

3690: A Journal of First-Year Student Research Writing

Volume 2020

Article 3

2021

Medical Injustices: Young Adult Literature Brings Them to Light

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Recommended Citation

Minton, Korinne (2021) "Medical Injustices: Young Adult Literature Brings Them to Light," *3690: A Journal of First-Year Student Research Writing*: Vol. 2020 , Article 3.

Available at: <https://fisherpub.sjfc.edu/journal3690/vol2020/iss1/3>

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Medical Injustices: Young Adult Literature Brings Them to Light

Abstract

Overview:

The term, “young adult” has a very loose definition. Some say it is only teenagers. Some say it can reach up to thirty year olds. The official definition is, “A person in their teens or early twenties” (Google), but one thing that can be agreed upon is that this period of life is a very rough one. People are just figuring out who they are, what they like to do, who they like and who they don’t like, who they can trust and who to not turn your back to. But most importantly, it is a period of growth and learning. At the early stage of young adults, many people try to control what these young people learn and what they read and watch and see on social media. But learning should be done without boundaries, and that is exactly what young adult literature does. It offers a way to encourage learning about any and all subjects. But sadly, many schools put blocks on these books because of the difficult subjects these books hold such as racism and rape. Many teachers and parents don’t want to expose their children to these horrid subjects, but these topics need to be taught. A change cannot be made without any knowledge. This age group has fresh minds craving information and by giving them this knowledge, they can grow with it and make a difference. One of these topics include racism. More specifically: racism in the medical field.

Author's reflection: My name is Korinne Minton and I am a current P1 pharmacy student at the Wegmans School of Pharmacy at St. John Fisher College. As much as I love chemistry and medicine I have a fondness for writing. In my research writing class our main topic of focus was young adult literature and for the final paper, Professor Barry said to connect it to our majors. As a pharmacy major it was difficult to find relevant literature to write about. I had to think back to previous books I had read and I was able to come up with an idea. The two books were “Fever 1793” by Laurie Halse Anderson and “The Immortal Life of Henrietta Lacks” by Rebecca Skloot. Both talked about the racial discrepancies in the medical field and I was able to take the idea from there. I want to thank my professor, Mrs. Maureen Barry, for pushing me to stick with my idea and helping me create one of my best papers and being a big supporter.

Medical Injustices: Young Adult Literature Brings Them to Light

Korinne Minton

Research Based Writing: Literature and Adolescence

Mrs. Barry

April 2020

I certify that this paper is mine alone with support from my teacher, an extra ear, and possibly the writing center in accordance to St. John Fisher's Academic Honesty Policy.

Korinne Minton

Korinne Minton

Maureen Barry

Research Based Writing

April 25, 2020

Medical Injustices: Young Adult Literature Brings Them to Light

The term, “young adult” has a very loose definition. Some say it is only teenagers. Some say it can reach up to thirty-year olds. The official definition is, “A person in their teens or early twenties”(Google), but one thing that can be agreed upon is that this period of life is a very rough one. People are just figuring out who they are, what they like to do, who they like and who they don't like, who they can trust and who to not turn your back to. But most importantly, it is a period of growth and learning. At the early stage of young adults, many people try to control what these young people learn and what they read and watch and see on social media. But learning should be done without boundaries, and that is exactly what young adult literature does. It offers a way to encourage learning about any and all subjects. But sadly, many schools put blocks on these books because of the difficult subjects these books hold such as racism and rape. Many teachers and parents don't want to expose their children to these horrid subjects, but these topics need to be taught. A change cannot be made without any knowledge. This age group has fresh minds craving information and by giving them this knowledge, they can grow with it and make a difference. One of these topics include racism. More specifically: racism in the medical field.

The U.S. has a long history of racism and segregation dating back to when the country was first born. But we will focus specifically on the medical industry. Racism in this industry has two different sides. One side it the professionals themselves are racist: or the programs that

teach them are racist and discriminatory. Let's start with the latter. For this research, mostly nurses are studied. And a pattern has been found that a good number of nurses have negative views about African Americans. Robin Steed, the Program Director and Associate Professor at LSU Health Shreveport wrote, "Caucasian Allied Health Students' Attitudes Towards African Americans: Implications for Instruction and Research" in the ABNF Journal and explained an experiment that was conducted at a college nursing program and the results were surprising. "Overall, the 244 allied health students in this study appeared to have a higher than average negative attitude towards African Americans, while the faculty's attitude was similar to the population average. It should be noted that only 53% of the Caucasian faculty completed the survey." (Steed 85). The study shows how a majority of nurses have a negative view on people of color and most likely other races as well. The survey was also voluntary, and a large number of people declined to participate, which may be perceived that they would not like their views to be known. But another study was done that shows how training in this area can have a great impact on upcoming nurses.

Many nurses understand that they do not know much about other cultures and are not prepared when it comes to having to interact with other cultures in a respectful manner. But the difference is, they want to learn so they can be prepared. Helen Vanderberg, an assistant professor at the University of Saskatchewan wrote, "Conceptualizations of Culture and Cultural Care Among Undergraduate Nursing Students: An Exploration and Critique of Cultural Education." Vanderberg explains how these nurses feel and how education in these areas can be of great importance. An experiment was done in 2010 where one group was not given any cultural training and another group was and at the end, a test was given that could determine cultural awareness and the group that was trained scored higher. In Vandenberg's article she

writes that:

Despite the differences in the ways that cultural care may be applied, nursing educators are encouraged and required to teach students about culture care (CNA, 2004).

However, little is known about the outcomes of current educational initiatives regarding culture or cultural care in nursing. Further research is needed to understand and critique how nursing students are taught about culture and cultural care (100).

It makes sense that more training leads to a better outcome. But many students are not given this training. Society is filled with many cultures that vary in beliefs which can interfere with medical practice such as vaccines and who makes decisions (i.e. patriarchal societies determine what happens to their daughters and wives). Some of these beliefs may go against our own beliefs and it is something we cannot argue. There are also issues with language barriers. Many medical practices have translators available. But they are not always used, and this training can help close that barrier and make better decisions for the patient when everybody can be understood.

Some colleges themselves are racist and discriminatory. And while that is against the law, it can just be a precedent followed by the college, or the people in charge of admissions are racist (any reason is unacceptable, but loopholes are sadly always found). Most nursing programs around the U.S. have a low percentage of African American students. Some of these schools may just be in areas with a low African American population. But for those who are not, there is still a low number of minorities in nursing programs most likely due to financial reasons and also the belief that they will not fit in. In M.E. Brooks article, "Voices of perseverance: A phenomenological exploration of the life histories of female African American registered nurses" she talks about the history of African American nurses and their stories. He states that the

number of minority nurses has always been low because they were not allowed an education that allowed them to enter nursing school. Even if they did, the higher education schools would not accept them. Brooks continues to say how those policies have only recently been changed, and even with the policies being illegal, admissions faculty are still finding excuses to not accept minority students. "Exclusionary admission to nursing education programs remained in place through the mid-20th century. Black students were relegated primarily to nursing programs located in the South. In 1925, of the 1,696 schools of nursing accredited by American Nurses' Association (ANA) in the US, only 6% (102) schools admitted Blacks (as quoted in Burnette, 2004) "(22).

Racist professionals. Now racism can take on multiple different forms. So, it's important to determine if the nurse is conscious of it and ignorant or they don't understand other cultures, which makes them less prepared as stated above. An example of just racist professionals is very prominent in the early-mid 1900s. Two major cases are the Tuskegee men experiment and the story of Henrietta Lacks. Charles Walker's, "Lest We Forget: The Tuskegee Experiment" explains the history of the experiment and the outcomes of it. The Tuskegee experiment was conducted in 1932, and the experiment was about "Bad Blood" a euphemism for syphilis during that time. Many poor, uneducated, African American men were offered treatment for the disease but were unethically experimented on. The tests lasted for four decades and no new drugs were tested, and no treatments were given. Yet, the men were coerced and bribed into continuous attendance. They would get a hot meal, free transport to the city, and a small insurance policy if they died. During that time and their economic standing, these were very enticing offers. But the most enticing was, as Walker explains, "Sympathetic attention from trained physicians and nurses was the most seductive inducement of all" (5). Many participants didn't know what was being done to them and were told that the procedures

they went through were normal. But of course, they were not. However, the people in charge knew that because many of these men had never been to a doctor before because they could not afford it or were turned away. Sadly, the only outcome of this experiment is a lesson on ethical practices. As Walker states, "The participants, nearly 400 African American sharecroppers from rural Alabama, demonstrate that the burden of medical experimentation has historically been borne by the most vulnerable populations - those who are least able to protect themselves from abuse and exploitation"(5).

Henrietta Lacks had a similar story. She was a young African American mother who went to John Hopkins Hospital with complaints about abdominal pain. John Hopkins was one of very few hospitals that would accept black patients and it was the "closest" to Mrs. Lacks. When she went, the doctors did a biopsy of a lump they found and later diagnosed as cervical cancer that quickly took Henrietta's life. But what Henrietta wasn't told is that the cells from her biopsy were used in experiments and were discovered to be remarkable. Her cells could live and replicate outside of her body, something that does not happen. Her cells are immortal. In Mario Salas' article, "The Ugly Medical Side of Racism", he talks about the poor treatment African Americans were getting during this time and he words the whole ordeal perfectly:

In the case of Henrietta Lacks, her cells were eventually used to create the polio vaccine and a host of other medical improvements. The family of Mrs. Lacks was never compensated for the use of her cells, yet Nazi-type researchers used her cells without her knowledge. In 1951, a scientist at Johns Hopkins Hospital in Baltimore, Maryland, named George Gey, created the first sustainable human cell line with a tissue sample snatched from Henrietta Lacks who had cervical cancer. (1)

Mrs. Lacks' cells have helped millions of people and have generated a lot of money. But not until recently did the family find out that the cells were stolen and that they could have been compensated which would have helped them a lot as they lived in poverty and could rarely afford their own medical bills. But Henrietta and the Tuskegee men were not the only stories.

As a result of this discrimination and these wrongdoings, there have been steps taken in the right direction. John Hopkins University is planning to name a new research building after Mrs. Lacks. A foundation has also been created in her honor by the author of the book, The Immortal Life of Henrietta Lacks by Rebecca Skloot.

Many people have experienced this discrimination and lack of concern for their beliefs, but it is not a widely known subject because nobody wants to speak up against their doctors, or they refuse to believe they are capable of anything but good. People view doctors to be impartial people because everybody is the same on the inside, and they entered this field to help people. But that is sadly not always the case. Many doctors are racist and do not try to help others to the best of their ability. Unfortunately, society is not fully aware yet, some media has portrayed it. Many shows about doctors and murder cases show how some of these professionals are racist by not providing care or saying they deserved it or saying that they should be fine, when someone the same race as them, gets higher and better treatment (i.e. Law & Order). Another way society is gaining awareness is through literature, and for this purpose, young adult literature specifically.

Young adult literature (YAL) has many different perceptions. Many people see YAL as just fictional stories about teenage romance and drama and that the whole genre is just for teenage girls, but that is not the case. Many YAL books contain very important lessons about modern day society. Many of them are fiction, which also makes it easier for young adults to

understand. And having a fictional base makes it more relatable, and the reader can relate to the characters and what they are going through. But it also raises the readers awareness of different issues going on around them such as racism.

One example is Laurie Halse Anderson's novel, *Fever 1793*. This book is about a family in Philadelphia in 1793 when the yellow fever epidemic hits. The family owns a coffee shop and runs it themselves with the help of their cook, Eliza, a black woman whose husband bought her freedom. The main character, Maddie, leaves the city with her grandfather because her mother is sick. But she eventually has to come back to the city. When she does, her mother is missing and her grandfather has passed away, and she is all alone. Maddie has to figure out how to survive in these harsh conditions all by herself, while still recovering from a deadly fever. But she eventually finds Eliza when she is helping with the sick and Maddie asks the obvious question of, "Why is Eliza working with the sick, won't she fall ill?" Anderson wrote:

The Doctors thought us Africans couldn't get yellow fever. Rev. Allen said this was a chance for black people to show we are every bit as good and important and useful as white people. The Society organized folks to visit the sick, to care for them and bury them if they died (176)

Anderson continues later to explain how that was an incorrect assumption on the doctor's part:

The Society has done a remarkable job, and I don't mind saying that with pride. The Africans of Philadelphia have cared for thousands of people without taking notice to color. If only the doctors had been right, we could look to these days of suffering as days of hope...After a few weeks of nursing the sick and burying the dead, our own people started to sicken. Black people can get sick with yellow fever just like white people or

Indians. I do know some who have never been sick, but then there are white people who can say the same thing (176).

During the 1700s, medicine was not very advanced, and people believed bleeding people would cure them. But they also had the insane logic that black people are immune to all diseases, and as we know, that is not true. The book also covers many other topics. Maddie's childhood friend passed away from the fever as well as her grandfather. Maddie had to assume the role and responsibility of a parent to the orphaned baby Nell she found all alone beside her mother's dead body. She had to run a coffee shop without prior knowledge of doing so, and she had to learn to grow up very fast and how to handle everything life handed her. Another interesting point about this book (and other Anderson novels) is her use of historical quotes to start chapters that relate to them. For instance, the start of chapter 15 had the following quote:

Wives were deserted by husbands, and children by parents. The chambers of diseases were deserted, and the sick left to die of negligence. None could be found to remove the lifeless bodies. Their remains, suffered to decay by piecemeal, filled the air with deadly exhalations, and added tenfold to the devastation

-Charles Brockden Brown

Arthur Mervyn; or Memoirs of the Year 1793

Books such as *Fever 1793* are a great example of interesting education. The books are fascinating and can always be interpreted to apply to modern day society. For instance, many children find themselves orphaned and sometimes the oldest of many siblings; thus, need to

take care of themselves and those who depend on them. Many teenagers face the deaths of their grandparents and sometimes even friends. And lastly, all who read this book are growing in one way or another, and this book can be applied to help give hope or inspiration that better days are to come as well as to teach about misconceptions about African Americans.

I have always loved history and science. They always caught my attention, and in school I had a natural knack for them. So, when I was entering freshman year English, we had a summer reading assignment, and I had to choose a book from a given list and I found a book titled, *The Immortal Life of Henrietta Lacks* by Rebecca Skloot. This is a story of a great injustice in the medical field by stealing cells and making money off of them without any consent or knowledge of the fact. While this book was more advanced in nature and information and format, the level of understanding a reader wants to reach correlates to the difficulty of the reading. This book is filled with lots of data that was plugged into the storyline. At times it is a little confusing to read. But the general idea is very easy to understand. Skloot makes the heartbreak and grief come alive. By adding the real data to back the story, the impact of the story is greater. The way Skloot writes though is very interesting, she makes comparisons that I would have never thought of making, for instance:

Another scientist calculated that if you could lay all the HeLa cells ever grown end-to-end, they'd wrap around the Earth at least three times, spanning more than 350 million feet. In her prime, Henrietta herself stood only a bit over five feet tall (2)

Skloot also has a way of using time to really emphasize her point and emotions. For example, "The caption said the family had found out just a few months earlier that Henrietta's cells were still alive, yet at that point she'd been dead for twenty-five years" (6). The story is so well written that it can grab anyone's attention, whether it be someone doing research or wanting a good

story to read about family. I especially love how Skloot also uses Henrietta's daughter Deborah's own words in the book to help explain. One can never replicate how someone is feeling or their emotions, so it is best to use their own words. As Deborah points out:

But I always have thought it was strange, if our mother cells done so much for medicine, how come her family can't afford to see no doctors? Don't make no sense. People got rich off my mother without us even knowin about them takin her cells, now we don't get a dime. I used to get so mad about that to where it made me sick and I had to take pills. But I don't got it in me no more to fight. I just want to know who my mother was (Deborah's Voice/prologue).

The story is so powerful and filled with so much knowledge and emotion and heartbreak and loss; yet so amazing all at the same time.

When I first read this book, I will admit that I didn't quite understand the "big deal". I thought, "so what they took her cells and didn't ask. Why would the family's lives change? It's not that big of a deal." But the more I thought about it and looked it up for even more information and reread the book, it made more sense as to why it is such a big deal. This kind of treatment is wrong and racist and cruel. Humans are not lab rats (which I am also against). But humans are emotional creatures who can at least speak their minds, but that innate right was taken away from them. They lost the ability to speak for themselves, so their health was put on the line. That is why this book should be read by all young adults. It is packed with so much knowledge and written in a way that it can be understood and enjoyed, while having a valuable lesson taught at the same time. The issue of ethics and race has always been an argued topic but the publication of Skloot's book made a very large impact on the industry and people's lives. Laura Beskow wrote, "Lessons from HeLa Cells: The Ethics and Policy of Biospecimens" and she discusses what we have learned from Mrs. Lacks and the impact Skloot's book has had. "Although the ethical and policy issues associated with biospecimen research have long been

the subject of scholarly analysis and debate (48, 118, 124), the publication of Rebecca Skloot's bestselling book *The Immortal Life of Henrietta Lacks* (130) captured the attention of a much broader audience. The book is a popular teaching tool and book club favorite (138), and the book and its author have been the subject of numerous reviews, news stories, features, commentaries, profiles, and interviews" (Beskow). The book had a large impact on more than just young adults and has reached many different platforms and has reached a very large audience and has pushed for many reforms.

The book *Sold* also talked a little bit about the doctors in India. The book is about a 13-year-old girl sold into human trafficking and was forced to have sex with men for money. A doctor would come once a month to give the girls shots so they wouldn't get pregnant and the one time he was there, he tried to have sex with the main character. The man they girls should trust even a little bit to help them, was just as bad as the rest of them. The book also has many other aspects such as the human trafficking and grief and hopelessness, but I feel adding the doctor made the situation that much worse. The one man continually there to help these poor girls was someone they could not trust.

These books also talk about different topics such as death and depression and struggle. But these books also teach their readers about these topics in a way that can spark a change. YAL can help people learn about societal issues in an "enjoyable" way, and once these issues are known, they can be changed, and that is the whole purpose of the genre. This genre also helps its readers develop emotionally and can give them some hope for situations they are in.

YAL is a growing genre that has a growing impact on its readers. It's most known authors such as John Green, J.K. Rowling, and Suzanne Collins write about a wide variety of topics including: mental health, rape, racism, school, bullying, and much more. And while these

are not the happiest of topics to write about, they are very important. Laurie Halse Anderson, a well known YAL author, was interviewed by Julie Prince and asked why she writes about such dark and deep subjects and her response was:

Sometimes I wish I could write more "happy" books because it is emotionally draining to spend a year or two immersed in these topics. But then I get amazing letters from readers who tell me that one of my books helped them get through a tough time, and I know that this is what I am meant to do. (Anderson).

And that is exactly what YAL books do. They help young adults develop coping mechanisms and makes it easier to communicate with people about what they are going through.

YAL also lets readers know that they are not the only ones going through what they are going through and that they can talk to people about it. Michael Cart wrote on the importance of YAL and how it benefits its readers and he stated, "By addressing these needs, young adult literature is made valuable not only by its artistry but also by its relevance to the lives of its readers. And by addressing not only their needs but also their interests, the literature becomes a powerful inducement for them to read". YAL has been forbidden in some classrooms because of topics such as sex and drugs and violence, but all that is doing is harming the students. They could be learning lessons about these harsh topics since people don't really talk about them. Teachers think that if their students don't read it, they won't do it, but that is not the case. YAL can teach students about what is wrong and what is right in society and they can then be better informed to then make better decisions. Ava McCall wrote, "Making a Difference: Integrating Social Problems and Social Action in the Social Studies Curriculum: A Journal for Readers, Students and Teachers of History" and in it she talks about the importance and empowerment YAL can have on its readers. "Educators who have engaged in significant studies of social

problems and incorporated social action projects with their students cite numerous benefits. Students, even at young ages, often feel empowered when they think about and voice their ideas, are listened to, and offer solutions to significant social problems (Danielson 1993)"(208). YAL is such a broad genre with such a large impact on its readers and it keeps growing. So the encouragement to read these books is essential because it can teach people about issues such as racism in the medical industry and it gives them an area of interest and can empower them to make a difference in the world.

Racism in the medical industry is just one issue in society that people don't know much about. Many are very willing to just deny the fact that it exists because they want to believe their doctors to be the best, but little do they know, the room next to them with a minority patient could be getting awful treatment. And many of these stories are not made that public. If, they are, it sometimes takes years for the truth to come out, for example Henrietta Lacks' family didn't find out until decades after, and a more recent example of the Olympic gymnast physical therapist guy who raped and molested the athletes, didn't come out for years. But as stated before, many people don't know that issues like these exist and for those who do; some don't see the problem or don't know what to do to help make a change. But telling younger people can stop the endless cycle of this kind of abuse. Teaching students about these difficult topics at a younger age can have a greater impact on their perception, and they will know to speak up if something is wrong, instead of letting it continue. And yes, these topics are not easy to comprehend or talk about, but YAL is the perfect solution. The books are written in an easy to understand way and can get these messages across very clearly and in a way that is relatable and can make a difference for somebody.

We, as a society, have a lot of work to do to make this world a better place to live in and a way for that to happen is to influence our young people. Don't coddle them and then throw

them to the wolves when they are adults. We need to be teaching them these lessons at a young age, because if an interest is developed, a solution can be made, and over all, the next generation will be filled with more open minded and more aware people, and hopefully good change won't be too far behind them. These children/young adults can learn about Henrietta Lacks and become doctors and want to make a change. They can learn about Eliza and learn to push through hardships and become something great and someone kind. They can learn about Lakshmi and open their eyes to the world around them and help people. These books create a blueprint for change- a blueprint to make the world a better place one book at a time - possibly to correct medical injustices going on in the system today.

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