Case 20-Savior Siblings

In 2000, Adam Nash was born so that his umbilical cord could save his sister Molly's life. Molly had Fanconi anemia, a rare genetic disease requiring a hematopoietic stem cell transplantation from a donor that was compatible with her- likely a genetic relative. Her parents were not compatible donors, and so they turned to researcher Yury Verlinksy and his team for help. Using human leukocyte antigen (HLA) and preimplantation genetic diagnosis (PGD) testing, Verlinsky tested 30 embryos for the disease and for stem cell compatibility, eventually landing on what would be Adam. He was the first 'savior sibling': a child born to save their sibling's life. He would not be the last.

Some object to having a savior sibling be born, claiming that it will put undue burdens, either psychological or physical, on the savior sibling. Being born to save your older sibling's life could stress family dynamics, or put pressure on them to give up bodily autonomy in sometimes risky medical procedures. Others object on the grounds of a slippery slope towards designer babies in general- genetic selection of embryos. Why, though, some ask, should having a child with the intent of saving their sibling be morally unacceptable?

Genetically selecting healthy children has occurred since 1959. Fritz Fuchs and Povi Riis performed amniotic testing in a Copenhagen hospital to determine the sex of a pregnant carrier of hemophila's child; were the child male, she would have aborted it, as the risk of hemophilia would have existed, while a female child would not have had hemophilia. Some objected to the procedure itself, but none to the fundamental concept of the procedure- seeing if the child had hemophilia in order to abort it if it did. Since then, genetic testing has only gotten more intensive; Denmark offers free prenatal Down syndrome screenings to all prospective parents, leading to a substantial drop in the births of children with Down syndrome.

Is there a problem with selecting any trait- no matter how frivolous- for your child; are designer babies acceptable? More narrowly, is it unethical to select genetically healthy children? Does having those children be born to save their siblings lives alter the situation at all, and, if so, why? What moral quandaries could arise from savior siblings' existences? Does special care need to be taken with how their parents interact with them medically? If parents can screen for healthiness, is it morally irresponsible to not, and potentially have a child with a preventable disease?

Study Questions

1. Is having a child for the purpose of having a savior sibling morally different from other motivations? If different, is it a better or worse motivation? Why?
2. Can savior siblings choose not to donate their body parts to their siblings? Is there any moral difference between their refusal and any other person's refusal to donate?
3. Is it morally acceptable to choose health-based traits for a child? What about non-health-based traits, such as attractiveness or intelligence? Why are these different, if they are?

Further Reading

Verlinsky Y, Rechitsky S, Schoolcraft W, Strom C, Kuliev A. "Preimplantation Diagnosis for Fanconi Anemia Combined With HLA Matching". *JAMA.* 2001;285(24):3130–3133. doi:10.1001/jama.285.24.3130

Zhang, Sarah. "Prenatal Testing and the Future of Down Syndrome." *The Atlantic*, 18 November 2020.