The Immortal Life of Henrietta Lacks

Questions for Nursing Students

Chapter 1

- 1. What is the history of Johns Hopkins Hospital?
- 2. Johns Hopkins started out as a charity hospital. In pre-Medicare days, how was it funded?
- 3. What are the S+S of cervical cancer?
- 4. That is the treatment for cervical cancer today?
- 5. Compare the treatments available for epilepsy then (1951) and now.
- 6. What is "asymptomatic neurosyphilis"?
- 7. Henrietta cancelled or failed to follow up on recommended diagnostic appointments. What is the responsibility of the health care provider to ensure that patients obtain follow up care?
- 8. Where are tissue samples stored in your clinical facility?

Chapter 2

- 1. Eliza Pleasant died in 10th childbirth. Compare childbirth mortality rates then (1951) and now.
- 2. Henrietta's body was taken home and buried in the cemetery "out back". Could this be done today? Are there legal requirements for post-mortem care and burials?
- 3. Henrietta had her first child at age 14. What is the impact of having a child at this age?
- 4. What are the S+S of neurosyphilis? Any association with retardation and epilepsy?
- 5. What are the health affects of breathing coal dust and asbestos?

Chapter 3

- 1. Compare how cancer is diagnosed then and now. What cellular changes are looked for?
- 2. Compare cervical cancer mortality rates then (1951) and now.
- 3. How did TeLinde set out to turn his beliefs about cancer progression into evidence-based practice?
- 4. Compare the treatment of cervical cancer then and now.
- 5. Compare radiation precautions then and now.
- 6. Compare the consent form quoted in the book to that used in your clinical facility today.
- 7. When radium was first discovered, it was considered "a positive cure for every disease." Are there current examples of newly discovered treatments that do not live up to expectations?
- 8. Because poor patients were treated for free, doing research on them was considered a form of payment. How has the attitude toward research subjects changed? What are the safeguards overseeing experimentation today?

Chapter 4

- 1. Geys collected umbilical cord blood for use as a culture medium ingredient. Is it still collected? If so, for what purpose and how is it stored?
- 2. Biologists did not know about sterility and contamination, although surgical nurses like Margaret Gey did. What is the history of the dissemination of knowledge regarding microbial contamination?
- 3. Gey had his spine fused so that he's stop throwing it out. How and why is spine fusion done now?

Chapter 5

- 1. Henrietta had tattooed black dots to target radiation treatments. Is this still done?
- 2. Henrietta claimed not to know that she would be sterile after her treatments, although informing patients of this was the standard. How does your facility ensure that patients are adequately informed and understand what they are told?
- 3. How is the degree of radiation burn from radiation treatments modulated today?

Chapter 6

1. In view of history, is there still a distrust of "white medicine" among African-Americans? What about other cultural/ethnic groups? Are there generational differences in attitude?

Chapter 8

- 1. Are there still instances of "benevolent deception"?
- 2. List other diseases in which mortality rates are greater among African-Americans than whites. Is it due to greater prevalence, greater virulence, or later diagnosis?
- 3. Compare pain management options then and now.

Chapter 11

1. Henrietta's kidneys could no longer remove toxins. What is the history of dialysis?

Chapter 12

- 1. No consent was needed to remove tissue from a live person however it was illegal to autopsy or remove tissue from a dead person without consent. What other inconsistencies have you encountered today?
- 2. It wasn't until Mary saw the polish on Henrietta's toenails that she realized that this was a real person. How can nurses keep a "professional" distance while also relating to patients as being real people?

Chapter 13

- 1. One of the first uses of HeLa cells was to address polio. How was polio brought under control? What is its prevalence and treatment today?
- 2. Research the polio epidemic of 1951. What were the treatment options pre-Salk?
- 3. The Tuskegee Center was the first institution to charge for and profit from HeLa cells. Discuss the ethics of capitalism vs. altruism as it relates to tissue research. Are there any free sources of tissue for research today?
- 4. Gey was told that he shouldn't have released HeLa cells or his findings to the general public until he had completed his own research and published the results. Discuss the ethical dilemma of personal/professional gain vs. public good. Give a current example.

Chapter 14

1. Compare the attitudes about anonymity of patients/ research subjects then vs. HIPAA. What is the history of HIPAA legislation? If Henrietta's correct name had been disclosed in 1953, her family would have learned much sooner about the research. Would this knowledge have benefitted the family?

Chapter 15

- 1. Compare TB treatment then and now.
- 2. Were there child protective agencies in 1953?
- 3. Lacks family deafness was undiagnosed. When did routine vision and hearing screening become standard in schools?

Chapter 17

1. The Nuremburg Code of Ethics was proposed in 1947 but was not a legal requirement. Discuss the history of informed consent laws. What information must be included in "informed consent"?

Chapter 21

1. Do you think Henrietta's family was more upset about what happened or that they weren't informed? What are the pros and cons of being forthcoming to patients and families about errors vs. not disclosing them unnecessarily (i.e. no harm was done?)

Chapter 26

1. What is the history of obtaining consent for release of medical records?

Chapter 27

1. Describe the association between various strains of HPV and cervical cancer. Research the development of Gardisil.

Chapter 33

1. What was the purpose of pneumoencephalography? What did it purport to show? Over what time period was it used? What replaced it?

General

- 1. Paternalism was common in medical care. Have attitudes changed? Give examples from your own clinical experiences. (Make sure you protect patient privacy.)
- 2. Deborah was driven by the desire to learn about her mother. From a developmental standpoint, what is the potential impact on a 2-year-old of losing a parent?
- 3. Was Henrietta or her family mistreated? What, if any, was the role of nursing?
- 4. Will genome sequencing be the next research field to come under patient protective scrutiny? What safeguards should be in place?
- 5. What would happen if nobody agreed to give tissue or DNA samples?