group commented with new examples referencing specific social determinants of health not previously mentioned at baseline. Common responses that illustrate these themes included those such as:

> *"An example of health disparity is living in a location that has a food desert (no access to grocery stores with health options), impacting your ability to make healthy choices related to food, or that component of your health, versus living in a community where there are numerous grocery stores with healthy and organic options"*

Another example:

> *"A low-income man on Medicare who has to choose between his heart medication and his thyroid medication because he can't afford both of them"*

In addition, post-test surveys trended on using more specific examples of health disparities that also involved race that were not previously reported in pre-test or comparator arms. Specifically an increased frequency of use of examples mentioning African American disparities were observed:

"The lower life expectancy in African American men vs. white American men"

While another:

"The difference in the proportion of African-Americans with high blood pressure compared to the proportion of Caucasians"

The above examples illustrate an increase in race-specific and African American-specific themes in the post-test survey results that had been lacking in the baseline responses. Moreover, post-intervention discourse within the category of *health disparities* also appeared better defined with clearer focus within the themes captured.

Education and personal behaviors emerge thematically when discussing ***health access*** at baseline, but post-intervention themes focus on the Affordable Care Act

Within the category of *health access*, consistent baseline responses included dominant themes of "lack of access" and "barriers to health care". Although few specific examples were identified, students demonstrated a high-level understanding of how low SES might impact the access issue. Of note was the theme of how access to broader services might influence personal health behavior. Common responses, such as this one from the comparator group, put health disparities into the context of access as:

"Differences in access to health care services and education,

> *as well as socioeconomic differences that influence health behaviors"*

When asked if everyone has the right to have health care access, 15 out of 17 in the pre-test group, and 1 out of 3 in the comparator group, answered “yes”. This demonstrates that the majority of the participants were in favor of broad health care access in the US; this did not change in the post-intervention dataset (Figure 4).

On balance, themes in the category of *health access* remained consistent with the baseline themes already identified. However, at post-test the theme that access to health care did in fact improve with the passing of the Affordable Care Act (ACA) and Medicaid expansion emerged as more pronounced. Typical responses that illustrate this theme were found such as:

> *"In the US, I think overall access to care has improved with the rolling out of ObamaCare, as well as opening up Medicaid to more individuals"*

Additional responses that mentioned the ACA also appeared to put the ACA in the context of being “a work in progress” toward achieving greater health care access. An example that highlights this theme:

> *"With the affordable care act, access has improved especially in terms of access to health insurance. I don't know the statistics and trends on provider shortages. I would think that the medical community is becoming more culturally and racially diverse with time, but that it still has a long way to go."*

The above statements were echoed throughout the post-intervention dataset, in some nuanced cases making reference to the importance of the social determinants of health and SES:

> *"The ACA has expanded access to health insurance. However, there can still be difficulty accessing health services in rural areas of the US or even in urban areas if people don't have the job flexibility or transportation to get to appointments."*

Interestingly, when asked whether everyone should have access to health care, 12 of 14 students in the post-test group responded “yes” as compared to 15 out of 17 in the pre-test group, demonstrating very little change post-intervention. The majority of students still believed in broad health care access post-intervention.

Within the category of *race, culture, and spirituality*, discrimination, cultural competence, language, and communication barriers are common themes at baseline; a new theme of religious sensitivity becomes apparent post-intervention

Noticeable in the above categories was that student perceptions on health disparities were already rooted in themes of inequality based on access issues and SES, as well as the interplay between education and culture. Within the category of *race, culture, and spirituality*, communication barriers emerged as the prominent theme. Baseline dataset responses illustrating this theme were similar:

> *"If the provider doesn't understand the cultural background, or appreciate the cultural background of the patient, they might not be able to adequately address their concerns or provide information about treatment in a way the patient can understand"*

Similarly, another typical response from this group:

> *"Culture is a complex dynamic and can affect the quality of care received in many ways. For example, treatments may be more or less compatible with existing cultural beliefs; providers and patients from different cultures are likely to have barriers to communication; and different cultures may begin with certain baseline benefits and detriments relative to a given health concern"*

Interestingly, recognition of personal bias and racism also emerged as a theme, as is seen in this statement from the comparator cohort:

> *"Discrimination among providers has been documented. Different people are treated differently in healthcare based on class, gender, and race"*

Similar comments were seen in the pre-test group:

> *"Differences in language, communication norms, educational level, and discrimination/prejudice can all affect the care received"*

Interestingly, within the category of *race, culture, and spirituality*, a new theme of religious sensitivity emerged thematically in the post-intervention responses as playing a major role in the acceptance of health care. The following statement, illustrating this theme, was common among the post-intervention cohort:

> *"Attention to religious beliefs is often absent from the health care provided or recommended. This can result in a mismatch between patient and provider perceptions of what is real or advisable in a given situation"*

Another example of the theme of religious sensitivity:

> *"If providers aren't sensitive to religious differences between themselves and their patients, this could have a huge impact. The provider could let their own religion drive their interaction and treatment (for example, if the provider doesn't believe in premarital sex and the patient needs birth control options counseling. If the provider lets their own beliefs enter the conversation, they might not provide the counseling/medical advice the patient needs). Also, the patient may have spiritual or religious beliefs that the provider needs to take into account"*

Discourse around the *distrust of medicine* leads to themes of health literacy as a means to facilitate physician trust but a physician's bedside manner and access to online resources emerge as distinct themes post-intervention

Within the category of *distrust of medicine*, most responses demonstrated that responders had favorable trust levels with their own physicians. Common themes from this category included the "expert" designation a licensed physician has as being key in influencing the trust between physician and patient. This is illustrated in the following post-test quote:

> *"Most people trust their physicians' decisions and do not question those decisions because they believe that their physician has more knowledge than they do"*

Moreover, participants acknowledged that their own educational level and "health literacy" or comfort level with health topics also contributed to the trust they placed into their healthcare providers. In contrast, in the post-test analysis, more responses highlighted potential distrust due to race or physician disposition as a new theme.

New themes that emerged within the domain of *distrust of medicine*, at post-test, included specific reference to the healthcare providers' bedside manner as being key to engaging trust. An example that highlights this was seen in responses such as:

> *"…if I feel the physician is being condescending or is unwilling to explain or answer questions, I am much less likely to follow his/her guidance"*

In addition, new themes of distrust now calling out race also emerged in the post-intervention surveys more commonly. A typical illustrative example:

> *"…I think for many non-white people in the US, there can be a distrust of health care providers…"*

An additional new thematic trend was the mention of resources available, such as the internet, that may play a role in one's acceptance of trust from health care systems. A typical post-intervention response that captures this theme:

> *"…internet makes medical information available, many people*
> *don't respect their physicians"*

***Ethical medical research* themes discussing the Tuskegee Syphilis Study and Stanford Prison Experiment are common at baseline while Henrietta Lacks emerges post-intervention**

Within the category of *ethical medical research*, student participants across all arms of the study consistently demonstrated an approval of research projects utilizing human subjects but only if the proper informed consent was obtained. Interestingly, 65% of students in the pre-test cohort responded that they have not been given an ethical framework for doing human research as a student of public health while 100% in the comparator arm felt that this framework was taught to them (Figure 4). When asked to give an example of research from US history, where human subjects were used unethically, two major themes of discourse emerged: the Tuskegee syphilis study and the Stanford University prison experiment.

Of particular interest within the category of *ethical medical research* was the change, at post-test, in the proportion of students who believed they had been taught an ethical framework for doing human research. In the pre-test data, 65% (11 out of 17) believed that they had not been taught such a framework, but this number decreased to 43% (6 out of 14) in the post-test responses suggesting that the intervention facilitated an increased confidence of these students regarding moral decision making around issues of ethical medical research (Figure 4). In addition, an additional notable difference in the post-intervention responses was the inclusion of Henrietta Lacks and the removal of Lacks' cervical cancer cells by Johns Hopkins' researchers to generate the HeLa cell line as a new theme amongst examples of unethical research on human subjects.

The category of *current and future health needs* generates discourse around open access health care models; "medicare for all" becomes a focal theme post-intervention

The category of *current and future health needs* included survey questions which asked whether health care reform was needed in the US. 100% of participants in both the pre-test group and the comparator group responded "yes" (Figure 4). The need for open access to health care was the predominant theme within this category. A typical response demonstrating this theme:

> *"Everyone should have access to health care. Health care should be affordable"*

In addition, the need for non-employer based health coverage also emerged as a theme. An example highlighting this:

> *"Health insurance should not be so tightly bound to employment"*

Some respondents also provided the specific example of the need for a single-payer system when probed on what the country's healthcare system should look like:

“A federal single payer system would be most efficient”

Though little changed in these core perceptions post-intervention, more specific mention of the types of open-access models possible emerged.

At post-test, within the category of *current and future health needs*, 100% of the post-test responders answered that health care reform is needed in this country (Figure 4). No change was seen from pre-test to post-test within this category. However, the specific use of phrases or allusions to "Medicare for all" were more prominent as themes in the post-test survey data. Respondents discussed these models as favorable:

“Medicare for all, plus a primary care provider gatekeeper”

And:

“A federal single payer system, Medicare for all”

Moreover, a number of new responses emerged admitting to not knowing a best solution to the US health care situation but conceded the need for still yet a better system to be developed, accounting for open-access and prevention-focused models, as well as universal availability:

“Heavy emphasis on preventative care and care provided
in a culturally sensitive environment”

DISCUSSION

This study delineates several themes of discourse surrounding student perceptions of health care, medical ethics, and health disparities. Interestingly, this discourse changed, becoming better defined with more focused themes, following the completion of a graduate level public health course focused on *The Immortal Life of Henrietta Lacks*. To establish a baseline level of understanding among the student participants, common themes from all three datasets (pre-test, post-test, and comparator) were identified. Themes were categorized under six domains of focus: *health disparities; health access; race, culture, and spirituality; distrust of medicine; ethical medical research; and current and future health needs*. The themes that were pulled from all three datasets demonstrated a sophisticated understanding of health care issues and health disparities; this was not surprising given the sample consisted of graduate level students in the field of public health.

The baseline themes identified, within the category of *health disparities*, included inequality, low SES, and race/culture. Interestingly, post-intervention data revealed some differences in post-test participant themes compared to baseline within this category. In particular, the social determinants of health were better defined in responses post-intervention and race emerged thematically as more robust. Skloot's biography covers the plight of Henrietta Lacks and her family who is impoverished. Vivid story-telling and robust descriptions paint a clear picture of the Lacks real-life family situation, both in the past, as well as in the present.

That post-test survey data now captures responses with more pronounced discourse on social health determinants suggests that the context of having taken HSERV 590 may have helped to shape some of the responses in the post-test cohort; the history described in Skloot’s biography may have helped the students contextualize these social determinants in a way they had not been previously thought about. It is possible that the vivid narrative provided a thorough understanding of the situation in which health disparities existed for the Lacks family and at post-test students felt compelled to specifically call these out. Alternatively, having taken HSERV 590 may have reaffirmed previous notions that were brought back to the forefront, or top of students' minds, in the post-intervention survey now enabling them to highlight very specific themes (Figure 3, Table 2).

Henrietta Lacks was an African-American woman who by Skloot's description would fall into the category of low SES. Issues of race, culture, and equity stream through the content of the biography. Moreover, in this academic cycle, HSERV 590 was taught by a tenured, African-American Professor in the School of Public Health; discussions of race were inherently a focus of the class. Interestingly, in the post-intervention data, specific race-focused examples were more prominent than in the baseline dataset. More examples specifically mentioning African-American populations were highlighted post-intervention. This suggests that having been immersed in a quarter-long course which regularly discussed race, participants became more raced-focused in their approach to answering in the post-test survey.

Common to all three datasets within the category of *health access*, were themes of education and personal behavior, speaking to a broad "health literacy" as being key to access. Notably, post-intervention data within the category of health access showed new thematic discourse addressing the Affordable Care Act (ACA) and the move toward opening up access to health care for the broad US population. It is possible that the HSERV 590 course discussions painted a real life picture of a family impacted by lack of access to health care, and as such, the original context from which study participants responded became more focused on the ACA as a way that we as a country are trying to address this issue. As the sample consisted of public health practioners, it is possible that students felt the need, post-intervention, to address solutions to access issues that have been accomplished in their lifetime such as the ACA.

Within the category of *race, culture, and spirituality*, language barriers, cultural competence, and discrimination were prominent themes at baseline. Post-intervention, religious sensitivity emerged as an important theme in how one might be receptive to health care providers. Spirituality is a topic addressed at length within the story of Henrietta Lacks as interviews with family members alluded to strong religious beliefs which impacted their understanding of what the HeLa cells line represented in the context of Henrietta Lacks' death. It is possible that the intervention changed the minds of participants in perceiving religious sensitivity as playing a bigger part in how patients approach their health care because of the interviews with Lacks family members within the biography.

Within the category of *distrust of medicine* were themes of health literacy and trusting the expert status of the physician. At post-test, new themes highlighting the lack of resources such as the internet appeared, qualifying an inability to question and understand healthcare providers compared to those who have such resources. Participants noted that as educated individuals, they have the tools and confidence to confirm, and therefore trust, their healthcare providers' decisions. Mentioned throughout the biography was the Lacks family's current health situation and lack of access to health care and resources. Themes of equity and health disparities were prominently discussed during HSERV 590 in the context of the Lacks family. The participants made a clear connection between access and SES, and that communication barriers, and in some instances either cultural or language barriers, play significant roles in preventing access across other categories of the study as well (Table 2, Figure 3).

Skloot's biography underscores a general mistrust amongst the African-American community for the broader US health care system. For example, in *The Immortal Life of Henrietta Lacks*, Lacks family members are cited as saying the streets of Baltimore are not safe for African-Americans as Johns Hopkins Hospital was rumored to be kidnapping this population for human experimentation. While anecdotal at best, this vivid imagery portrayed in the biography, and discussed in HSERV 590, may have shaped participant responses. While in the baseline dataset where most discourse suggested participants trust of their healthcare provider was based on their own education and health literacy, new discourse emerged in the post-intervention data suggesting a distrust by participants who felt their healthcare provider was condescending, unapproachable, or culturally misunderstanding. This is in striking contrast to baseline themes where typical responses emerged suggesting a general trust in the expertise of a physician. Again, it is possible that the HSERV 590 intervention provided context for why one might distrust the health care system as illustrated throughout *The Immortal Life of Henrietta Lacks* and this was reflected in differences seen in the post-test data.

Within the category of *ethical medical research*, the majority of the student participants in the pre-test and comparator groups did not feel that they had been given the proper framework for making decisions around ethical human research in the baseline dataset. Interestingly, post-intervention, the majority of students now felt that they had a good ethical framework as a student of public health. Given that HSERV 590 is an ethics course, harboring thought provoking philosophical and moral debate, it is likely that the intervention impacted student confidence in this category. The biography broaches an interesting moral topic as Johns Hopkins researchers took Henrietta Lacks' cervical cancer cells (ostensibly) without her informed consent, but the act led to downstream discoveries having influenced progress in the cancer research field from which science and medicine still benefit today.

A shift in the post-intervention responses toward the student perception that they now had a better framework for the ethical use of human research subjects could be due to the context through which HSERV 590 discussions took place. Interestingly, post-intervention, the description of the removal of Henrietta Lacks' cervical cancer cells was now mentioned as unethical where the only two previous themes that emerged were the Tuskegee syphilis study and Stanford prisoner study. The mention of Lacks was absent in the baseline data suggesting the story of Lacks was either largely unknown to the respondents prior to the intervention or, perhaps, not considered particularly unethical.

One theme that did not change among baseline and post-intervention responses was the need to overhaul the US health care system. Baseline student beliefs pointed toward the need for change in the US health care system, opening access to all citizens. In the category of *current and future health needs*, one theme suggestive of such overhaul, that became more prominent post-intervention was "Medicare for all". Again, in-course discussions focused on equity, access, SES, and health disparities, may have led respondents in the post-test to identify more specific, concrete examples. In addition, mention of specific attributes that would be important to take into consideration in open-access models were now mentioned post-intervention. Clearly, deeper thought with more specific, more explicit examples emerged in the post-intervention data. Taken together, the number of new emergent themes observed after students participated in the intervention suggests that the intervention did impact student beliefs and perceptions, or at the very least, how students represented those beliefs and perceptions on the post-intervention survey.

Limitations

Limitations of this study include its small sample size and the quasi-experimental, mixed qualitative nature of the methodologic design. We chose to develop our own survey tool in order to elicit specific discussions of interest. Utilization of a previously validated survey tool addressing health disparities might have been considered instead. In addition, a survey tool designed to probe students about how they felt their perceptions were directly impacted by the biography would have also been an additional component to consider. Moreover, it is possible that post-test survey responses may have been influenced by participants having previously answered the questions in the pre-test survey.

Because the students may have been taking a series of additional public health oriented courses simultaneously, and/or completing a practicum or thesis research project, we cannot rule out that those (or similar outside influences) also served to impact student beliefs and perceptions. Moreover, as addressed above, since the participants were all graduate students in public health, their belief and perceptions may have been well formed previous to the intervention. However, it is interesting that post-test data did identify unique responses, suggesting that even if baseline beliefs were well formed due to student background, the intervention still had some impact - which may be due to the immersion of discussion within the categories of interest, fostered by taking HSERV 590.

Conclusions and future directions

This study demonstrates the power that discussions of race, health disparities, and equity may have on student beliefs and perceptions. We also show how utilizing a biography such as *The Immortal Life of Henrietta Lacks* can serve to put these types of important discussions into a context that everyone can understand. Understanding the communities in which health inequities exist is paramount to bridging cultural gaps between people (7). As such, *The Immortal Life of Henrietta Lacks*, could be a plausible tool in relating how health inequities really can impact individuals and communities. This study suggests that Skloot's biography may have utility both inside and outside of the classroom setting, potentially serving as a springboard for discussion in broader communities or potentially even as a cultural competency training tool in health care or public health agency settings. As the importance of discussing race, culture, and inequities in our country comes to the forefront of a national stage, finding unique ways to put our differences and similarities into context will be crucial. Given the results presented here, we believe *The Immortal Life of Henrietta Lacks* can be a good starting point for having these types of discussions.

Figure 1. Conceptual diagram pre-intervention

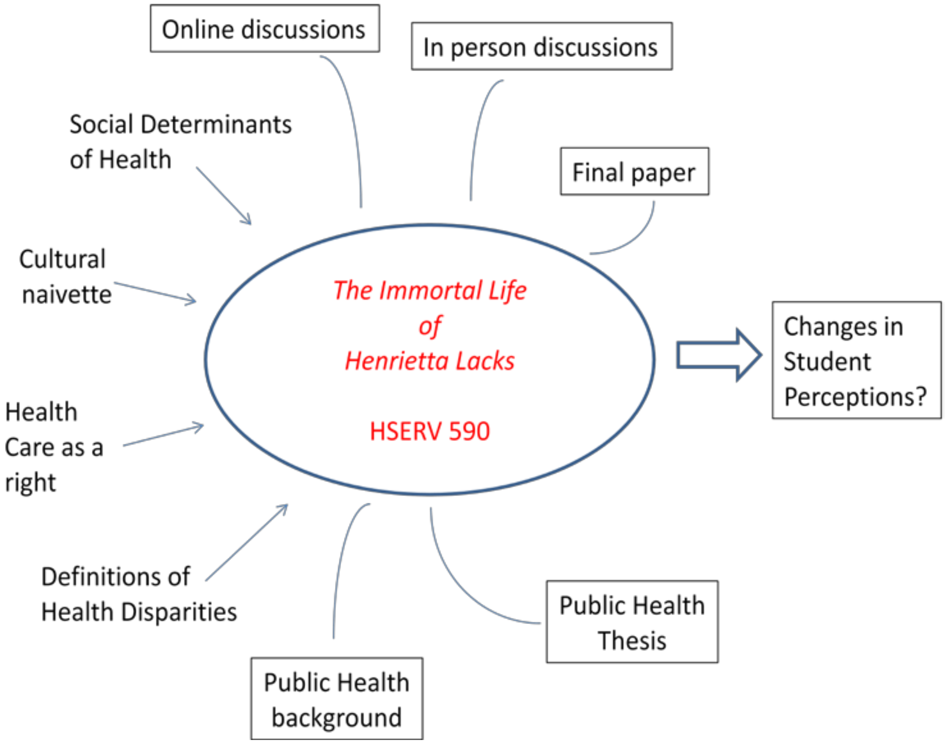


Figure 2. Quasi-experimental study design

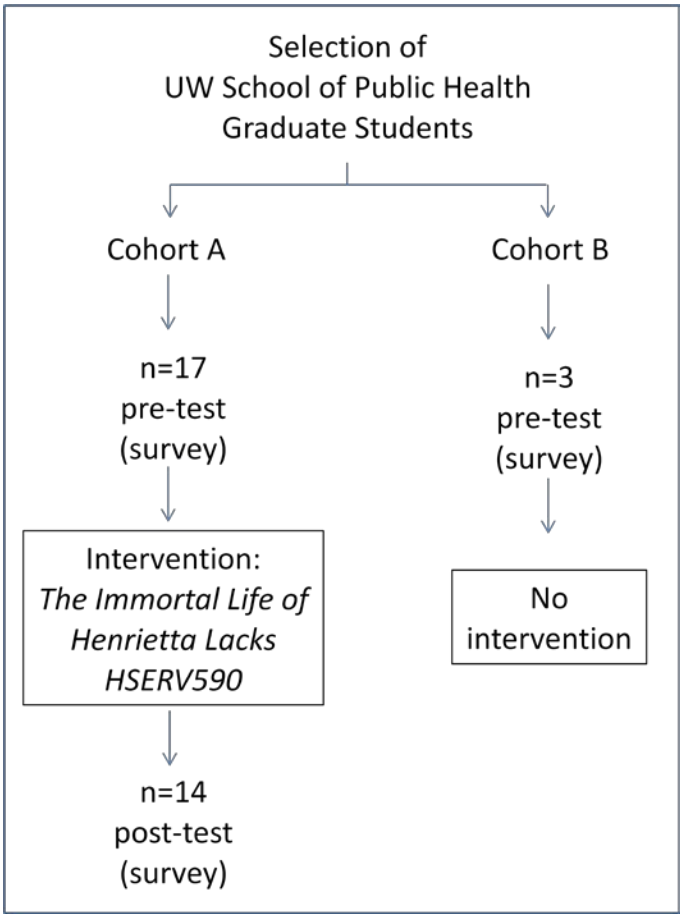


Figure 3. Conceptual diagram post-intervention

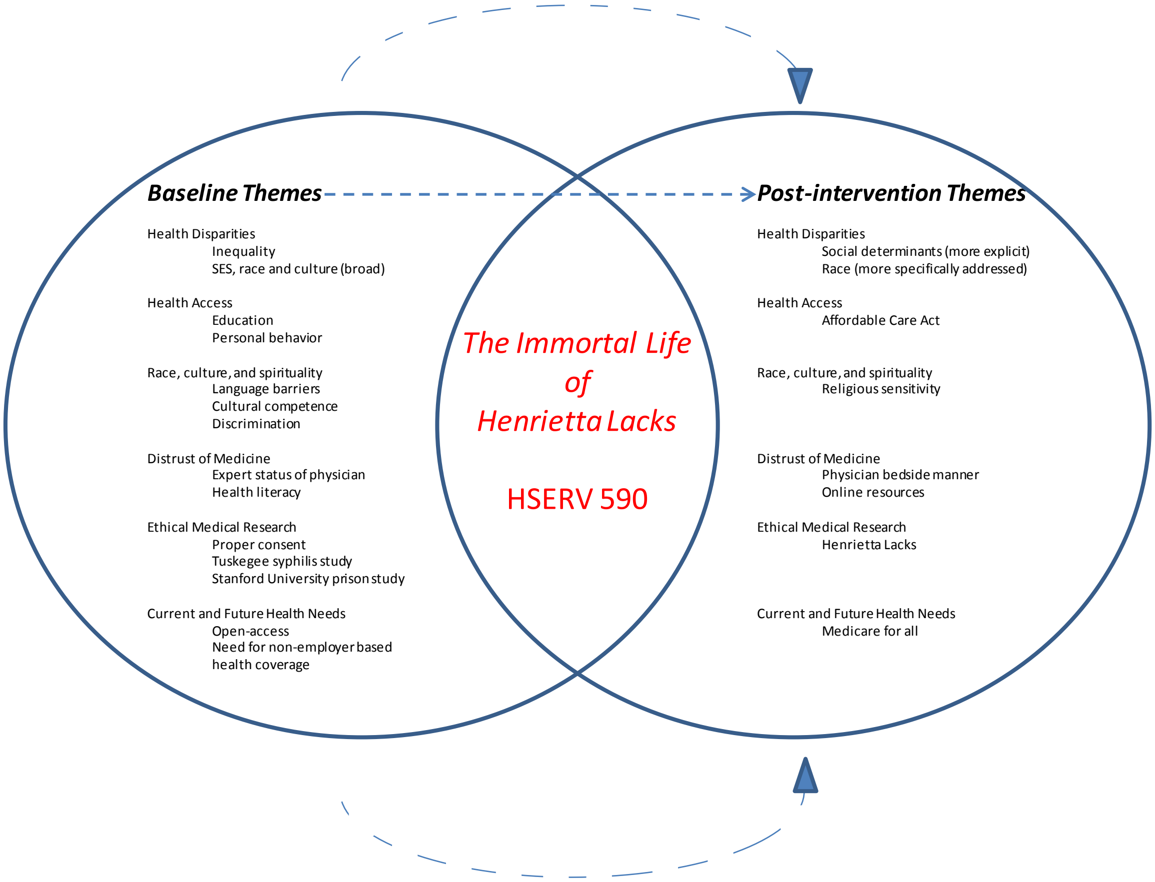
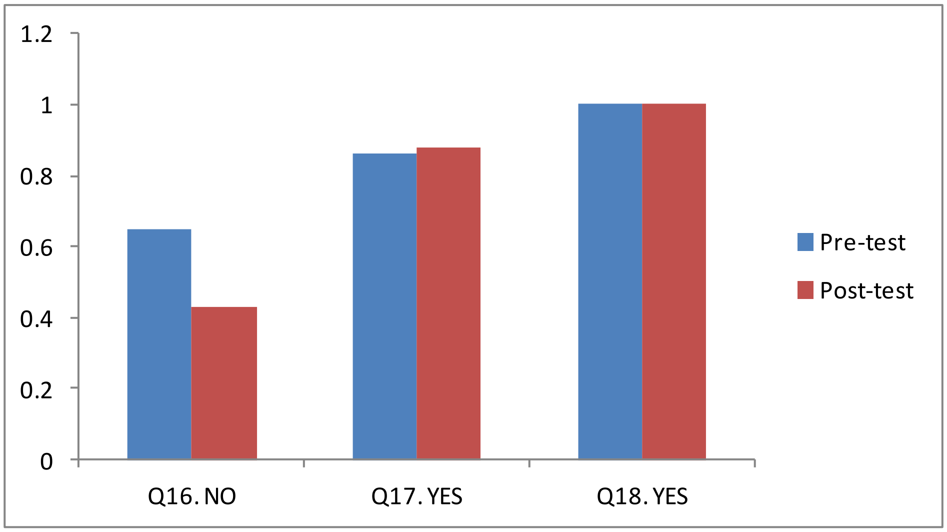


Figure 4. Yes/No responses to survey questions 16-18



Q16	As a student of public health, do you believe you have been taught an ethical framework by which research on human subjects should be done?
Q17	Do you believe that health care is a right and that everyone should have access to health care?
Q18	Do you believe that health care reform is needed in the US?

Table 1. Survey questions

Q1	If you had to guess, what percentage of the US population do you believe receives no health care?
Q2	How do you define health disparities?
Q3	Name 3 factors that you think contribute to health disparities.
Q4	Give an example of a health disparity.
Q5	What is your perception of access to health care?
Q6	In the question above, do you think that access to health care has improved overall over time?
Q7	If adjusted for access to care (ie: if regardless of race or socioeconimc status, people had access to health care), do you believe that disparities in health care received would still persist? If so, why?
Q8	Do you believe that cultural differences can impact the health received at a healthcare provider? If so, how?
Q9	How do you think spirituality/religion plays into how patients receive health care?
Q10	Do you trust the opinions and treatments given by the physicians you see as your healthcare provider?
Q11	How does asymmetric knowledge (the fact that a physician knows much more than you about how to treat a medical problem) impact your willingness to follow a physician's guidance?
Q12	What factors contribute to people's ability to make informed health care decisions?
Q13	Do you believe that most people question the decisions made by their physician? Why or why not?
Q14	Do you believe in conducting medical research on human subjects?
Q15	Can you name examples of unethical medical research on human subjects from US history?
Q16	As a student of public health, do you believe you have been taught an ethical framework by which research on human subjects should be done?
Q17	Do you believe that health care is a right and that everyone should have access to health care?
Q18	Do you believe that health care reform is needed in the US?
Q19	What do you think health care SHOULD look like in the US?

Table 2. Categories with Baseline and Post-intervention Themes

Category	**Baseline Themes**
Health Disparities	• Inequality • SES, culture, and race (broadly addressed)
Health Access	• Education • Personal behavior
Race, Culture, and Spirituality	• Language barriers • Cultural competence • Discrimination
Distrust of Medicine	• Expert status of physician • Health literacy
Ethical Medical Research	• Proper consent • Tuskegee Syphilis Study • Stanford University Prison Experiment
Current and Future Health Needs	• Open access • Non-employer based health care
Category	**Post-intervention Themes**
Health Disparities	• Social determinants of health (more explicit) • Race (more specifically addressed)
Health Access	• Affordable Care Act (ACA)
Race, Culture, and Spirituality	• Religious sensitivity
Distrust of Medicine	• Physician bedside manner • Online resources
Ethical Medical Research	• Henrietta Lacks
Current and Future Health Needs	• Medicare for all

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