

Trevor McCarthy

The Creation of Savior Siblings

Earlier this year, Prince Harry sparked controversy with the release of his memoir *Spare*, describing his tumultuous upbringing, complicated family life, and departure from his Royal Family role. As the title suggests, Harry felt that his upbringing, indeed his whole reason for existence, was to act as a spare, a living organ bank in the event that William needed a transplant. While some may feel Prince Harry's reflection to be hyperbolic, it would not be the first time that a child was conceived for the purpose of tissue donation.

Developments in reproductive technology, such as pre-implantation genetic diagnosis (PGD), can be paired with tissue typing to aid in the creation of so-called "Savior Siblings"—children whose genome and tissue compatibility are assessed *in vitro* to ensure a viable donor, should a family member require a transplant.¹ Today, I would like to introduce some of the basic science that allows for the creation of savior siblings and then discuss some of the ethical considerations involved.

Organ transplantation has been around for some time. The first kidney was transplanted in 1954 between identical twins, and the introduction of the immunosuppressive drug cyclosporine in 1983 drastically reduced the risk of rejection.² Still, the critical determinant of transplant success is the match between donor and recipient. Starting in the 1950s, research on mice and, eventually, human models demonstrated that small molecules on the surface of cells called human leukocyte antigens (HLAs) were associated with transplant success.³ A match

¹ Dickens, B. M. (2005). Preimplantation genetic diagnosis and 'savior siblings'. *International Journal of Gynecology & Obstetrics*, 88(1), 91-96.

² Philogene, Mary Carmelle, and DABHI Daniel C. Brennan. "Kidney transplantation in adults: HLA matching and outcomes."

³ Thorsby, Erik. "A short history of HLA." *Tissue antigens* 74, no. 2 (2009): 101-116.

between donor and recipient HLAs indicates a greater chance of success, while a mismatch means a greater likelihood of rejection.

Though this discovery significantly increased the number of transplants, there are still patients for whom no match is available. As seen with the first kidney transplant, genetic similarity, the kind found between siblings and close relatives, is strongly associated with the likelihood of a match. Parents may naturally conceive a child in hopes that the new sibling will be a match, but this method only works around 25% of the time. The rise of preimplantation genetic diagnosis (PGD) in the 1980s and 90s allowed for exact matches to be found by analyzing the genetics of early-stage embryos created *in vitro*.⁴ Originally developed to screen for heritable genetic diseases, PGD can select for various traits and, when used in conjunction with HLA typing, can assess tissue compatibility. Stem cells are collected from the umbilical cord upon birth, but when this cannot happen, savior siblings may provide a bone marrow transplant. It should also be noted that PGD presents minimal physical risk to the embryo when done properly.⁵

With the theoretical framework in place, the first savior sibling, named “Adam,” was born in 2000, with the stem cells from the umbilical cord used to treat his sister, who suffered from Fanconi Anaemia.⁶ Since this first procedure, hundreds of savior siblings have been born worldwide.

One of the most common arguments against the creation of savior siblings has to do with the instrumentalization of the newborn. Immanuel Kant’s famous categorical imperative,

⁴ Sermon, Karen, André Van Steirteghem, and Inge Liebaers. "Preimplantation genetic diagnosis." *The Lancet* 363, no. 9421 (2004): 1633-1641.

⁵ Sermon et al., 1638

⁶ Lai, Amy TY. "To Be or Not to Be My Sister's Keeper? A Revised Legal Framework Safeguarding Savior Siblings' Welfare." *Journal of Legal Medicine* 32, no. 3 (2011): 261-293.

described in his *Groundwork of the Metaphysics of Morals*, tells us to treat others as ends in themselves and not merely as a means.⁷ Some would argue that creating a child for the purpose of saving another functionalizes that child.⁸ However, a standard response to this argument states that the child is not being used *merely* as a means. Sure, the child is being used for the benefit of another, but they are still loved in their own right as a unique individual.

Another issue concerns the possible harm to the savior child, both physical and psychological.⁹ While PGD itself does not cause physical harm, the savior sibling may be expected to donate bone marrow if stem cells from the umbilical cord cannot be gathered or multiple transplants are needed. This form of transplantation does involve non trivial risk to the child. Savior siblings may also feel that their purpose in life is secondary to their sibling, causing emotional and psychological distress.

Complicating the matter is that children are typically not afforded full decision-making capacity under the law; in other words, they cannot consent to the donation.¹⁰ If anyone is familiar with the Jodi Picoult novel *My Sister's Keeper*, the story recounts a savior sister and her legal battles for medical emancipation from her parents.¹¹ In medical decision-making, the risks of the procedure are weighed against the benefits. While the benefits to the recipient sibling are apparent and potentially life-saving, the donor sibling may also benefit from the donation. For example, they may enjoy the pleasures of having a companion in childhood or the satisfaction of having helped a family member. One argument posits that savior children benefit because they

⁷ Kant, Immanuel (1993) [1785]. *Groundwork of the Metaphysics of Morals*. Translated by Ellington, James W. (3rd ed.). Hackett. p. 30. ISBN 0-87220-166-X.

⁸ Sheldon, Sally, and Stephen Wilkinson. "Should selecting saviour siblings be banned?." *Journal of Medical Ethics* 30, no. 6 (2004): 534.

⁹ Sheldon, Sally, and Stephen Wilkinson, 535.

¹⁰ Shapiro, Zachary E. "Savior siblings in the United States: ethical conundrums, legal and regulatory void." *Wash. & Lee J. Civ. Rts. & Soc. Just.* 24 (2017): 419.

¹¹ Picoult, Jodi. *My Sister's Keeper-Movie Tie-In: A Novel*. Simon and Schuster, 2009.

would not otherwise have existed. Interestingly, that is also an argument used by some in response to animal rights activists who protest meat eating.¹²

In addition to these ethical considerations, savior siblings also should be considered in policy and legislation. The United States, in many regards, is the wild west of emerging reproductive technologies. Only the clinical validity of PGD is assessed through CLIA, and no federal legislation exists to regulate the creation of savior siblings.¹³ The United Kingdom, on the other hand, heavily regulates PGD through the Human Fertilisation and Embryology Authority (HFEA), which lists conditions eligible for savior sibling creation and authorizes the PGD.¹⁴ The role of physicians in relating information relating to savior siblings is also the subject of debate. Public opinion holds that doctors have a duty to inform parents of the creation of savior siblings as a potential course of action, although conscientious objection might be defended.¹⁵

As technology continues to advance, the ethical questions being asked become more complex. For example, the advent of CRISPR-Cas9 could affect how savior siblings are created. The arguments I have presented are by no means exhaustive, but I hope to have captured your interest in this ongoing discussion in bioethics.

¹² Zangwill, Nick. "Our moral duty to eat meat." *Journal of the American Philosophical Association* 7, no. 3 (2021): 295-311.

¹³ Burke, Wylie. "Genetic tests: clinical validity and clinical utility." *Current protocols in human genetics* 81, no. 1 (2014): 9-15.

¹⁴ "[Human Fertilisation and Embryology Act 1990](http://www.opsi.gov.uk)". *www.opsi.gov.uk*.

¹⁵ Strong, Kimberly, Ian Kerridge, and Miles Little. "Savior siblings, parenting and the moral valorization of children." *Bioethics* 28, no. 4 (2014): 187-193.

Discussion Questions:

1. Do you think the United States should regulate PGD and tissue typing in the creation of savior siblings more? And if so, how?
2. Can you think of any other arguments either for or against the creation of savior siblings?