

SASH Bookworms Twitter Transcript

May 2021 – Book: *The Immortal Life of Henrietta Lacks* by Rebecca Skloot

Question 1 – Discuss the following quote: ‘*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*’ (p. 9)

‘I agree it was strange that people could profit from the cells while the family couldn’t afford the basics. I guess there was no precedent at that time, but thankfully we can learn from the mistakes of the past.’

‘Agree. Also made me feel very grateful for the NHS and care from cradle to grave.’

‘Definitely! So many people I know wouldn’t even be here at all without free access to basic medical care.’

‘That sense of frustration that some companies were profiting from their mother cells, but that the original institution hadn’t, must have been difficult for her family to come to terms with.’

‘Do you think that Henrietta’s family are entitled to compensation for the profit they made from her cells?’

‘Morally they are surely entitled to apology and recognition. Don’t know enough about law regarding financial compensation’

‘I suspect legally they are not as there is no legal mechanism for this but morally, yes I think they should be. The book suggests that they would struggle to benefit from their mothers ‘gift’ because they can’t afford to access healthcare themselves’

‘Quite. It would be great if the companies who benefit could use profits to ensure basic healthcare for people who can’t afford it. My sense is that family might have appreciated that?’

‘That’s a tough one. Legally, probably not. Morally, I think yes.’

‘We agree on that – crossed tweets!!’

‘Interesting point, would advances in medical research be possible if money was given to everyone who took part in medical trials and research?’

‘If the donor isn’t paid should their cells be sold, or should they be given away for free?’

‘It doesn’t make any sense! The treatment of the Lacks family was completely unjust, and

was unfortunately a similar experience for many people at this time.'

'Sadly inequalities persist even if approaches to consent have improved.'

'Represents healthcare inequalities and the remuneration and recognition for contributing to research.'

Question 2 – Discuss the argument that the good that came out of the research using Henrietta's cells outweighs the bad of taking them without her knowledge

'It's difficult, Deborah and her brothers came to terms with it and were pleased with what was achieved. The other issue is patient confidentiality of naming Henrietta, implications for the children who share her DNA.'

'I think this is a matter of perspective. For her family members, I doubt it. From what I understood, this was standard practice and not intended to make money, so I judge the doctor less harshly than I would if this happened today.'

'I suspect there have been quite a few scientific advances over the years which are based on research which wouldn't stand up to today's guidelines on informed consent?'

'Interesting point regarding standard practice of the time. Perhaps there is not blame for the individual doctor rather than the culture and system of taking samples.'

'Some of the difficulty comes from the fact scientists hadn't predicted the cells would grow so prolifically so hadn't consented for such wide use.'

'The positive impact has been huge but there's still a person and family at the heart of this and the difficulty involved in gaining consent is not an excuse for not asking for consent. I always found it harder to take consent for research than for medical care, but I think the evidence suggests that people are usually really keen to participate in and support research when asked.'

'Agree, I am always humbled by the people I meet who are keen to be involved in research that will benefit others even when they are dying themselves.'

'I agree the advancements that have been made because of the HeLa cells have been ground-breaking, but you always have to remember that these cells came from someone who was taken advantage of. We can be thankful medical consent has come a long way since.'

Question 3 – Is ethics relative? Do our values change over time? If it was ethical and standard practice at the time to take Henrietta's cells without her knowledge, can we say today that it was unethical?

'Values definitely change over time. I don't think we can judge their actions by today's

standards but, now we know better, we also can't behave in old ways.'

'I think our approach does change over time and maybe we should ensure we continue to challenge ourselves about whether our approach is appropriate or right even if we follow the current norms. That's why we need lay members in our assurance systems.'

'Yes society's view of what is right and wrong changes over time but that doesn't mean we can't look back and say that something was wrong, judged by today's standards. And we should always remember future generations will judge us.'

'Yes, great point about continuing to challenge ourselves and not assuming we've arrived.'

'I agree the role of MTD ethics discussions which include lay people is a very important part of how research is carried out today, and didn't exist in the past.'

'I think values are based on our surroundings and cultural norms, which doesn't always mean they are ethically correct. We should recognise these and know when to challenge them.'

'I agree and I think we need to be proactive about being open to challenge and that perhaps means ensuring that we have the right people in the group discussing current issues so that we don't allow ourselves to become culturally or ethically deaf.'

Question 4 – what impact does the effect of medical racism (historical and current) have on groups accessing healthcare/testing/vaccination in 2021?

'I think the book highlighted intersectionality didn't it? Race, poverty, education, all linked factors leading to disadvantage. Still true in 2021.'

'Covid-19 pandemic has highlighted the global disparities between communities and healthcare.'

'I think the impacts are huge especially in education and so they are perpetuated; the basing of dermatology teaching on Caucasian skin, the calibration of equipment on Caucasian subjects etc. There's work going on how to now to address this but there's a long way to go.'

'This book helped me to understand that some inequalities in access are related to lack of trust.'

'Yes, and the book helped me to understand some of the origins of the lack of trust and fear of medicine and doctors.'