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(البحث العلمي وسياسة حضارية لتطوير العملية الاشرافية والنهوض بالواقع التربوي)
وتحت شعار
(البحث العلمي والاشراف التربوي رؤى مشتركة لبناء عملية تربوية ناجحة)
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Violation of Bioethics in Ann Patchett's *A State of Wonder*

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Abstract

Bioethics form a basic part of medical research and experiments. This field has been solidly established in modern and postmodern eras in order to avoid the past transgressions that were done against participants in medical field. This paper aims to discuss the intersection of bioethics and racism in Ann Patchett's *A State of Wonder*. This novel presents the journey of American doctors who venture into Amazon forests in order to research the fertility qualities of native people there.

Keywords: Bioethics, racism, medical research

1.1. Introduction

P.R. Wolpe and J.R. Howard (2007) define bioethics as “the modern manifestation of the venerable field of medical ethics. Bioethics includes the categories traditionally known as medical ethics – the proper way to treat patients, ethical principles around death and dying, abortion, euthanasia, confidentiality, and so on” (p. 682). In his 1978 introduction to the *Encyclopedia of Bioethics*, Warren T. Reich defined bioethics as the systematic study of human behavior in life sciences and healthcare, evaluated through moral principles and values. While this definition gives clarity about the general focus of bioethics, it also shows how broad the term is. This wide scope of Bioethics makes significant disagreements among scholars. These disagreements stand against a stable and precise definition. A brief exploration of the history of bioethics along with its formative period, social and cultural background, and political context reveals the complexity of this discipline (Cascais, 1997, p.9). Reich highlights three aspects that led to the creation of bioethics in his introduction to the *Encyclopedia of Bioethics*. These factors are the rise of interest in ethics in modern era, intellectual debates about moralism, and the increasing of multidisciplinary research.

The research on bioethics started after world war II. Ethical questions related to health care have been part of medicine since its earliest days. However, international efforts to establish ethical standards in medicine



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became popular after the Nuremberg trials of 1947. These trials exposed the horrors of Nazi medical experiments on human participants. The principles developed during the Nuremberg trials and became known as the Nuremberg Code. These principles emphasize informed consent of the humans who are participating in the experiment along with their voluntary and the avoidance of unnecessary suffering or harm. These aspects became the basics for modern bioethics and research ethics. The research on bioethics has different aspects and features:

One characteristic that distinguishes bioethics from its forbearers, however, is the attention it pays to biotechnological solutions for health problems. From genetic medicine, stem cells, and biologics to [brain imaging](#), artificial hearts, and other biomechanical treatments, bioethics grapples with the impact of our extraordinary technological virtuosity on the human body (Wolpe & Howard, 2007, p. 682).

Given that ethics are the product of social, political, psychological, cultural, and even scientific factors, it is not a wonder that the field of bioethics is quite diverse and it interacts with many ideas and aspects in the modern society.

One important idea that race has to grapple with is race and racism, especially in the united states. Racism and white supremacy have been central to the US since its founding and still deeply affect society today, including health care and bioethics. Racism is a moral wrong that harms everyone in different ways. Since racism is socially constructed, it can also be socially dismantled. The field of bioethics has a duty to help eliminate racism within its own practices. This leads to questions about when and how bioethics has treated racism as an ethical issue. The focus here is on how bioethics has tackled racism and when it has made racism a central concern (Galarneau, 2022, p. 62).

The history of racial abuse in American medical and scientific research is extensive. One of the most infamous American cases is the Tuskegee Syphilis Study that was conducted by the U.S. Public Health Service. This study lasted 40 years in Alabama, and involved about 400 poor black men who has syphilis. Many of the infected men were falsely told they were being treated for “bad blood.” In reality, they were given no treatment. They did not receive the standard treatments available in 1932 when the study began, nor did they get the effective cure in 1943. The Public Health Service actively prevented these men from receiving treatment elsewhere. They were



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pardoned from the draft and their names were given in the clinics to stop them from receiving treatment. The study aimed to document the "natural progression" of syphilis but it ultimately produced no useful findings. Researchers sought to follow the men until their deaths to offer "free burials" as a reward to obtain their bodies for autopsy (Russell, 2016, p. 45).

According to A.A. van Niekerk (2016) racism is an ideology based on the belief that biological differences between groups of people make one of them better than the others. It claims these differences justify the unequal or harmful treatment of certain individuals or groups. This ideology goes against all principles of biomedical ethics, especially the principle of respecting people's individuality.

This study utilizes bioethical principles to examine the violation of Latin people's rights in the novel *A State of Wonder*(2011) by Ann Patchett. The novel follows pharmacologist Marina Singh as she travels to Brazil to gather details about a remarkable drug research project led by her former mentor, Dr. Annick Swenson. The novel was published by Bloomsbury in the UK and Harper in the US. It received critical acclaim and was nominated for awards like the Wellcome Trust Book Prize and the Orange Prize for Fiction. For the past twenty-five years, Ann Patchett has written novels with international appeal, works that explore the role of family in the modern world. Ann Patchett's focus on family aligns with the tradition of many Southern writers, but she broadens the family beyond the regional norms that are typical of Southern literature. Most of her stories take place outside the South, with settings from Kentucky and New England to Los Angeles, Philadelphia, and even South America. For her *A State of Wonder*, she chooses Brazil as her setting.

1.2. literature review

The field of bioethics is studied from different perspectives, especially to address racial inequalities and include marginalized voices. Charlene Galarneau (2022) looks at how racism has been discussed in bioethics. She shows that bioethics often ignored racism in its history. For example, in the 1970s, reports like the Belmont Report focused on informed consent and justice. However, they did not directly address the racism seen in cases like the Tuskegee Syphilis Study. These reports described racial minorities as "vulnerable" but did not talk about the structural racism causing their vulnerability. Galarneau says that bioethics needs to tell the truth about its history to fight racism.



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Sandra Soo-Jin Lee and her team (2024) share ideas from the REDI Task Force, which was created by the Association of Bioethics Program Directors. The task force points out barriers in bioethics education that cause racial inequalities. They suggest adding anti-racist principles to bioethics programs. They also support mentorship for scholars of color and fair funding practices. Their work shows that bioethics programs can influence the field's norms. The task force calls for community involvement and justice in knowledge to make bioethics more inclusive .

Ashley Russell (2023) studies the ideas behind bioethics and their weaknesses in dealing with people's differences. She criticizes bioethics for relying on abstract ideas like universal values. These ideas often ignore differences caused by race and status. Russell gives examples like the Tuskegee Syphilis Study and the exploitation of Henrietta Lacks. These studies show how bioethics treated minority groups as outsiders. She argues that bioethics should focus more on social justice instead of only individual rights. This means taking responsibility for its history, changing education, and working toward structural reforms.

Ann Patchett's novel *A State of Wonder* (2011) addresses such violations of bioethics that are carried out because of racism. The novel did not get the academic attention that it deserves given the complicated topics that it discusses. This paper is an attempt to study a novel that is worthy of research in order to analyze the violation of bioethics that happen in it.

1.3. Bioethical Issues in *A State of Wonder*

The novel begins with the pharmacologist Marina Singh who was assigned to retrieve the body and belongings of her friend and colleague, Anders Eckman, from a small location of scientific research deep in the Amazon rainforest. She is told that Eckman he had presumably died of a fever. Marina is in a relationship to her older manager Mr. Fox. The two have a conversation about how difficult it was for Anders Eckman to go to Brazil and that she must go to bring his body home and to check on the place of research where he used to work. On her way there, Marina gradually lose all her belongings.

Marina's losses represent a gradual shedding of her identity and beliefs. On her journey to know what remains of Anders and the truth about his death, she loses her luggage. This leaves her without her usual clothes, which symbolize her identity as a doctor and a woman. She also loses her phone cutting her off from her lover and boss, Mr. Fox. In Manaus, she buys cheap



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clothes but they are soon lost again when she reaches the Lakashi village, leaving her with only the clothes she is wearing because she "walked off and left her suitcase on the boat" (p. 191). Eventually, Lakashi women take her rain-soaked clothes to dry them, but instead the women disappear with the clothes. She feels bitter when she realizes that she is "scammed" (208). Left with nothing but a thin native shift and flip-flops, Marina's identity changes so much that tourists at a trading post mistake her for a local and take photos with her (Bennett, 2013).

Marina learns that the company is conducting a research on a Brazilian tribe that lives in a village in the middle of a forest. This tribe, the Lakashi tribe, has a unique capacity for procreation. When he was alive, Andres told her that the doctor leading the research is doctor Swenson, She found a village of people in the Amazon, a tribe, [...] where the women go on bearing children until the end of their lives [. . .] Their eggs aren't aging, do you get that? The rest of the body goes along its path to destruction while the reproductive system stays daisy fresh. This is the end of I.V.F. No more expense, no more shots that don't end up working, no more donor eggs and surrogates. This is ovum in perpetuity, menstruation everlasting (Patchett, 2011, p. 26).

The Lakashi women are strong and do not suffer from a menopause. Their fertility attracts doctor Swenson's attention. Marina has known doctor Swenson from her college years. Swenson was her rigid mentor who is known for her stiffness and discipline. When Marina arrives to the building of the company in Brazil, she realizes that there is too much secrecy around the research and the figure of the doctors involved. She also realizes that staff and workers do not know a lot about the research, its results or even its proceedings and findings even though it has been running for over than thirty years:

Dr. Swenson's secret research, conducted over years of steely, exhausting work, may be one quixotic attempt to belie this notion and give finer meaning to an enterprise of medical research ripe with greed and dominated by a focus on small, often therapeutically irrelevant gains and new fads (A riely, 2012).

When Marina meets Dr. Swenson eventually, she senses that something is wrong with the way Swenson carries out the work. She tells her that her friend Andres Eckman had died because he had fever and he wanted to rest instead of treating it and going back to work. The first of patients' rights is to receive good treatment of their sickness or injury regardless of who they are.



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However, Swenson expects her patients to be grateful no matter how little care they receive, they have no right to complain or get further rest or care:

The man who had been sent to prod me along in my work was keeping me from it. He had crossed over a line from feeling that he would recover quickly to feeling he was too ill to travel. He told me he wanted to wait until he was in a better condition. He didn't want to be out on the river. [...] He was an impediment to me (Patchett, 2011, p. 140)

Dr. Swenson treats the Lakashi people in ways that show major ethical problems. She ignores bioethics when it comes to consent and experiments. In the story, she uses the Lakashi people for her research without respecting their rights. They become test subjects for a new drug she wants to develop. Swenson tricks them by pretending to help them but she does not explain the truth about her work. This is clear when she talks about her fieldwork saying that "I tamed them...It was our life's work, Dr. Rapp's and mine, earning their trust" (Patchett, 2011, p. 215). The Lakashi people were not driven by force to become a research samples, they rather did it willingly because they were unaware of the nature of Dr. Swenson's work. They also believed that the simple medical care that Swenson and her team gave was a privilege that they must exchange everything for:

As for the Lakashi, they were patient subjects, submitting themselves to constant weighing and measurement, allowing their menstrual cycles to be charted and their children to be pricked for blood samples. Dr. Swenson deserved the credit for that and she accepted it readily, telling stories about the tireless cajoling and gift giving that had once been required for even the most basic examinations (Patchett, 2011, p. 215).

Swenson refers to the Lakashi as if they were animals to be "tamed" for her benefit. Her language reveals a lack of care for their humanity. She reduces them to research subjects rather than full human beings in their own account. Informed consent is an important role in bioethics. It means people must know the risks and benefits before joining medical research (Elgesem, 2002, p. 197). But Swenson does not follow this rule. She experiments on the Lakashi people without asking for their permission. This takes away their right to decide for themselves. Swenson tries to defend her actions by saying: "How quickly we put our medical ethics aside. I developed this drug. If I believe in it, and clearly I do, then I should be willing to test it on myself" (Patchett, 2011, p. 247). Her words show that she thinks her research is more important than following ethics. She believes her work is so valuable that it



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excuses breaking the rules. She cares more about her scientific goals than the rights of the people she uses in her experiments.

To her surprise Marina did not know that Swenson was pregnant. Swenson is seventy-three years old woman. She decided to follow the same practices of the Lakashi people in order to make it possible for herself to bear a child at this age. She discovers that Lakashi people eat from a sacred tree's park that is called the Martin. This tree prolongs and strengthens the procreation organs in their women who continue to bear children for the rest of their lives. She analyzes and tests the components of this park in order to know its secrets and when she does she extracts a cure out of it. Swenson tests the cure on her body before it was safe. By that she violates another sort of bioethics which is to discard all unnecessary harm. Not to mention that, she has no guarantee that the child will be healthy or complete after bearing it in her old age. She, however, discards all these possibilities and proceeds in her research. Marina tells her:

I understand that you are conducting an extremely limited initial trial on yourself but the end result of this experiment will be a child and, with all good wishes for your longevity, you may not be around as long as you might like to look after it. If there is no father in the traditional sense, then what happens to the outcome? (Patchett, 2011, p. 248-9)

Swenson and the company of Mr. Fox do not take into consideration the social, psychological, or physical outcomes for carrying children in an old age. As long as something can give them their miraculous cure is worth investing. The medical condition of the Lakashi women is meant for them alone "not for us" (p. 247).

Swenson looks after a boy from the village who is name Easter. He is little child who lives and works with her as a guide through the jungle. Swenson tells Marina that her child will be raised and cared for just like Easter, by someone else from the village. Marina gives up on persuading Swenson of her mistakes and decides to proceed in her search to know what happens to her friend Andres Eckman.

On her journey and investigation Marina learns about the damage that the research could do to the women of the Lakashi people. Swenson tells her that the tests that are done on these women is not enough, nor is Swenson's experiment on herself. She states that once the cure is proven effective, she will have to carry the research out on more people:



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And how shall we test it further? We would have to find a great many childless seventy-three-year old women who were willing to be impregnated in order to evaluate safety. Chances are we would kill the lion's share of them in the course of the drug trials (Patchett, 2011, p. 311).

Marina forms a negative attitude towards the violation of the bioethics that is done in the experiment. She informs her manager and lover Mr. Fox about what Swenson has done hoping that he would stop her. Mr. Fox, however, is carried with joy once Marina tells him about Swenson's pregnancy. She tells him that the experiment is bad for her old age, "Her blood pressure is high," Marina said. Mr. Fox looked up and Marina shook her head. "She's tired. She just needs rest, that's all. There should be as little stress as possible." (p. 313). Mr. Fox is another figure who violates the medical ethics in the novel. He is willing to let Swenson continue with her experiment even though she is going through complications because of it. Research ethics is strongly linked to human rights in general. The main goal behind establishing research ethics in the first place is to create a balance between aims and methods, that is to guarantee the rights of the participants while being capable of carrying out the research appropriately. According to Eynon (2017) and Schreoder "any emphasis on the rights of research participants must be considered alongside other rights and values including [...] interests in pursuing knowledge" (p. 20). These rights seem absent from the mind of the company managers and scientists as they only care about obtaining their cure.

On their journey amid the native tribes in the Amazon jungle, Mr. Fox and his associates see a white man who is surrounded by natives that attack the tourists' boats. He goes back and tells Marina and Swenson that this white man can be Andress Eckman since his death is not confirmed yet. Marina and Swenson go on a trip to find out what happens and if the white man is Eckman. Easter insists on accompanying with them. In the middle of their journey, Swenson surprises them with a cry of help. She asks Marina to help her to deliver her baby. Marina is shocked that she has to help a seventy years old woman to give birth in the middle of the jungle and without any medical tools. She is given few pills and insufficient tools. She insists on delaying the delivery but the stiff Swenson emphasizes: "You get what you get, and I was lucky to get that" (Patchett, 2011, p. 279). From the beginning of her visit to the lab and village of Dr. Swenson, Marina knew that this place is not prepared for treating patients, "[t]he point is we don't have anything approaching sterile conditions. The chance of her dying from a postoperative



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infection is enough to indicate that turning the baby is worth a try” (p. 279). The medical service provided by the company was not decent enough to cover the basic needs for healthcare. However, they convinced the locals that this is enough to become research subjects to get it. Eventually, Dr. Swenson does deliver her awaited baby. Once the child comes to the outside of her womb, Marina and everyone is shocked not only the baby is dead but also it has a unique physical distortion:

Sirenomelia, Mermaid Syndrome, the legs of the fetus are fused together into a single tail, no visible genitalia. It is nothing you're likely to see. And there it went; with a click and a brief flash of blackness they were on to the next slide. The only person who ever stood to know what it would have been like to have Dr. Swenson for a mother had not lived to meet the experience. A life of such extraordinary beginnings had, in the end, amounted to little more than a science experiment. (Patchett, 2011, p. 288)

Swenson's experience resulted in her excessive pain, fever, high blood pressure, swelling, and side effects of Caesarian. Her experience on the Lakashi women has also resulted in their Nausea, headache, and other effects. These impacts came after neglecting patient's consent and wellbeing. The bioethical codes are outlined to ensure the safety of participants. the experiment gave no results beyond what is already known. Swenson realizes: “I am glad to have conducted this piece of research on myself because it makes me realize something I might not have otherwise taken into account: women past a certain age are simply not meant to carry children” (Patchett, 2011, p. 248). Despite the fact that doctor Swenson has went through terrible pain and perhaps some unsaid regret, she nevertheless continues her research after. Big effort is done by Marina to change how things are done by the company or Swenson but nobody listens to her. She departs home after finding Eckman alive while knowing that the medical exploitation of people there will continue.

Conclusion

Bioethics is an important part of medical research that can ensure the safety of participants and receivers alike. The novel shows that there are significant violation of bioethics that happen when dealing with people from third world countries. Bioethics must come free of race or ethnicity prejudices. However, from the beginning of the journey that Marina takes in Brazil, she realizes that the company experiments on these people because their poverty makes them more vulnerable and easier to be silenced. The ends



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with a realistic conclusion which is that these violations will continue to happen no matter how single individuals seek them out. It takes a community work to wend such violations, along with more attention to the dignity and worthiness of the life of research participant.

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