



PROJECT

Bioethics

frederickuu.org/fcc

DATE

6 sessions

CLIENT

March 12, 10-11:30am (6 sessions)

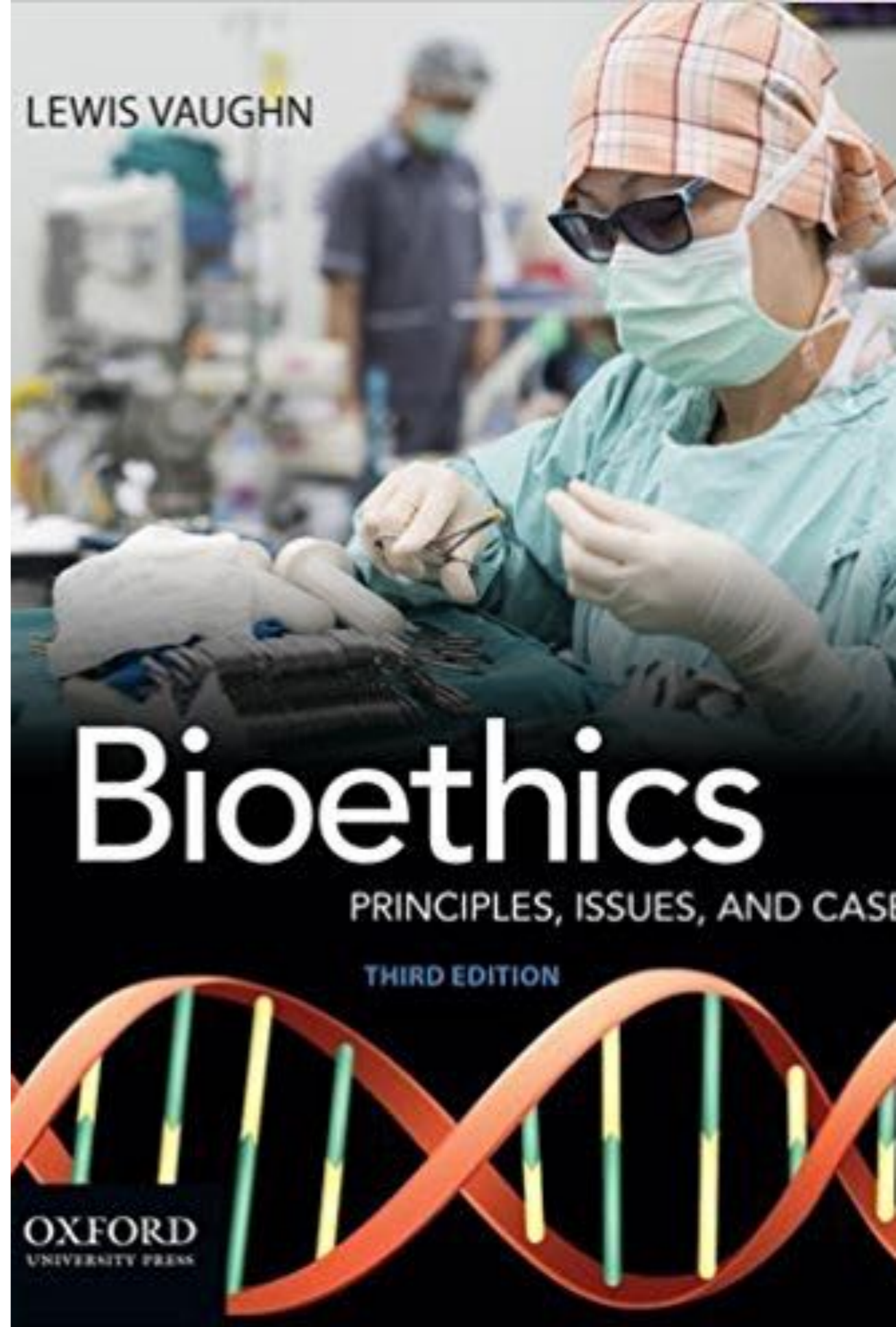
Covenant

- Use **“I” statements**: *Speak from your own experience.*
- **Ask permission before sharing** other participants’ stories outside the group.
- **Lean-in/back**: be conscious of the level of participation that you bring to the conversation. Allow everyone a chance to speak before you speak again.
- You always have **permission to “pass.”**



Housekeeping

- [Are you receiving emails?]
- 21-page Case Study PDF

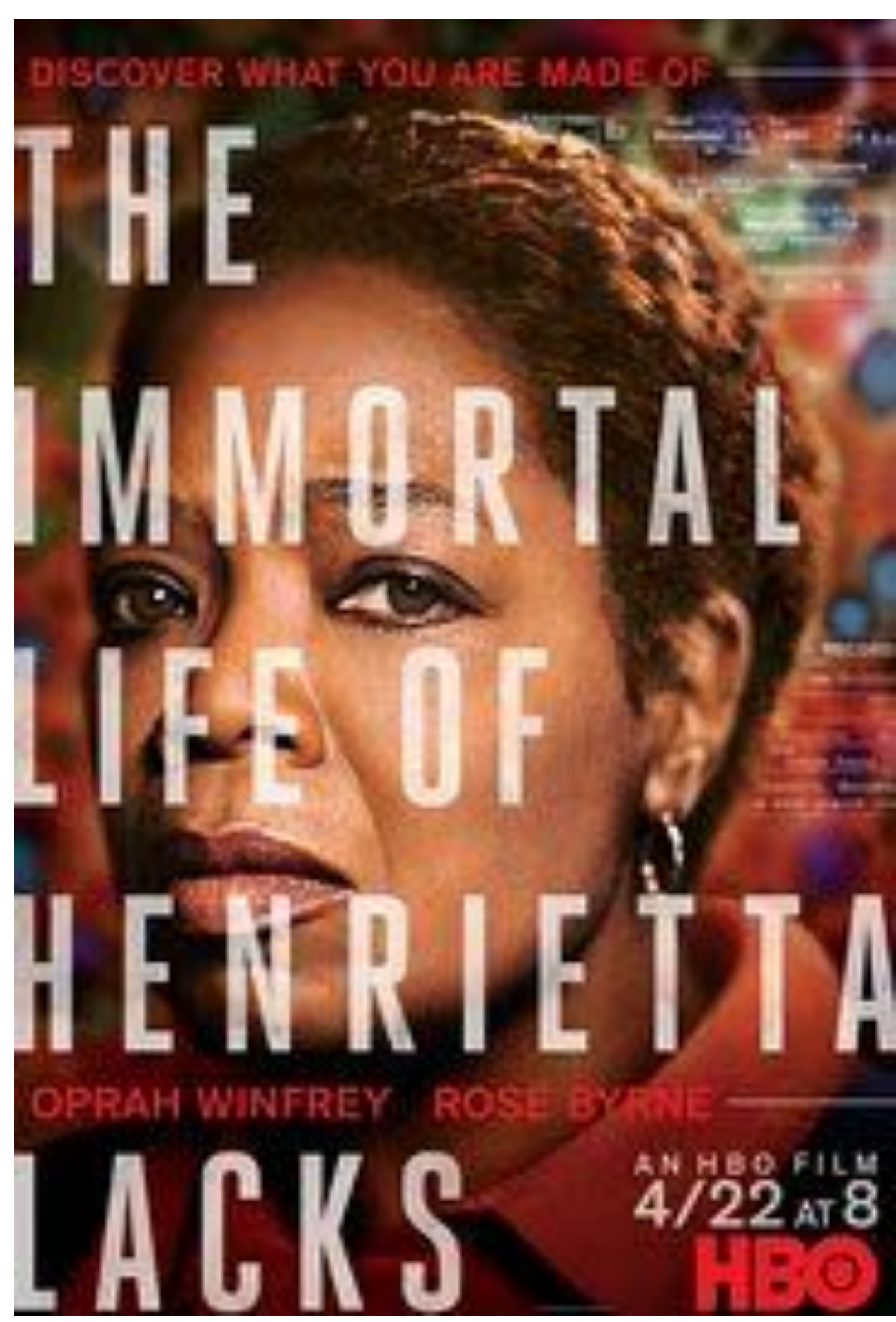


Check-in

- Further thoughts on previous sessions?
- “Show & Tell”

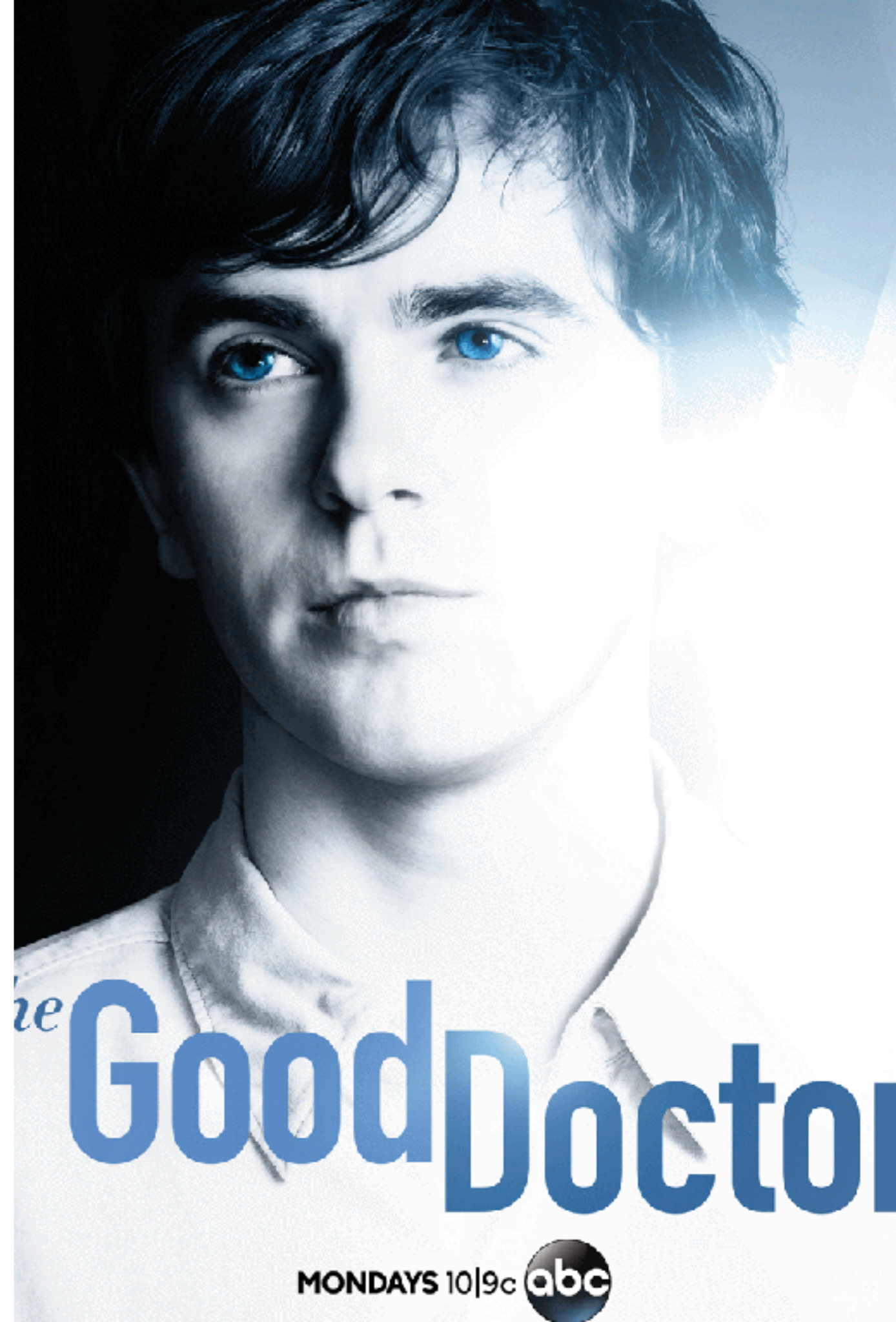
Film & Book

- about Henrietta Lacks and the immortal cell line, known as HeLa, that came from Lacks's cervical cancer cells in 1951.
- Notable for its science writing and dealing with ethical issues of race and class in medical research.



[abc.go.com/shows/
the-good-doctor](http://abc.go.com/shows/the-good-doctor)

- A young surgeon with autism and savant syndrome relocates from a quiet country life to join a prestigious hospital's surgical unit.



* *Session #1: Contemporary Issues: Revolutionary genome-editing technology CRISPR*

* *Session #2: Contemporary Issues: Biotechnologies that will boost human physical & mental performance to unprecedented levels*

* *Session #3-4: Biotech, continued*

* *Session #5: Moral Reasoning, Paternalism & Autonomy*

* Truth-telling & Confidentiality: read "Ch. 4" ("pages 152-153")

* Informed Consent: Before class, read "Ch. 5" ("pages 206-207").

* Human Research: read "Ch. 6" ("pages 254-258")

* Reproductive Technologies: Before class, read "Ch. 8" ("pages 425-427").

* Genetic Choices: read "Ch. 9" ("pages 557-558")

* Dividing Up Health Care Resources: read "Ch. 11" ("pages 732-735")



“Why do you always have to be so paternalistic?”

Paternalism

- bestselling author Atul Gawande tackles the hardest challenge of his profession:
- how medicine can not only improve life but also the process of its ending
- Medicine has triumphed in modern times, but in the inevitable condition of aging and death, the goals of medicine seem too frequently to run counter to the interest of the human spirit.
- Gawande, a practicing surgeon, addresses his profession's ultimate limitation, arguing that **quality of life** is the desired goal for patients and families.
- Gawande offers examples of freer, more socially fulfilling models for assisting the infirm and dependent elderly, and he explores the varieties of hospice care to demonstrate that a person's last weeks or months may be rich and dignified.

#1 NEW YORK TIMES BESTSELLER

Atul Gawande

Being Mortal

Medicine and What Matters in the End

"Wise and deeply moving" — OLIVER SACKS

PICADOR

“Soft Liberal Paternalism”

- Nudge is about choices—how we make them and how we can make better ones.
- Drawing on decades of research in the fields of behavioral science and economics, a new perspective on preventing the countless mistakes we make—ill-advised personal investments, consumption of unhealthy foods, neglect of our natural resources
- Show us how sensible “choice architecture” can successfully nudge people toward the best decisions.
- Must-read for anyone interested in our individual and collective well-being.

NEW YORK TIMES BESTSELLER

MORE THAN
750,000
COPIES SOLD



Nudge

Improving Decisions About
Health, Wealth, and Happiness

Richard H. Thaler and Cass R. Sunstein

Revised and Expanded Edition

“One of the few books I’ve read recently that fundamentally changes the way I think about the world,” —Steven D. Levitt, coauthor of *Freakonomics*



Truth-Telling & Confidentiality

- * Medical Ethics: “Do no harm”
(*non-maleficence*)
- * No: “duty of truthfulness/disclosure” in Hippocratic Oath
- * Overriding principle: perceived therapeutic good for patient—that is, “do no harm” interpreted as *delicately managing what patients know about their own case*.
- * Truth can be harmful, unsettling, depressing [*brutal honesty vs. truth in love*]
- * 1980: first time AMA directly addressed dealing honestly with patients [*culture change around patient autonomy and informed consent*]



Truth-Telling & Confidentiality

1961: 90% of physicians would avoid telling patients of a diagnosis of cancer

1979: 97% of physicians would disclose a cancer diagnosis.

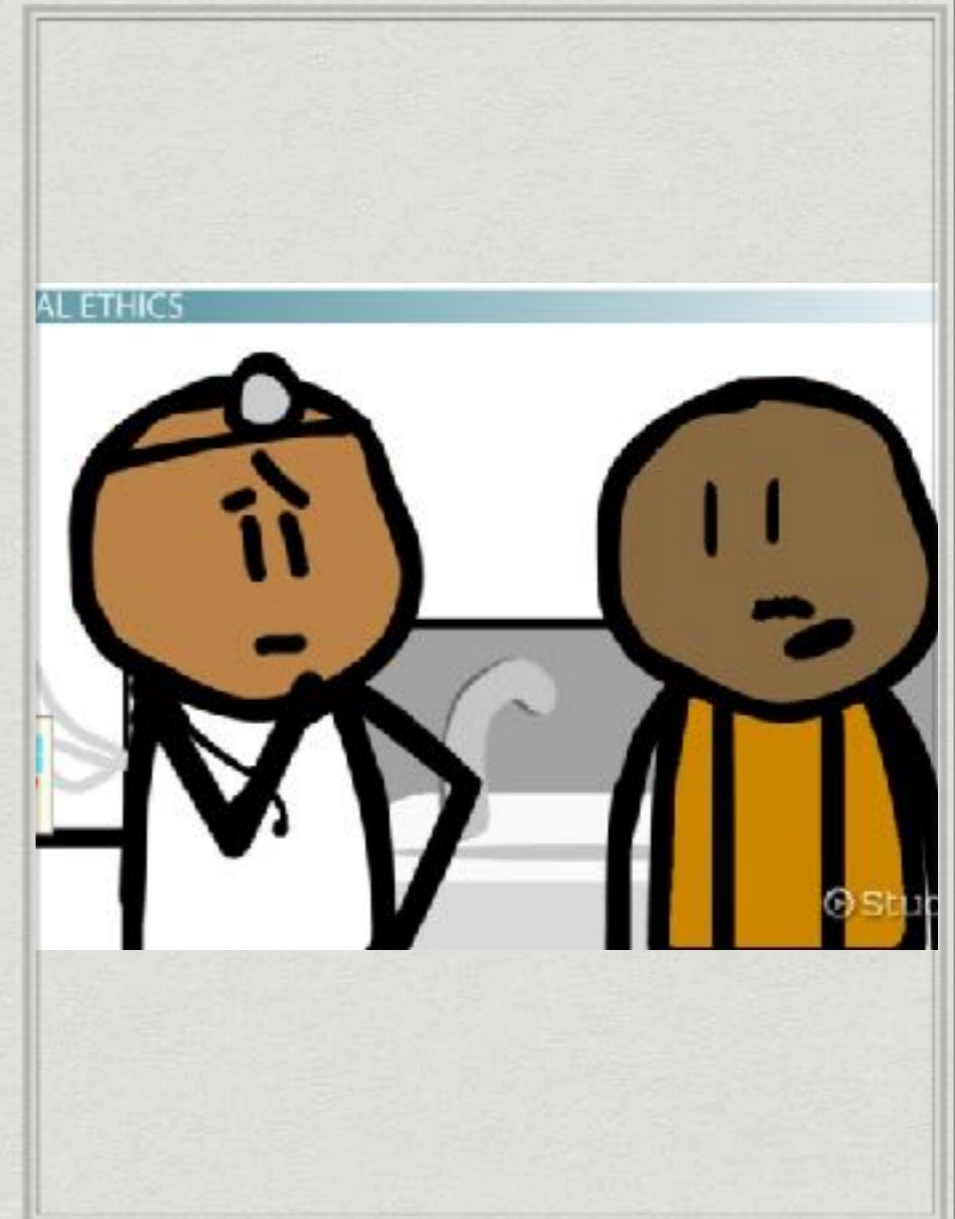
More recent research: fewer doctors tell cancer patients about their *prognosis*.

Patients differ in the kinds of medical information they would like to have and how it is communicated to them.



Truth-Telling & Confidentiality

- * Deception can breed distrust
- * Do we need paradigm shift from “not telling” to “*better* telling”?
- * Caveat: technical complexity of medicine can mean telling the whole truth is impossible to convey to a non-expert. *[same problem described by lawyers, electricians, mechanics, computer technicians]*



Truth-Telling & Confidentiality

- * Tarasoff v. Regents (1976): duties of patient-psychotherapist confidentiality can be overridden when “a patient poses a serious danger of violence to others.”
- * Does that undermine therapeutic relationship?
- * p. 148

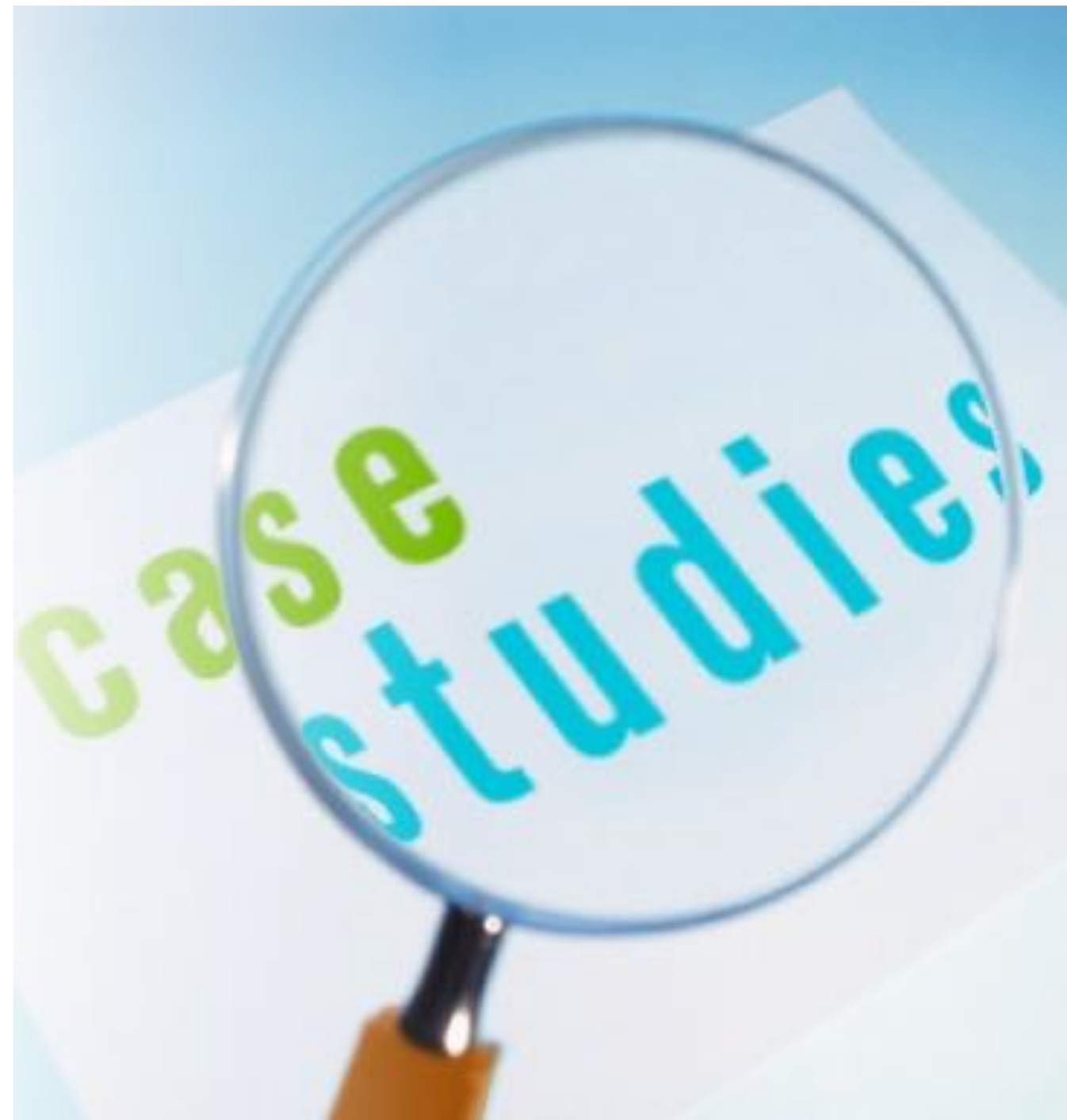


CONFIDENTIAL

Truth-Telling & Confidentiality

p. 152-153

- **Define** the situation (*What's happening? Cast of characters? Chronology?*)
- **Analyze** the case (*Basic issues and values?*)
- **Alternatives** available (*Motives behind each? Consequences?*)
- Are you **consistent** in your ethical framework/approach as case studies change? (*Why or why not?*) (*Is consistency a virtue or vice?*)
- Is there a pattern/logic/reason/emotion **underneath** your reactions/decisions?
- Do you find yourself **changing** from your initial "gut" reaction through the discussion process. (*Why or why not?*)



Does Mrs. Durham have a moral obligation to inform her sister of the results of the test? Why or why not? For Dr. Bartlett, what moral principles are in conflict? If Mrs. Durham refuses to inform her sister, should Dr. Bartlett tell her? What should Dr. Bartlett do if he can't subtly ask Mrs. Weir to be tested (that is, if he can't ask her without revealing the real reason for his request)?

4.1: “Disclosing Information about the Risk of Inherited Disease”

What moral principles seem to be in conflict in this scenario? How would you resolve the conflict? Suppose John's only options are either to maintain confidentiality or to violate it by revealing the subject's HIV status to her boyfriend (the subject refuses to notify him voluntarily). What should John do, and on what grounds could either action be justified? Suppose that state law prohibits researchers from revealing a subject's HIV status. Would this fact change your judgment? Should any such legal fact change your judgment?

4.2: "HIV and a Researcher's Duty to Warn"

Should the physician maintain doctor-patient confidentiality? Should he tell the police that his impaired patient probably broke the law and may have hurt others? What moral principles are relevant to deciding what to do? How much weight would you give to them? Should regard for public safety and the law ever outweigh doctor-patient confidentiality? Explain.

4.3: “Emergency Department Dilemma”

Informed Consent

- * Schloendorff v. Society of New York Hospital (1914): “every human being of adult years and sound mind has a right to determine what shall be done with his own body” (*no suggestion consent had to be informed*)
- * Salgo v. Leland Stanford Junior University Board of Trustees (1957): coined legal term “informed consent” —that, “a physician violates his duty to a patient and subjects himself to liability if he withholds any facts which are necessary to form the basis of an intelligent consent by the patient to the proposed treatment.



Informed Consent

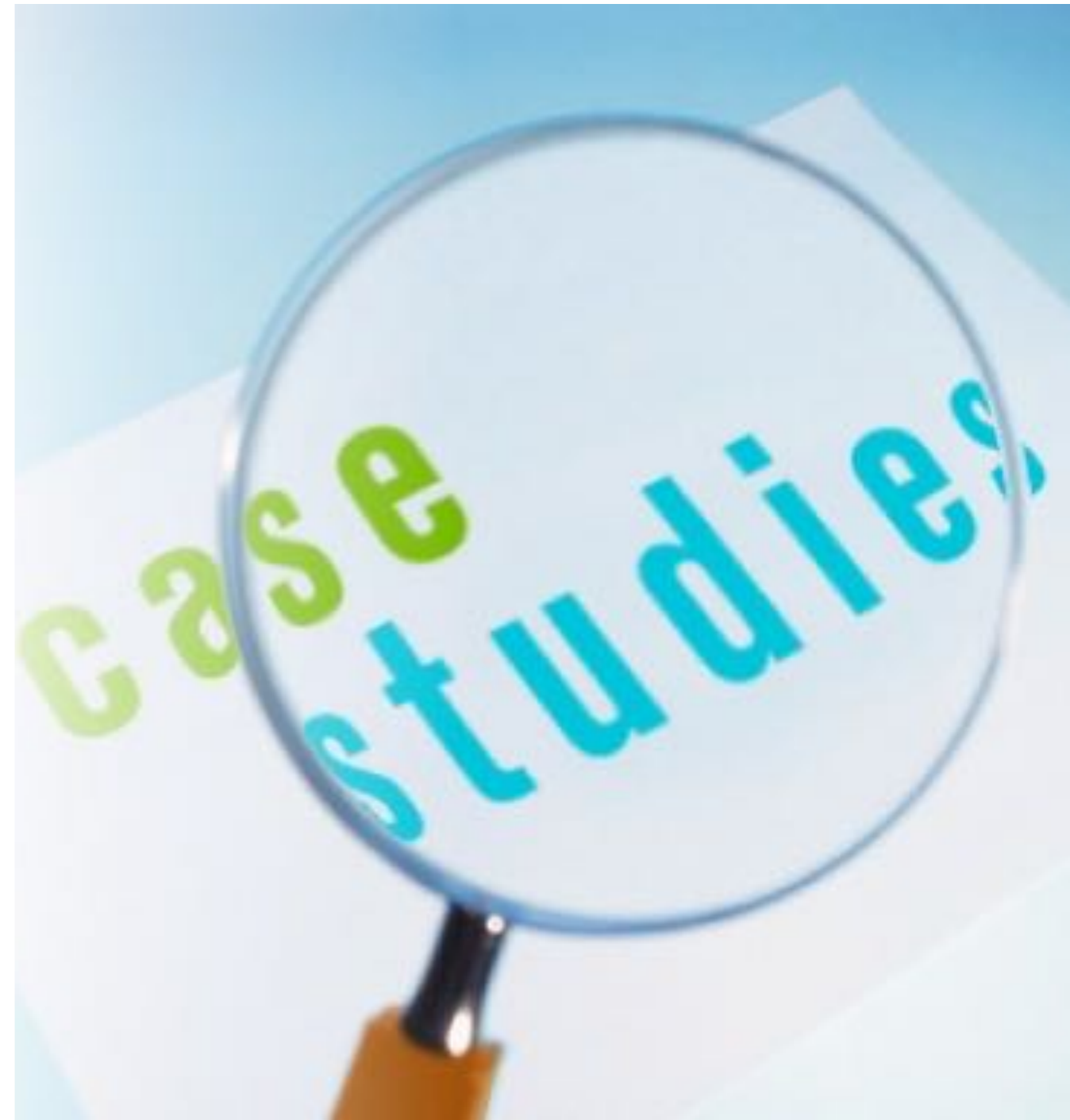
- * Much remains *unsettled*—and *unsettling*
- * Too often a patient can sign a form disclosing treatment risks *but may not actually be informed.*
- * p. 200



Informed Consent

p. 206-207

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Explain your answers: Has the woman given her informed consent? Should she be judged competent? Should her final agreement to the procedure be sufficient to establish informed consent, or should her earlier waffling and confusion also be taken into account?

5.1: “Informed Consent or Not?”

If Jane Doe had not become infected with HIV and hepatitis after her transplant, would the failure of the donor network and the university to fully inform her about the donor have been morally wrong? If so, why? Would her consenting to the transplant have been permissible if she had known that the donor was high risk? Should a patient have the right to consent to and undergo risky treatments? Explain.

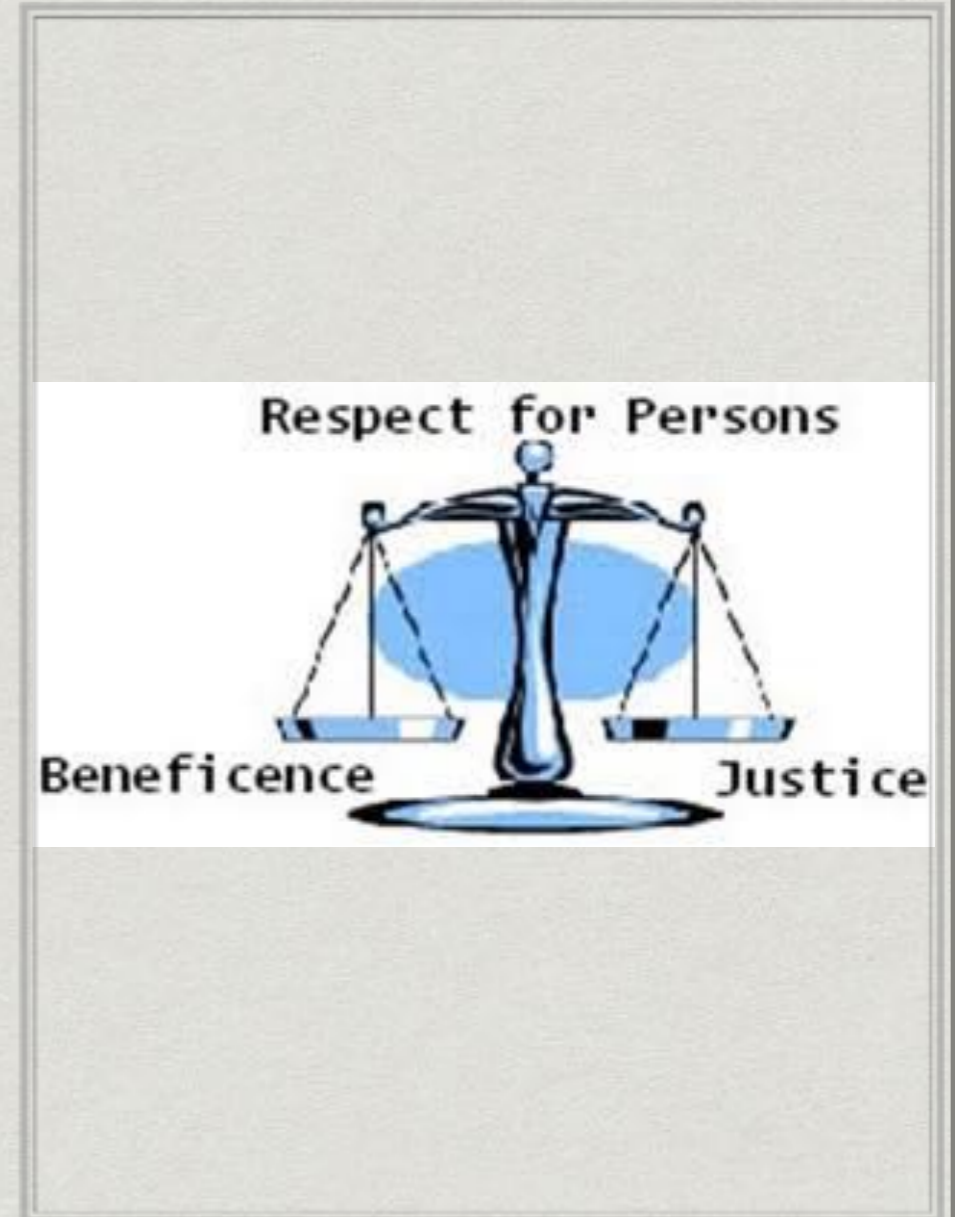
5.2: “Informed Consent and Organ Transplants”

Who, if anyone, in this scenario should be allowed to give informed consent to treatment (or no treatment)? Why? Should the physician regard the 14-year-old as a mature minor? What actions should the physician take if she regarded him as a mature minor? What actions would the physician likely take if she decided to set aside the issue of informed consent and act only in the patient's best interests?

5.3: “Adolescent Informed Consent”

Human Research

- * Joseph Mengele
- * Tuskegee Study
- * p. 239-240



Clinical

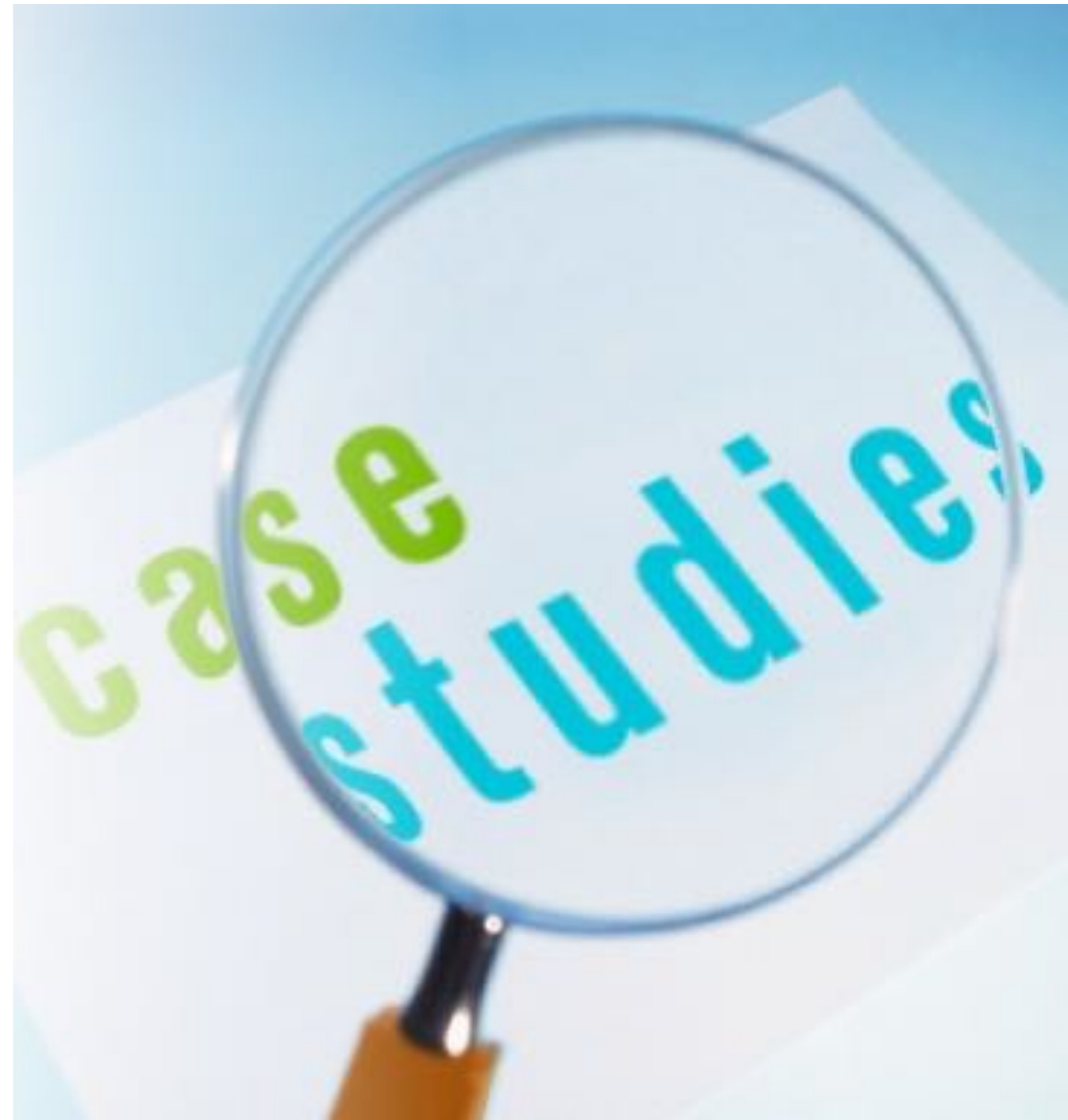
- * Benefits
- * Drawbacks
- * p. 248



Human Research

p. 254-258

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Is giving children placebos in clinical trials ever morally permissible? If so, under what conditions should placebos be used? What if in a clinical trial some children suffer asthma attacks because effective treatment is withheld from them—is that acceptable? What if no effective treatments for some childhood diseases could be developed without

6.1: “Giving Placebos to Children”

Is the Cornell research ethical? Should subjects in the study get the same AIDS treatment available to people in the United States? Should the researchers provide stronger warnings to subjects about the dangers of not using condoms? Is the informed consent process morally acceptable? Explain your answers.

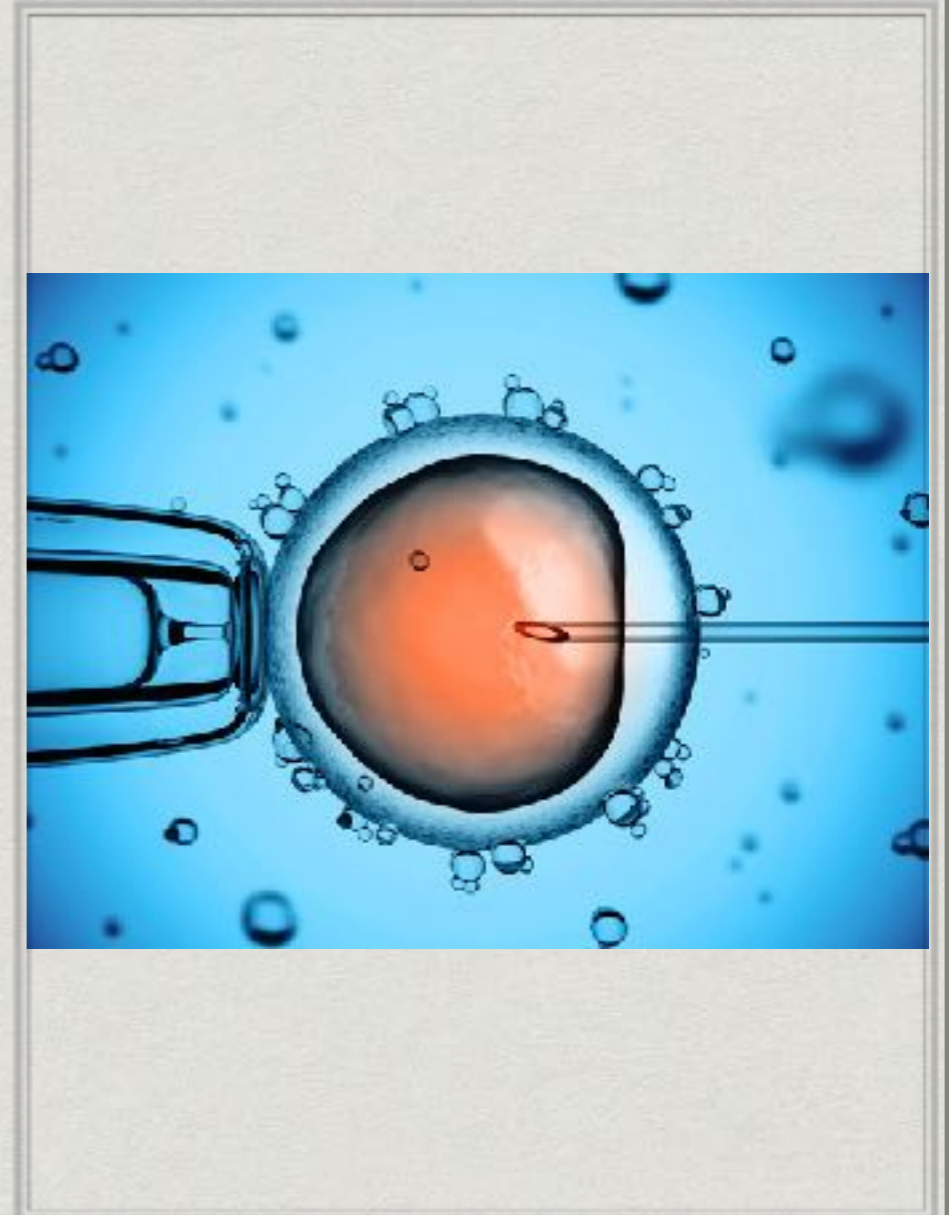
6.2: “Research and Medicine Collide in Haiti”

Were the researchers right to halt the breast cancer study early? Suppose by extending the trial the scientists could gain valuable knowledge that would help save many women's lives in the future. Would halting the trial early then be wrong? Suppose extending the trial would save lives in the future but also result in the deaths of some women in the study. Would the extension then be permissible? Was the use of placebos ethical? Explain your answers.

6.3: "To Stop or Not to Stop a Clinical Trial"

Reproductive Technology

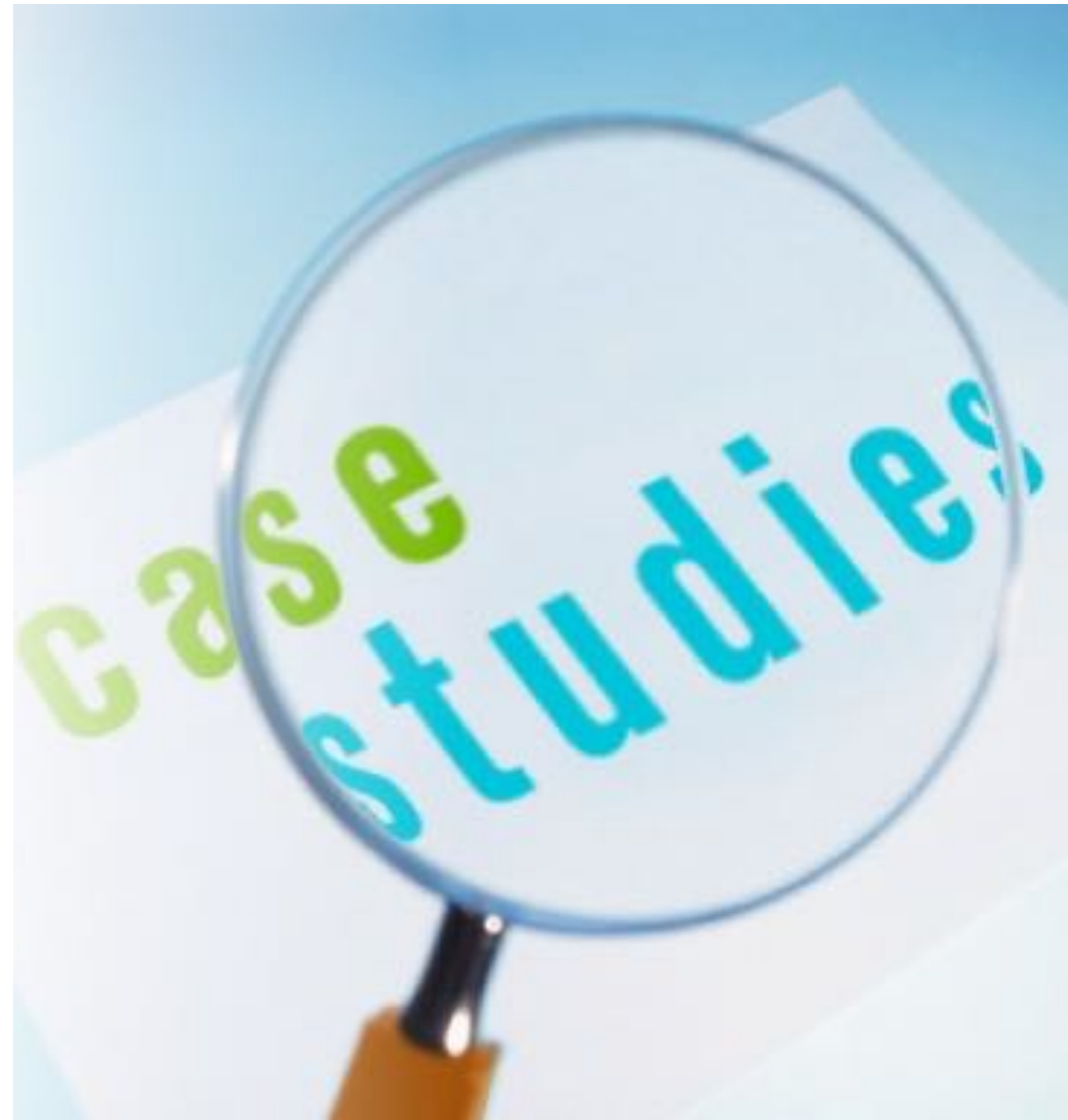
- * Then & Now (p. 409)



Reproductive Technology

p. 425-427

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One study estimates that as many as 400,000 embryos remain frozen in fertility clinics in the United States; this survey tried to document what happens to them. If you were faced with trying to decide what to do with frozen embryos, which of the options described here would you choose? Why? Do you believe that parents should have a say in what happens to their embryos? Do you think embryos have a right to exist regardless of the parents' wishes? Explain. Given that a frozen embryo is minute (comprising only two to four cells), do you think it merits a disposal ceremony? Why or why not?

8.1: "Fate of Frozen Embryos"

Should the father have any rights to the child in this case? Is Florida law correct in giving the surrogate the right to decide to keep the child up until 48 hours after the birth, even if she had signed a surrogacy contract? In determining the custody of a child, should who gestates it carry more weight than genetic links to it (that is, where the egg and sperm come from)? Should genetic or gestational links carry more weight than the ability to properly care for the child? Explain your answers.

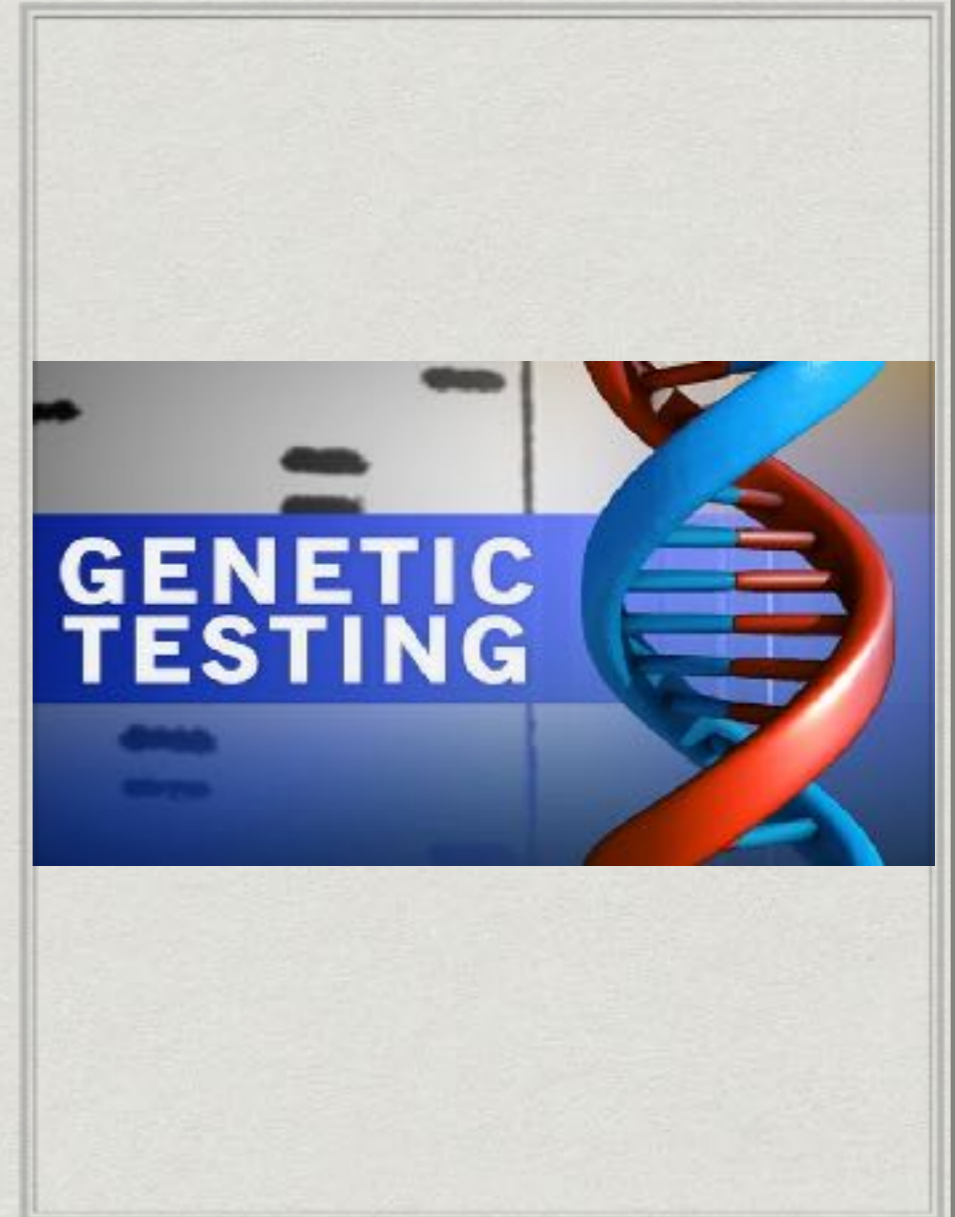
8.2: “Surrogate vs. Father”

If Katharine Gordon could give birth to a clone of her deceased daughter, should she? Is grief over the loss of a child a morally legitimate reason for wanting to clone him or her? Is there a morally relevant difference between sexually producing a child to replace a lost one and producing a child through cloning for the same reason? Explain your answers.

8.3: “Cloning to Bring Back a Child”

Genetic Choices

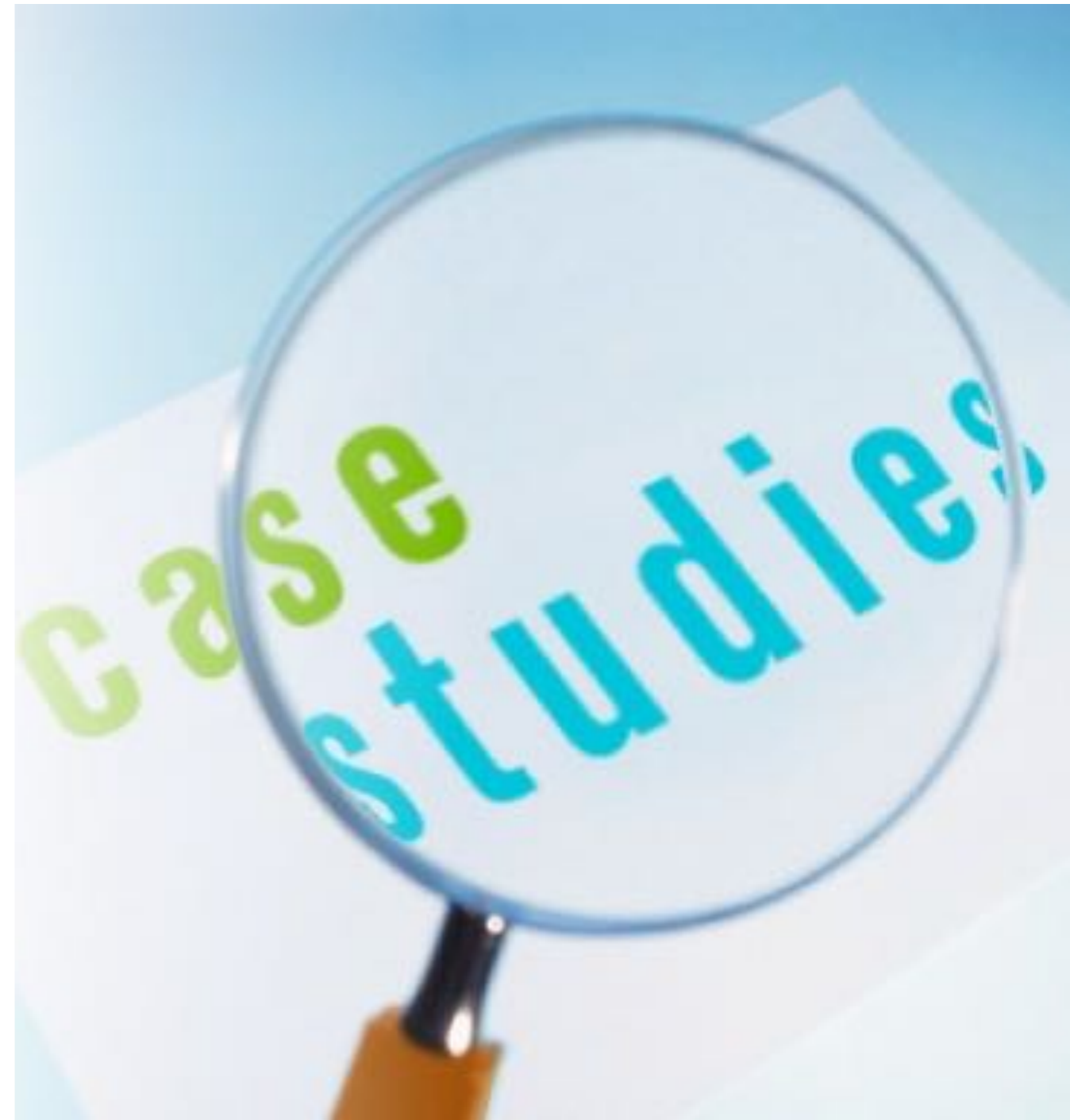
- * Moral obligation to know?
- * Duty to warn?
- * p. 544



Genetic Choices

p. **557**-559

-
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to test embryos for EH will
Paul Senhal, of University

Is it wrong for parents to screen out embryos with disorders that are treatable? What about embryos that will

536 PART 2: LIFE AND DEATH

probably—not certainly—develop a serious disease? Or those that will develop a fatal disease only in middle age? Is it morally permissible to cause to exist persons who are severely disabled and likely to suffer horribly throughout their lives? Give reasons for your answer.

*Is it right to deliberately c
therapy that her operation
why not? Should medical a
restrict the use of IVF and I
and her? If I had a son,*

9.1, “Selecting Babies”

Is it right to deliberately cause a child to be deaf and thereby limit her opportunities in life? If so, why? If not, why not? Should medical authorities or the government restrict the use of IVF and PGD to selecting only healthy embryos? If both prospective parents have inherited deafness, there is a high probability that their child will be deaf. So their failing to use IVF/PGD to select healthy embryos would almost guarantee a deaf baby. Is such a failure morally wrong? If so, is deliberately selecting impaired embryos equally wrong? Explain.

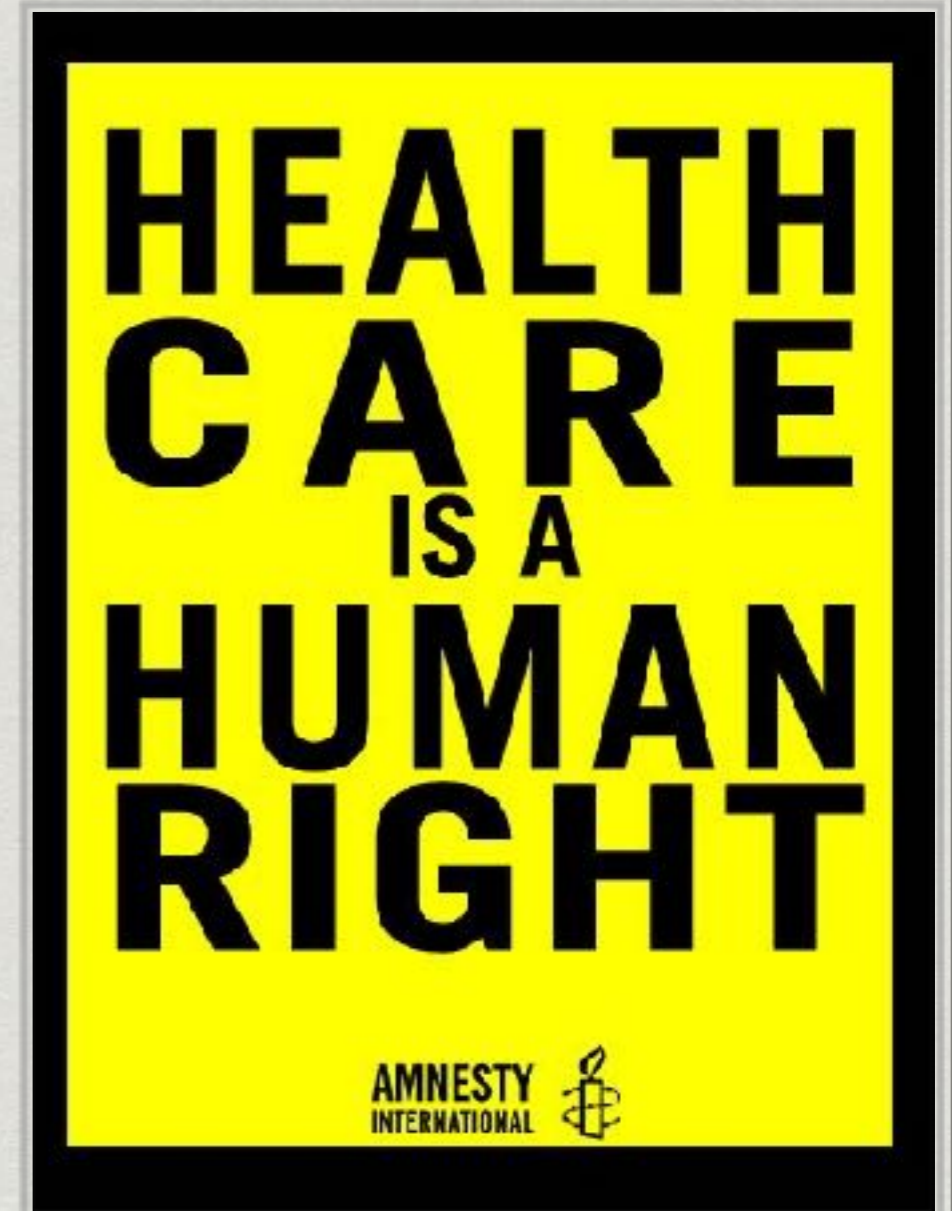
9.2, “Causing Deaf Children”

Should prospective parents be permitted to screen their embryos for cosmetic reasons? Is there a moral difference between embryo selection against severe disabilities and embryo selection against cosmetic imperfections that cause the child to suffer psychological distress or social discrimination? Is embryo selection for cosmetic reasons a form of discrimination or disrespect for people with disabilities or imperfections? Explain your answers.

9.3, “Cosmetic Embryo Selection”

Dividing Up Health Care Resources

- * Who should get health care?
- * Who should provide it?
- * Who should pay for it?
- * Whose justice? Which rationality? (*Who decides? Who benefits? Who is harmed?*)
- * p. 719

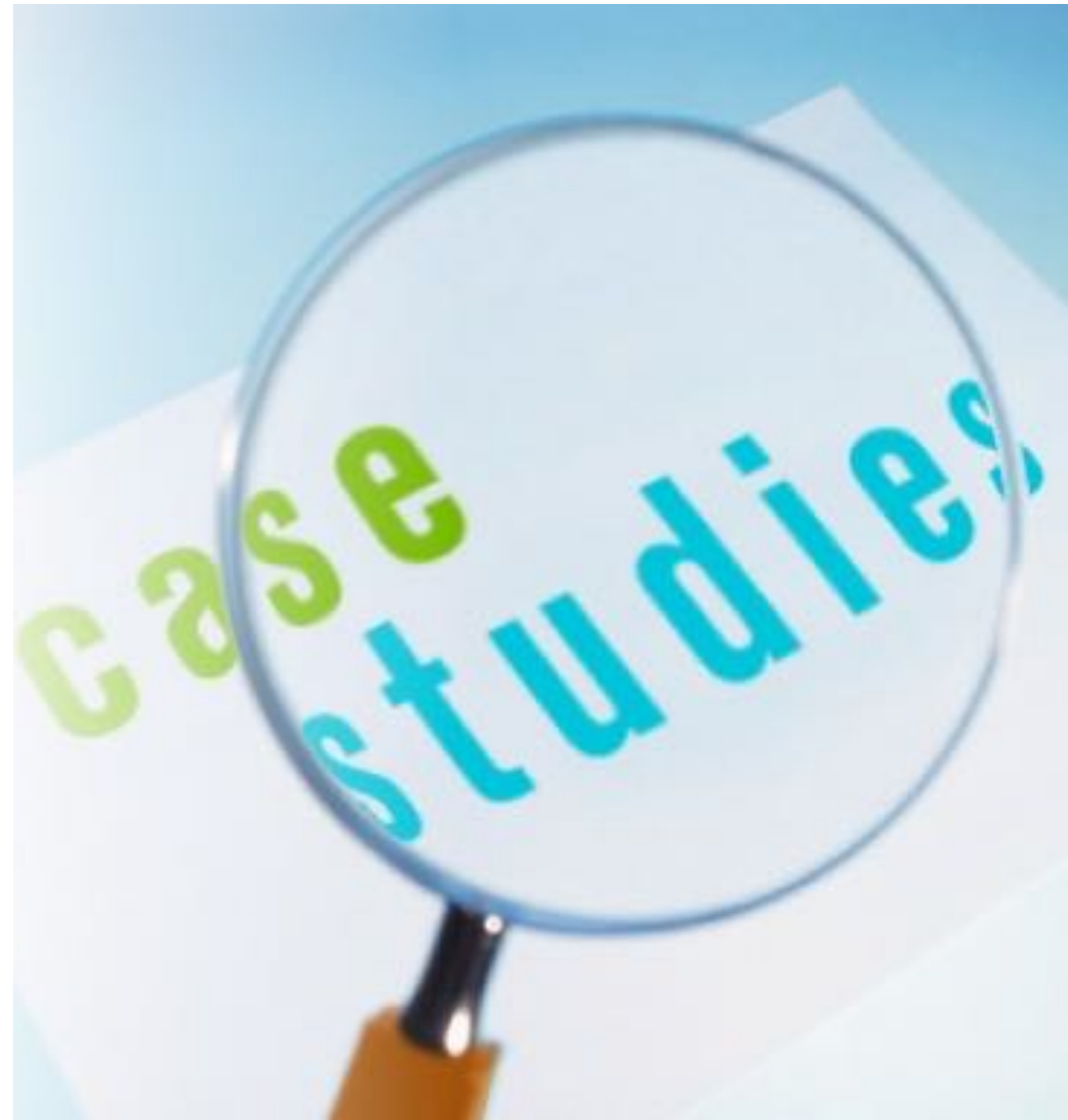


Inalienable NOT Inevitable

Is Health Care a Right?

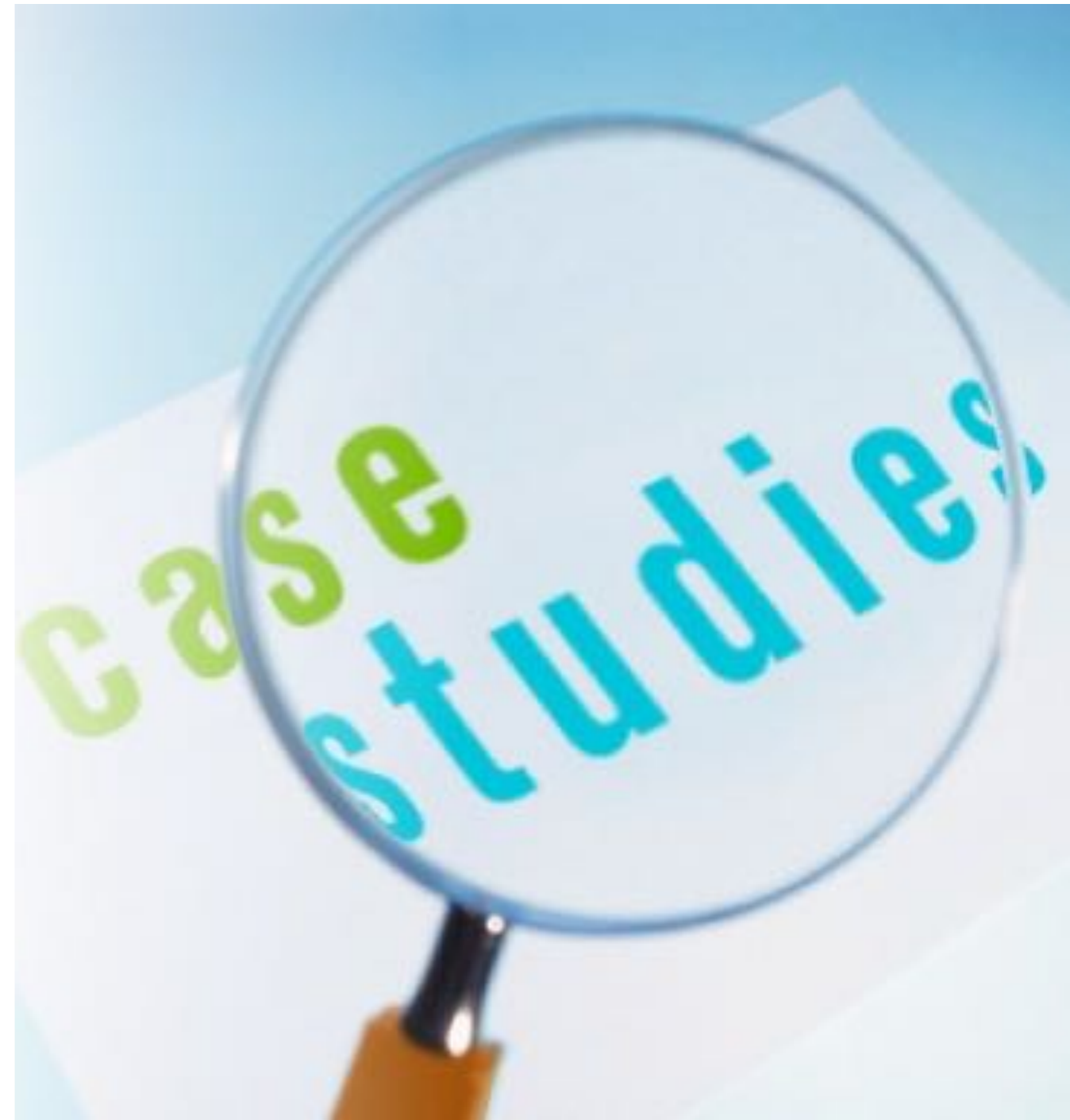
(New Yorker, 10/2/17)

- **It's a question that divides Americans, including those from my home town. But it's possible to find common ground.**
- **by Atul Gawande**
- newyorker.com/magazine/2017/10/02/is-health-care-a-right



Dividing Up Health Care Resources p. **732**-735

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Is it morally permissible to sell your own organs? Is it morally permissible to buy organs from consenting adult donors? Should organ selling be illegal in all cases? Are the Indian organ donors described in this article being exploited? How? Give reasons for your answers.

11.1, “Black Market in Organ Transplants”

Is society obligated to prolong the life of felons like Reyes-Camarena? As thousands of dollars are spent each year by the state to provide him with health care, many lawful citizens cannot afford critical care and die as a result. Is this arrangement just? Do prisoners have a right to health care? Does anyone have a right to health care? Explain your answers.

11.2, “Expensive Health Care for a Killer”

Should the United States establish a system of universal health care? Why or why not? What moral principle seems to underpin opposition to such a system? What moral principle seems to favor it? What would be the negative effects of having universal health care? What would be the positive effects?

11.3, “Should We Have Universal Health Care”

Check-out

- * What **“ah-ha”** moments of insight have you had during this class?
- * How do **think about yourself, others, or the world differently** as a result of this class?
- * How will you **act/live differently** as a result of this course?

