

Bioethics Book Club



My Sister's Keeper by Jodi Picoult
Washington Square Press, 2005

Summary¹

By age thirteen, Anna has undergone countless surgeries, transfusions, and shots so that her older sister Kate can fight the leukemia that has plagued her since childhood. The product of preimplantation genetic diagnosis, Anna was conceived as a bone marrow match for Kate - a life and a role that she has never challenged... until now. Like most teenagers, Anna is beginning to question who she truly is. But unlike most teenagers, she has always been defined in terms of her sister - and so Anna makes a decision that for most would be unthinkable, a decision that will tear her family apart and have perhaps fatal consequences for the sister she loves. *My Sister's Keeper* examines what it means to be a good parent, a good sister, a good person.

Ethics Issues

- Genetic testing
- Pediatric ethics
- Informed consent
- Substitute decision-making
- Patient-family relationships
- Organ transplantation
- Honesty and truth-telling
- End-of-life decision-making

Discussion Questions

1. To what extent are family members morally obligated to ensure each other's well-being? What are the limits of these obligations?
2. Brian and Sara's decision to use preimplantation genetic diagnosis allowed doctors to test their embryos for genetic diseases in order to identify the embryo that is healthy and best genetic match for Kate. Discuss the parents' choice to conceive Anna through preimplantation genetic diagnosis in order to be a donor for Kate. What ethical issues underlie this decision?
3. Discuss the parent's choice to take leucocytes, bone marrow and cord blood donations from Anna in order to benefit Kate. What ethical issues underlie these decisions?
4. Would there be different ethical considerations around taking human tissue from Anna if she had not been conceived to be a tissue match with her sister?
5. Is there an ethical difference between Anna providing the aforementioned tissues and asking Anna to donate a kidney to Kate? Discuss the different views held by the parents, Brian and Sara, on this issue.
6. How should parents balance the needs of their children, especially when the well-being of one depends on a sacrifice on behalf of another? Is it ethical to do whatever it takes to save a child's life, even if that means infringing upon the rights of another?
7. Brian states "We didn't ask for a baby with blue eyes, or one that would grow to be six feet tall, or one that would have an IQ of two hundred. Sure, we asked for specific characteristics—but they're not anything anyone would ever consider to be model human traits. They're just Kate's traits. We don't want a superbaby; we just want to save our daughter's life." Do you agree with Brian that

¹ Adapted from the publisher's summary

there is a moral difference between selecting traits that are socially desirable versus medically desirable?

8. Kantian ethics instructs that people should not be used as a means to an end, but should be understood to be ends unto themselves. Was Anna conceived and utilized merely as a means to an end? Is this ethical under these circumstances?
9. Discuss Kate's request of Anna. How would you react if you were Anna? What ethical issues underlie the request?
10. Discuss Anna's decision to seek "medical emancipation" – do you agree or disagree with her reasons?
11. Did finding out about Kate's decision change your opinion about Anna's choices?
12. When he takes the stand, Dr. Campbell describes the principles his ethics committee use to guide their decision-making (autonomy, veracity, fidelity, beneficence, non-maleficence, and justice). What values and principles would your committee consider in this case?
13. Other than the ruling, what consequences did the legal trial have on the characters in this story?
14. This book is written from the perspectives of many of the characters. What insight does this provide to you on the complex ethical issues at hand?
15. Discuss the following passages in the book:
 - "There are two reasons not to tell the truth - because lying will get you what you want, and because lying will keep someone from getting hurt."
 - "Maybe who we are isn't so much about what we do, but rather what we're capable of when we least expect it."
 - "Sometimes to get what you want the most, you have to do what you want the least."
 - "There are always sides. There is always a winner and a loser. For every person who gets, there's someone who must give. "
 - "There are some things we do because we convince ourselves it would be better for everyone involved. We tell ourselves that it's the right thing to do, the altruistic thing to do. It's far easier than telling ourselves the truth."
 - "When you care more if someone else lives than you do about yourself- is that what [love is]?"
 - "Traditionally, parents made decisions for a child, because presumably they are looking out for his or her best interests. But if they are blinded, instead, by the best interests of another one of their children, the system breaks down. "
 - "We are all, I suppose, beholden to our parents - the question is, how much?"