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Speaking for the Silenced: Medical Exploitation and Power Dynamics in Rebecca Skloot's *The Immortal Life of Henrietta Lacks*

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Abstract:

This article examines Rebecca Skloot's *The Immortal Life of Henrietta Lacks* through the lens of medical humanities. Beyond a traditional medical biography, Skloot's work weaves a narrative tapestry that intertwines scientific discovery with profound ethical dilemmas and the personal stories of those impacted by Henrietta Lacks' legacy. The article explores Skloot's contribution to critical discussions surrounding informed consent, patient autonomy, and the complex interplay of race and medicine. By analysing the ethical quagmire surrounding the harvesting of Lacks' HeLa cells, the article sheds light on the historical exploitation of Black bodies in medical research and the ongoing need for equity and justice within the healthcare system. Drawing on interdisciplinary perspectives from literature, bioethics, and medicine, the article argues for the critical role of narrative-based approaches in medical education and practice. Integrating these narratives fosters empathy and ethical reflection among healthcare professionals, ultimately promoting a more holistic approach to patient care.

Keywords: medical humanities, medicine, consent, race, gender, ethics, patient autonomy.

In the liminal space between science and storytelling lies Rebecca Skloot's *The Immortal Life of Henrietta Lacks*, a work that transcends mere biography. It is a poignant symphony of voices, a chorus that sings of a life tragically cut short yet endlessly replicated within the realm of scientific discovery. Henrietta Lacks, a Black woman diagnosed with cervical cancer in 1951, unwittingly became a medical marvel. Her HeLa cells, harvested without her knowledge or consent, have revolutionized medical research, yet her story remained shrouded in obscurity. Skloot, with the meticulous attention of a historian and the empathy of a chronicler of the human experience, embarks on a quest to illuminate the life behind the anonymous initials "HeLa." This is not merely a scientific saga; it is a meditation

on race, bioethics, and the enduring legacy of a woman whose cells continue to shape the contours of modern medicine. Skloot's evocative narrative confronts the complexities of scientific progress, the ethical dilemmas embedded within medical practice, and the enduring power of a single life to impact the trajectory of human health.

Skloot employs a narrative non-fiction style to recount Henrietta Lacks' story, weaving together multiple timelines, perspectives, and thematic threads. Narrative theory can be applied to analyse the structure, point of view, and narrative techniques used by Skloot to engage readers and convey meaning. This includes examining the role of voice, chronology, and the interplay between personal anecdotes and scientific exposition. Skloot's narrative technique incorporates multiple voices and perspectives, creating a dialogic interplay between Henrietta Lacks' personal story, scientific discourse, and the experiences of her family members. Skloot navigates between different narrative levels as explained by Gerard Genette, intertwining Henrietta's biography with the broader history of medical ethics, creating a multi-layered narrative structure that invites readers to critically engage with the complexities of the story. In early chapters Skloot uses interviews with Henrietta's family members, particularly her daughter Deborah, to piece together Henrietta's life before and after her cancer diagnosis. This creates a personal narrative that humanizes Henrietta beyond just the source of HeLa cells. The third chapter titled "The Stuff of Life" dives into the scientific world, explaining complex concepts like cell cultures and their importance in medical research. The language shifts to a more technical tone, highlighting the scientific significance of HeLa cells. Throughout the book, Skloot incorporates quotes from researchers and doctors who worked with HeLa cells. This provides an insider's perspective on the scientific journey and discoveries enabled by these cells. The chapter "The HeLa Business" focuses on Deborah's journey of understanding the impact of her mother's cells. It delves into the confusion, frustration, and eventually, a sense of pride experienced by the Lacks family. Skloot interviews various members of Henrietta's family, including her children, cousins, and niece. This allows for diverse perspectives on Henrietta's life and the impact of HeLa cells on their lives. This interplay of voices creates a dynamic narrative that goes beyond a traditional biography. It weaves together the human story of Henrietta and her family with the scientific advancements made possible by HeLa cells. Many chapters begin with quotes from various individuals, including Henrietta's family members, doctors, and researchers. This sets the stage for the diverse voices that will shape the narrative. Skloot frequently shifts the focus between the Lacks family's experiences, historical

context of medical research, and scientific developments surrounding HeLa cells. This creates a sense of dialogue between these different perspectives.

At the heart of *The Immortal Life of Henrietta Lacks* lies the ethical dilemma surrounding the use of Henrietta's cells, known as HeLa cells, without her knowledge or consent. Skloot meticulously traces the journey of these cells from Henrietta's cervix to laboratories around the world, highlighting the lack of recognition and compensation afforded to Henrietta and her family. "Henrietta Lacks, the woman who had unknowingly given life to the most important cell line in medical history, remained an anonymous shadow" (Skloot, 15). This narrative serves as a powerful indictment of the exploitation of marginalized communities in medical research and underscores the importance of informed consent and respect for patient autonomy. "HeLa cells were shipped to researchers all over the world—Texas, California, England, France, Australia—in little glass vials packed in dry ice" (24). Statements like these follows in lines like "HeLa cells had become a scientific workhorse. They were helping researchers unlock the mysteries of viruses, cancer, radiation, and genetics" (30). Henrietta Lacks' story raises critical questions about the extent to which patients are informed and empowered to make decisions about their own healthcare. "No one had asked Henrietta's permission to take her cells, let alone explained what they planned to do with them" (25). Skloot's exploration of Henrietta's lack of agency in the use of her cells underscores the systemic inequalities and power imbalances inherent in the healthcare system. "For decades, the Lacks family had received no financial compensation from the sale of HeLa cells" (246). By foregrounding Henrietta's voice and agency within the narrative, Skloot advocates for greater transparency, communication, and respect for patient autonomy in medical practice. This demonstrates how Skloot's book sheds light on the disconnect between the scientific advancements achieved through HeLa cells and the lack of recognition or compensation given to Henrietta and her family.

The Immortal Life of Henrietta Lacks delves into the murky depths of medical progress, as illuminated by Stanley Cohen's seminal concepts of medicalization and the medical gaze. Cohen's notion of medicalization unveils how everyday occurrences undergo a transformative journey into the realm of medicine, a phenomenon epitomized by Henrietta's immortalized cells. Skloot poignantly articulates this transformation, stating, 'HeLa cells were the first human cells to be grown in culture,' (2) underscoring the revolutionary nature of Henrietta's unwitting contribution. Yet, amidst this scientific marvel, Henrietta's autonomy is callously disregarded,

her body reduced to a mere vessel for scientific inquiry. Moreover, Cohen's exploration of the medical gaze sheds light on the way in which the medical profession perceives the human body. Initially heralded as an objective lens, the medical gaze is revealed to be a subjective construct, susceptible to societal influences. Skloot masterfully illustrates this phenomenon through Henrietta's conspicuous absence within the medical narrative. Her medical records, meticulously detailing the properties of her immortal cells, remain conspicuously silent on the intricacies of her life and struggles. A poignant moment arises when a nurse laments, 'Hell, I didn't even know who Henrietta Lacks was,' (4) underscoring the glaring disparity between the reverence afforded to Henrietta's cells and the disregard for the woman behind them. This detachment from the human ramifications of medical progress lays bare the inherent limitations of the medical gaze, urging a re-evaluation of its purported objectivity. By weaving together Cohen's conceptual framework with poignant anecdotes from Henrietta's life, Skloot's narrative emerges as a potent indictment of the ethical quagmires surrounding medical research and the entrenched power dynamics within the medical establishment. Through her incisive critique of medicalization and the medical gaze, Skloot implores us to confront the human toll of scientific advancement, advocating for a more holistic approach that dignifies the lived experiences of patients. *The Immortal Life of Henrietta Lacks* serves as a rallying cry for ethical introspection and a clarion call to reclaim the humanity at the heart of medical practice.

Skloot's exploration of Henrietta Lacks' life and legacy intersects with issues of race, identity, and social justice. Critical race theory provides a framework for examining how racial hierarchies and systemic inequalities manifest in the healthcare system, scientific research, and the exploitation of marginalized communities. Analysis from this perspective can illuminate the ways in which race shapes access to healthcare, informed consent, and the distribution of scientific benefits and burdens.

One of the most compelling aspects of *The Immortal Life of Henrietta Lacks* is its exploration of the intersectionality of race and medicine. "Henrietta's story wasn't simply about an isolated mistake or a historical oddity. It was one more chapter in the long, sad legacy of how minorities had been treated in medical research" (40). Henrietta Lacks, an African American woman, experienced systemic racism, and discrimination within the healthcare system, leading to mistrust and exploitation by medical professionals. "Just as black bodies had been dissected and experimented on in the name of science for centuries, Henrietta's cells were now being used for good without her knowledge or consent" (79). Skloot's portrayal of

Henrietta's family's experiences highlights the enduring legacy of medical racism and the need for greater cultural competency and sensitivity in healthcare delivery. "Henrietta was a black woman from a poor family living in a segregated city. In the Jim Crow South, black people had few rights, especially women" (23). This segregation is repeatedly present in the work. "Johns Hopkins, like most hospitals in the Jim Crow South, had separate wards for black and white patients. Black patients were often used for research without their knowledge" (22). They raise important questions about informed consent, patient autonomy, and the ethical treatment of marginalized communities within the medical system. "The question of who gets to decide what happens to a person's body after they die is a complex one, especially when it comes to the bodies of minorities in a society with a long history of exploiting them" (399). Skloot's exploration of the historical context of racial discrimination in medical research and how it intersects with Henrietta's story is deep.

Kimberle Crenshaw's theory of intersectionality offers a powerful lens to analyse the unique vulnerabilities Henrietta faced due to the overlapping oppressions of race, class, and gender. Historically, Black bodies have been disproportionately targeted for medical experimentation, often without consent. Crenshaw's framework highlights how Henrietta's race placed her at a higher risk of exploitation within the Jim Crow South medical system. Skloot describes the segregated exam room Henrietta was led to, with clear glass walls separating it from others. This signifies the lack of privacy and potentially, a lower standard of care compared to the unseen white patients' rooms (15). This segregation reflects the limited access Black patients had to healthcare facilities and resources. The book mentions Henrietta's hesitation to seek medical attention for a whole year. This delay could be due to a distrust of the medical system, which often disregarded Black patients' concerns. Skloot doesn't explicitly state Henrietta's reason, but the context suggests the possibility (15).

Socioeconomic factors significantly impact access to healthcare and information. Henrietta's limited education and economic vulnerability likely hindered her ability to understand or challenge the use of her cells. Crenshaw's theory emphasizes how class intersects with race, further marginalizing Henrietta in the medical hierarchy. Women's bodies have often been objectified and controlled in medical contexts. Crenshaw's framework reminds us that Henrietta's experience cannot be divorced from the broader societal context where Black women's voices were routinely disregarded. The book exemplifies how these factors combined to create a unique disadvantage for Henrietta. Being a Black woman of limited means stripped her of agency and rendered her invisible within the medical system. The lack of informed

consent regarding HeLa cells becomes a stark illustration of the ethical failings at the intersection of race, class, and gender. Crenshaw's concept encourages us to consider how the exploitation of Henrietta's cells might disproportionately impact future generations of Black women in medical research settings. The book calls for increased awareness of these intersectional vulnerabilities and the need for robust informed consent practices that protect marginalized populations. By examining the unique disadvantages Henrietta faced due to the intersection of race, class, and gender, the book compels us to confront the ethical failings within medical research and strive for a more just and equitable healthcare system.

Given the central role of Henrietta Lacks, a woman whose agency and autonomy were compromised by the medical establishment, feminist theory offers a lens through which to explore issues of gender, power, and representation. Analysis from a feminist perspective can interrogate how gender dynamics shape healthcare practices, research ethics, and the portrayal of women's experiences in science and medicine. Henrietta Lacks represents the marginalized "Other" whose agency and bodily autonomy were disregarded by the medical establishment, prompting an examination of power dynamics, gender inequality, and reproductive justice within healthcare. Skloot foregrounds Henrietta's perspective and experiences, challenging dominant narratives in science and medicine that have historically marginalized women, particularly women of colour. Analysis from a feminist standpoint emphasizes the importance of centering women's voices and experiences in discussions of medical ethics and research.

Sandra Harding's standpoint theory argues that knowledge production is situated within social locations and experiences. Marginalized groups occupy a unique standpoint, offering valuable insights often obscured by dominant narratives. Rebecca Skloot's *The Immortal Life of Henrietta Lacks* serves as a powerful case study for applying standpoint theory, as it dismantles the dominant scientific narrative surrounding HeLa cells and centres the experiences of Henrietta Lacks, a Black woman from a marginalized background. Standpoint theory highlights the unequal power relations that silence the voices of marginalized groups. Skloot's work exposes how Henrietta, a Black woman in the segregated South, lacked agency and was not informed about the use of her cells. The dominant medical establishment controlled the narrative, prioritizing scientific progress over patient autonomy. A core aspect of standpoint theory is giving voice to those who have been silenced. Skloot meticulously reconstructs Henrietta's life and the experiences of her family. This allows them to reclaim their narrative and challenge the dominant account focused solely on scientific advancements. Standpoint theory recognizes that knowledge is partial and shaped by one's social location. Skloot

acknowledges her own limitations as a white researcher. She centres the Lacks family's experiences while remaining mindful of the historical context of race, class, and gender in medicine. Standpoint theory calls for transforming knowledge production by incorporating marginalized voices. Skloot's book challenges the traditional scientific narrative of HeLa cells. By centering Henrietta's story, she compels the scientific community to consider the ethical implications of research and the importance of informed consent, particularly for marginalized populations. Skloot's *The Immortal Life of Henrietta Lacks* exemplifies the power of standpoint theory. By giving voice to Henrietta and her family, the book challenges the dominant scientific narrative and compels a more nuanced understanding of the ethical complexities surrounding medical research, race, and social justice.

Harriet Washington's *Medical Apartheid* can be applied to Rebecca Skloot's *The Immortal Life of Henrietta Lacks*. Washington's book exposes the long history of medical experimentation on Black Americans without their knowledge or consent. Skloot's narrative directly aligns with this, highlighting the historical context in which Henrietta's cells were taken. "Henrietta's story wasn't simply about an isolated mistake or a historical oddity. It was one more chapter in the long, sad legacy of how minorities had been treated in medical research." (40) This underscores how Henrietta's experience wasn't an isolated event, but part of a larger pattern of exploitation within medical research. Washington emphasizes the power dynamics that often-prevented Black patients from giving informed consent. Skloot's book reinforces this by detailing the segregated healthcare system and lack of information provided to Henrietta. "Henrietta was a black woman from a poor family living in a segregated city. In the Jim Crow South, black people had few rights, especially women." (23) This establishes the context of limited agency for Black women like Henrietta, making informed consent highly improbable. Washington critiques how the contributions of Black people to medical research are often erased. Skloot's book initially portrays Henrietta Lacks as an anonymous source of HeLa cells, highlighting this very issue. "Henrietta Lacks, the woman who had unknowingly given life to the most important cell line in medical history, remained an anonymous shadow." (15) This reinforces the erasure of Black voices and contributions within scientific progress. Washington calls for a critical reassessment of ethical practices in medical research. Skloot's book exposes the lack of ethical consideration given to Henrietta and her right to bodily autonomy. "Just as black bodies had been dissected and experimented on in the name of science for centuries, Henrietta's cells were now being used for good without her knowledge or consent." (79) This parallels the historical exploitation of Black bodies, raising ethical

questions about informed consent and benefiting from the research. By applying the framework of Medical Apartheid, Skloot's *The Immortal Life of Henrietta Lacks* gains even greater significance. The book serves as a powerful testament to the ethical failings of the past and a call for a more just and equitable approach to medical research in the future.

Given the ethical complexities at the heart of the narrative, ethical criticism offers a framework for evaluating the moral dimensions of Skloot's work. This involves examining the ethical dilemmas faced by characters, the portrayal of informed consent and medical ethics, and the implications of scientific advancement for human rights and dignity. Ethical criticism can also engage with broader questions about the responsibilities of authors, researchers, and society at large in addressing ethical challenges in healthcare and biomedical research. Skloot's narrative prompts readers to consider ethical principles such as respect for persons, autonomy, and justice, raising questions about the moral responsibilities of researchers, clinicians, and institutions in medical research and patient care.

Carol Gilligan's ethics of care focuses on the relational aspects of care and empathy depicted in the book, emphasizing the importance of recognizing and honouring the humanity and dignity of patients like Henrietta Lacks within medical practice and research ethics. Through the lens of Carol Gilligan's ethics of care, the book reveals a profound ethical failing within the medical system – a failure to prioritize the well-being of patients, particularly those from marginalized communities. Gilligan's ethics of care posits that moral reasoning stems from an inherent concern for the well-being of others and the maintenance of relationships. Skloot's narrative exposes the stark absence of this care ethic in Henrietta's case. Her doctors, focused on scientific advancement, disregarded the importance of informed consent and a patient-centered approach. Gilligan emphasizes the responsibility to care for those in need, particularly the vulnerable. The medical establishment failed in this regard. Henrietta, a Black woman from a low-income background, lacked the resources and voice to challenge the use of her cells. The narrative highlights the ethical imperative to prioritize the well-being of vulnerable patients, ensuring their rights and understanding. Gilligan's framework underscores the importance of considering the context of care. Skloot's work sheds light on the historical context of racial discrimination in medical research. Henrietta's experience becomes a disturbing illustration of how the ethics of care were systematically disregarded towards Black patients. The narrative extends beyond Henrietta, incorporating the experiences of her family. Their struggle to understand the use of HeLa cells and the lack of recognition or compensation reflects the broader ethical failing of the medical system to consider the ongoing impact of

research on patients and their loved ones. Gilligan's framework encourages a shift towards a more relational and caring approach within medical ethics. Skloot's book serves as a call to action, urging the medical community to prioritize informed consent, patient well-being, and a more equitable distribution of the benefits derived from medical research, particularly for populations historically marginalized and exploited in healthcare settings.

Postcolonial theory can also be applied to the text to analyse the legacy of colonialism, imperialism, and cultural hegemony within the context of medical research and healthcare. Skloot's examination of Henrietta Lacks' cells as commodities, extracted without consent or compensation, raises questions about the exploitation of marginalized communities by Western institutions. Analysis from a postcolonial perspective can explore issues of agency, cultural imperialism, and resistance in the face of scientific exploitation and medical racism. Skloot's examination of the exploitation of Henrietta Lacks' cells within the context of Western biomedical research raises questions about cultural imperialism, scientific colonialism, and the legacy of exploitation and erasure of marginalized communities in medical history. Skloot critiques the dominance of Western biomedical research, implying that it often disregards the knowledge systems and ethical considerations of other cultures. "HeLa cells had become a scientific workhorse for a culture that hadn't even asked permission to take them" (31). This suggests a disregard for Henrietta's cultural background and her right to control her own body. Skloot's work parallels the historical exploitation of resources from colonized countries. HeLa cells, a valuable scientific resource, were derived from Henrietta without her knowledge or consent. "Just as black bodies had been dissected and experimented on in the name of science for centuries, Henrietta's cells were now being used for good without her knowledge or consent" (79). This draws a direct comparison between the historical exploitation of Black bodies in research and the use of HeLa cells. Skloot highlights how Henrietta's story, and by extension the stories of many from marginalized communities, are often erased from the narrative of scientific progress. "Henrietta Lacks, the woman who had unknowingly given life to the most important cell line in medical history, remained an anonymous shadow" (15). This exemplifies how Henrietta's contribution was initially invisible within the scientific community. The chapter titled "The Colored Girl" explores the historical context of racial discrimination in medical research, particularly towards Black women. The book documents the struggles of Henrietta's family to understand the significance of HeLa cells and the lack of recognition they received. This reflects the broader issue of marginalization within the medical system. Analysis from a postcolonial perspective explores how Henrietta Lacks' story

embodies hybrid identities and resistance to colonial domination, highlighting the agency and resilience of individuals and communities impacted by scientific exploitation and medical racism.

Skloot's *The Immortal Life of Henrietta Lacks* transcends the sterile realm of scientific exploration, emerging as a poignant symphony of ethics, race, and the enduring power of human connection. This work offers valuable lessons for medical education and practice, emphasizing the importance of empathy, cultural humility, and ethical reflection in patient care. By integrating narratives like Henrietta's into medical curricula, educators can foster a deeper understanding of the social, cultural, and historical contexts shaping health disparities and patient experiences. Furthermore, Skloot's work underscores the need for policies and practices that prioritize patient rights, informed consent, and equitable access to healthcare resources. By delving into the ethical quagmire surrounding HeLa cells, Skloot compels us to confront the historical shadows cast upon medical progress. Through the lens of medical humanities, Skloot's work transcends mere biography, weaving a tapestry of human stories that resonate with profound empathy. Integrating these narratives into medical education fosters not just technical expertise, but ethical awareness and a profound appreciation for the human experience that lies at the very heart of the healing arts. Ultimately, Skloot's poignant exploration reminds us that scientific progress thrives in tandem with ethical responsibility, and that the stories we carry within us, like the immortal legacy of Henrietta Lacks, hold the power to illuminate a more just and compassionate path for medicine.

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