

My Sister's Savior

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What does it say about a society which permits, no, which condones the use of medicine and technology for the sole purpose of creating human life just to destroy it? It says we are a culture that has morally and tragically lost its way.

My Sister's Keeper, Jodi Picoult's 2004 novel, out on the big screen in America. Joining other profoundly bioethical films such as *Gattaca* (1997; addresses genetic engineering of super humans), *Million Dollar Baby* (2004; tackles assisted dying), and *The Island* (2005; deals with the creation of human clones to be spare parts for the wealthy sick), *My Sister's Keeper* takes on a real-life issue commonly known as "savior sibling."

A "savior sibling" refers to the creation of a genetically matched human being, in order to be the savior of a sick child in need of a donor. This requires creating human embryos in vitro, which literally means "in glass" (i.e. a test tube), using the egg from the mother and fertilizing the egg with the father's sperm. Then, using pre-implantation technology, the embryos are tested, and the one deemed genetically compatible is implanted into the mother's womb in order for the embryo to grow and develop. Once that baby is delivered, the cord blood is often collected because it provides a perfect match for the sick sibling. Later on, bone marrow, blood, or even organs, can also be taken and used for transplantation for the sick sibling.

Savior siblings are already a reality, and the use of such practices in the United States is not prohibited. Adam Nash was the first savior sibling in the U.S. Adam was born in 2000 to rescue his sister Mollie, who was diagnosed with Fanconi's anemia. Mollie would have otherwise succumbed to death if not for a matched donor. The Nashes created 30 embryos and went through four rounds of in vitro fertilization (IVF) to finally produce Adam, who was the match Mollie needed.[1] Of course, the ethics of the disposition of the 29 other embryos is quite problematic. Adam was chosen, 29 other human lives were not, simply because their DNA was not able to rescue Mollie from a deadly diagnosis.

In Picoult's story, the film opens with a voice-over narration of Anna Fitzgerald, the savior sibling. Anna describes herself as a "designer baby." Note to self: Beware of euphemisms. Euphemisms are rampant in the world of IVF. Selective reduction refers to a situation in which many embryos are transferred into a mother's womb, and then if too many of them implant, the physician, (with the parents' consent), removes the "extra" embryos. Although the removed embryos die because a lethal dose of potassium chloride is injected into the fetal heart, we politely talk about selective reductions. Family balancing, social sex-selection and gender selection are terms used to discuss the use of these technologies to intentionally select your children based on their sex and your preference for a boy or a girl. Of course, these euphemistic phrases are used to play down the fact that people are ordering; that is shopping for; their children purely based on parents' desires. If you want a boy, you screen the embryos, select the male embryo, and discard the female ones in order to "balance" your family. Heaven forbid we should have unbalanced families! The practice of social sex-selection is banned in Canada, so Canadians who wish to order the sex of their children come to the U.S. Social sex-selection is just another euphemism with deadly ramifications. Healthy babies discarded because they are the wrong sex? Surely these are symptoms of a culture in decline!

Anna Fitzgerald, the self-described designer baby in Picoult's story; designer not as in Prada, or Coach, or Gucci, but more or less like a cafeteria-style menu selection; was designed for the purpose of being the donor for her sister, Kate. Kate, diagnosed as a young child with leukemia, needs a bone marrow transplant, but none are available. Family members are tested, but no one is a match. She is dying and time is running out, so the family's physician recommends something "off the record." He suggests creating a donor sibling.

In the opening of the film, Anna suggests that while her method of coming into the world is not conventional, since most babies born are unwanted, she at least was a wanted child. But she is wanted as a product; as a medical treatment; as a donor. Actually, the most recent statistics, taken from a study done in 2001, show that overall 49 percent of babies born in the U.S. are from unintended pregnancies.[2] After that report came out, steps were taken to reduce that number to 30 percent by 2010. We shall see how successful the educational efforts have been when the next report comes out. But of course, as all studies of this nature go, the actual statistics break out quite differently when looked at from educational, economic and age categories.

Also, Anna is not quite accurate in her description of how she was made. She suggests that the doctors took the best part of her mom's DNA and the best part of her dad's DNA and voila?; the perfect match was made. If we as a society are going to be able to have an earnest conversation on the ethics of creating savior siblings, we must be intellectually honest with the facts and accuracy of the procedure. Embryos?;as in multiple embryos, were created, and then tested, and only the one that would provide the genetic match was brought to term. The other embryos were discarded. As was the case with the Nash family, 30 embryos were created and only Adam was selected. This is high-tech eugenics: being selected only because of your ?good? genes or being destined for demise because you had the wrong or ?bad? genetic make-up.

From this point on, the film does a good job of addressing some real issues head on, showing the complexity of the ethical realities, while fortunately not leaving the audience with a romanticized ?happily ever after? ending.

The film poignantly shows the absolute devastation parents face when told that their child has a dreadful disease that will most likely kill her. There is no sugar coating of the stress that is placed on a marriage or other children in the family, and the strained family dynamics when a child is seriously or chronically ill. That means gut-wrenching decisions, and the constant suggestion that all hope is lost and all you have to grasp for are straws.

The film deals directly with Anna's life and experience, as she has lived it knowing that she is a product who only exists because someone else desperately needed her?;or parts of her at least.

And here is the heart of the ethical matter at hand. Technology, apart from any ethical or moral compass, has progressed to the point where, for the first time in history, we are able to intentionally create human life and allow it to fully develop solely because we need that life to save another. And perhaps even more worrisome is the reality that other lives were created, and then destroyed because it did not perfectly meet the need of another. Realistically, there could be several embryos which provided the genetic match, but since only one is needed; even embryos which make the cut are discarded. In our desire to relieve suffering, to seek healing and cures, and to avoid death, we have crossed a bright ethical line by seeking to use one human life for the good of another.

Whether we look for moral guidance from our religious texts or to secular historical documents, it is important that we as a society remain rooted in the belief in the inherent dignity of all persons. The U.N. Declaration on Human Rights warns that wherever there is ?disregard and contempt for human rights,? ?barbarous acts? are sure to follow.[3] Surely, the rights of the savior sibling have been denied when from their first breath they are being used as a means to an end. The World Medical Declaration of Helsinki claims that, ?the duty of the physician is to promote and safeguard the health of patients.?[4] Isn't there an immediate conflict of interest between the doctor and the patient, not to mention the savior sibling, who has nothing to gain, but perhaps is exposed to medical risk while not even being a patient? Organ donation is perhaps one of the greatest altruistic deeds a person can do. But in organ donation, the gift is freely given. It is never taken, coerced or bought. Creating a savior sibling is a direct violation of the dignity of that person. It treats human life as something to be made, manufactured and used as a commodity.

Early in the film, Anna hires an attorney and announces, ?I want to sue my parents for the rights to

my own body.? From the moment of birth, the savior sibling has been denied the full rights to her own body, and to willingly and freely be her sister?s keeper.

[1] <http://www.cmf.org.uk/literature/content.asp?context=article&id=1317>

[2] <http://www.ncbi.nlm.nih.gov/pubmed/16772190>

[3] <http://www.un.org/en/documents/udhr/>

[4] <http://www.wma.net/e/policy/b3.htm>