

Bioethics Book Club



The Adoration of Jenna Fox by Mary E. Pearson *Henry Holt Books, 2008*

Summary¹

A seventeen year old girl wakes up after a year in coma. She is told that she has been in an accident and that her name is Jenna Fox. Jenna is still recovering from the accident and struggles to remember her past. Her parents show her videos from her life before the accident, but Jenna finds it hard to identify with the girl in the videos. Is she really the same girl as she sees on the screen? As she starts remembering, she also begins to question what happened after the accident. Her mother is very protective of her, but Jenna insists on going to school and being able meet other kids at her age. Events at home and in school has Jenna suspecting that her parents haven't told her the whole truth about what happened after the accident.

Note: The book is recommended for young adult readers and for those who are looking for an easy read that provides a good foundation for an ethics discussion around advances in biomedical engineering and how these can influence our perception of what it means to be human.

Ethical Issues

Identity	Biomedical Enhancement
Authenticity	Naturalness
Autonomy	Personhood
Bodily integrity	

Discussion questions:

- What defines a human being?
- Discuss to what extent Jenna is still the same girl as she sees on the screen?
- Opponents of modern biotechnologies such as cloning and genetic modification sometimes argue that scientists are 'playing God' or that these technologies are morally wrong because they 'go against nature' or are 'unnatural'. Most of Jenna is created in a lab; does that make her less human? Less natural?

¹ Partly adapted from publisher's summary.

- In the book, ethics committees have set limits as to how much body reconstruction is allowed. To what degree do you think that all modifications to the human body are justified in the quest of health care?
- Jenna decided to destroy the back-ups she found of her two friends. Do you think she had a right to destroy them?
- Do you think Jenna's parents really saved Jenna?

Discuss the following passages from the book:

- "I close my eyes in the darkness and whisper the name. I feel my feet on the floor, my place in the world. I belong here. I deserve to be here. How can a middle name do all that? Are the details of our lives who we are, or is it owning those details that makes the difference?"
- "What about brains? Ethan asks. 'What are they worth?' 'Brains are pretty much illegal. Only biodigital enhancement up to forty-nine percent is allowed to restore some lost function and that's it.' 'That's an odd number,' I say. 'Why only forty-nine percent?' 'You have to draw a line somewhere, don't you? Medical costs are terrible economic drain on society, not to mention all the ethics involved. And by restricting how much can be replaced or enhanced, the FSEB [Federal Science Ethics Board] knows you are more human than lab creation. We don't want a lot of half-human lab pets crawling all around the world, do we?'"
- "How much is me?" Lily intervenes. "Ten percent. Ten percent of your brain. That's all they could save. They should have let you die.'... 'The butterfly, Jenna. That's what they call it. The heart of the brain. That you still have.' And the rest? My memories? My history? Those aren't all in the butterfly. What is the rest?"
- "Look at me! I can never have a child!" She softens. "We saved an ovary, darling. It's preserved at an organ bank. And a surrogate mother won't be a problem-' God! Bits of me have landed everywhere. It would be funny if it wasn't so horrifying."
- "When I was a child there were only a handful of vaccines; now there's a vaccine for nearly everything because we've engineered ourselves right into the corner. That's progress?"
- "There are plenty of good reasons why we have so much regulation.' 'Like?'... 'Engineering corn to resist pests wiped the original species from the face of the planet. Laws are too late for that,' she says, her eyes drilling into me. 'And a simple thing like overusing antibiotics created a strain of bacteria so deadly it killed my husband and a quarter of the world's population.'"