

Savior Siblings: An Ethical Analysis

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I. Introduction

Men are endowed with gifts of will and intellect. Judgement to certain acts whether it is good or bad is left to the reasons of men. It is imperative that men exercise their own moral judgment to any act whether it is morally permissible or impermissible.

This is the challenge given to every rational being and that is to always desire what is good and is morally right. However, varying perspectives have brought men to different levels of understanding and in judging an act.

Apparently, inquiries into what is right or wrong invoke questions of morality, and its discussions led to grappling with ethical quandaries (Walker & Futrell, 2009).

This paper on Jodi Picoult's *My Sister's Keeper* aims to provide a theory-based ethical analysis on moral issues posted in this best seller novel and box-office film about "Savior Siblings" or children who were conceived by IVF or in-vitro fertilization. Moral theory of Immanuel Kant or Kantian Ethics (Respect for others) will be the basis of this analytical paper. This further aims to decide on this issue whether it is morally permissible or impermissible grounded on this moral theory.

Therefore, the following moral inquiries are to be resolved:

(1) Is it morally permissible or impermissible to use genetically-selective in-vitro fertilization (or designer babies) to create embryos that would act as perfect-match donors for older siblings with serious medical conditions such as leukaemia? Or "Is the deliberate selection of an embryo as a tissue match for a terminally ill child ethical? Or is it morally right or wrong to create Saviour Siblings through Human Leukocyte Antigen (HLA);

(2) Is it also morally right or wrong for Anna to claim for her

right to her own body by suing her parents?

(3) In the case of the mother, Sara, is it morally permissible or impermissible for her to born a child who is genetically modified for the purpose of saving her other child?

While there are a lot of bioethical concerns about the creation of savior siblings, the proponent would like to contextualize moral judgments on the basis of an ethical theory.

II. Discussion

A. My Sister's Keeper by Jodi Picoult

The story is about the Fitzgerald family working through the cancer struggle of their fifteen year old daughter, Kate. The mother, Sara, is a fierce, relentless warrior-mom, doing everything she possibly can to let her daughter survive. The father Brian is a little mellow, and tries to ensure his daughter's happiness. But when it becomes clear that Kate is going to need a lot of tough medical work, the two decide the best route and that is to create little Anna. She is genetically engineered in vitro to be a perfect match for Kate, a bag of organs and blood that will be able to swap sisters when Kate really needs it. And she does, a lot. Anna has undergone numerous procedures, some fairly serious, by the time she is 11, all in the name of helping her sister. But one day, little 11 year old Anna walks into the law office of Campbell who wants to sue her parents for the medical rights to her own body. They have recently learned Kate needs a new kidney, or she will go into complete renal failure and die. Turning to their spare-daughter once more, Anna seems to decide she can't take it. The risks of having one kidney, and the cost it will lay on her later in life (she couldn't be as active as the other girls, would have to be more careful, there are more risks in pregnancy, etc.) is too high.

Brian, the good father, has "lost the love of his life" according to Kate, since Sara has dropped everything to help her daughter, including her husband. Brian doesn't resent this, and understands the struggle. He cares immensely for his daughter's happiness, and it shows. Brian seems to understand the dilemma more than Sara, who thinks Anna is killing her sister. But Anna, protective of and devoted to her sister, is clearly her best friend. Jesse, on the

other hand, is a largely forgotten character. It's implied that he is somewhat of a delinquent brother.

Sara (the mother) makes it quite clear that her loyalties lie with her eldest daughter; and her eldest daughter alone. Anna is not a selfish girl wanting her sister to die, but Sara just can't lose, and shields herself from the glaring truth; however, Kate wants it to end. Sara has never listened to her when she's spoken like that, always telling her to keep pushing, so Kate has to resort to getting her younger sister to fight the battle for her. And though Sara is stubborn, she is doing it for all the right reasons, and it would be hard to judge a person in her situation. She also has glimmering moments of kindness when she shaved her head bald to look like her daughter, and gets giddy when taking pictures of her daughter before a dance.

The ending of the movie is sad. Anna won her lawsuit and Kate died of cancer, ending up Sara's long years of battle in making her daughter live. However, the Fitzgerald once again been reunited as family, Brian (the father) and Jesse (the brother) and Anna were back to life of Sara who were once lost all for the love of Kate.

B. Kantian Moral Theory

Immanuel Kant, a German Philosopher lived from 1724 to 1804 and during his lifetime created many theories on ethical conduct and human motivation. Kant believes that the morality of our actions has nothing to do with the results but has everything to do with our intentions. For Kant, "it has everything to do with our intentions and reasons for action, those that are embedded within the principles we live by."

Kant is responsible for the most prominent and well-known form of deontological ethics. Kant's moral theory is based on his view of the human being as having a unique capacity for rationality. No other animal possesses such a propensity for reasoned thought and action, and it is exactly this ability that requires human beings to act in accordance with and for the sake of moral law or duty. Kant believes human inclinations, emotions and consequences should play no role in moral action; therefore, the motivation behind an action must be based on obligation and well thought out before the action takes place. Morality should, in theory, provide people

with a framework of rational rules that guide and prevent certain actions and are independent of personal intentions and desires. (<http://sevenpillarsinstitute.org>)

Kant developed certain formulas or guidelines that will help identify the logic behind our moral or immoral actions. Ideas and theories developed by Kant to identify the morality of the action include the categorical imperative, principle of universalizability, and the concepts of good will. (Kant's ethics and epistemology, 2011)

According to Kant, moral judgment comes from a person's own reasoning. When we act, whether we achieve what we intend with our actions is sometimes beyond our control and the morality of our actions will not depend upon the outcome. The only thing we can control is the will behind the action and the morality of the action must be evaluated based on the reason of the desire. The moral worth of an action is determined by the human will, which is the only thing in the world that can be considered good without qualification. Good will is exercised by acting according to moral duty/law. Moral law consists of a set of maxims, which are categorical in nature- we are bound by duty to act in accordance with categorical imperatives.

Kantian ethics provides that an act done from duty has its moral worth. The Moral worth of an action does not depend upon the results expected from it, and that any moral action proceeds from the proper motive, that is the "good will" or "recognition of duty." Duties are unconditional (or categorical) demands on our behaviour and are determined by reason alone. Duties are determined by the attempt to universalize the maxim underlying the action. If the maxim can be universalized without contradiction then it is a moral maxim and so a duty.

The theory of deontology comes from the Greek word deon, meaning duty. The theory of deontology states we are morally obligated to act in accordance with a certain set of principles and rules regardless of outcome. The rules (or maxims) in Kant's deontological theory derive from human reason. Deontological theories hold that some acts are always wrong, even if the act leads to an admirable outcome. Actions in deontology are always judged independently of their outcome. An act can be morally bad but may unintentionally lead to a favourable outcome. (<http://>

Three Formulations of Kant's Categorical Imperatives (Immanuel Kant, *Groundwork of Metaphysic of Morals*, 1785)

“Act only according to the maxim whereby you can at the same time will that it should become a universal law without contradiction.” –A moral maxim must be disconnected from the particular physical details surrounding its proposition and should be applicable to any rational being.

“Act in such a way that you treat humanity, whether in your own person or in the person of any other, never merely as a means to an end but always at the same time as an end.” - or; “Act in such a way that you treat humanity, whether in your own person or in the person of another, always at the same time as an end and never simply as a means.”

A second version of the categorical imperative states that we should always treat others as ends in themselves and never as means to our ends. The Realm of Ends is the ideal moral community in which everyone treats everyone else as end in itself. In Kantian ethics, one cannot treat another person as a means to an end and must maintain her moral duty to seek an end that is equal for all people.

“Therefore, every rational being must act as if he were through his maxim always a legislating member in the universal kingdom of ends.”

Kant suggests that people treat themselves and others always as ends and never merely as means. People ought to act only by maxims that harmonize with a possible kingdom of ends. (<http://www.philosophypages.com>)

As Kant puts it, a rational being belongs to the kingdom of ends as a member when he legislates in it universal laws while also being himself subject to these laws. He belongs to it as sovereign, when as legislator he is himself subject to the will of no other. A rational being must always regard himself as legislator in a kingdom of ends rendered possible by freedom of the will, whether as member or as sovereign.

Therefore, the practical reason in each of us determines the universal maxims of morality that all must obey.

C. Major Issues of Savior Siblings

1. Factual Issues

Preimplantation Genetic Diagnosis (PGD) is a genetic selection process done outside of the woman's body. In vitro fertilization techniques are used to fertilize eggs in a Petri dish. A cell is removed from the embryo at the eight cell stage (after about two days of growth) and analyzed. An embryo with the desired genotype is then chosen to be implanted into the uterus to be carried to term. Using this technique, families can create an embryo that is a genetic match, and therefore a viable donor, for a sibling. PGD has now been linked to the creation of "savior siblings" who can provide bone marrow or other transplant tissues to sick older siblings. The embryo is screened to see if its stem cells found in the cord blood or bone marrow will be a compatible for transplantation. (Rounds, 2008)

The current level of scientific knowledge does not allow any accurate assessment of the risks that the donor child has because of his/her chosen tissue type. It cannot be said with any confidence that a person's tissue type does not have any health implications in terms of longevity, or susceptibility to late-onset disorders. In choosing a certain tissue type, parents may be choosing to have a child who will later go on to suffer higher morbidity and earlier mortality than a non-compatible child. (Turner, 2001)

In connection to this, the movie *My Sister's Keeper*, the 13-year-old Anna Fitzgerald sued her parents for medical emancipation. They expect Anna to give up one of her kidneys for her older sister Kate, who has had leukaemia since she was 2 years old. Her parents conceived Anna because they needed a donor of umbilical cord blood to keep Kate alive, and since then Anna has donated bone marrow and stem cells to Kate when she relapsed. But now she no longer wants to continue being used as an organ bank for her sister, and her only resort is the law. (Perring, 2004)

Apparently, these facts lead us to these moral questions; whether Sara (the mother) is selfishly doing all these only in favour of Kate (the older sibling) and that she no longer care about Anna's welfare or Anna (the donor sibling) is being selfish of her body that she does not want to help her sister anymore and decided

to seek legal assistance for her freedom from this preconceived duty- to be a saviour sibling!

2. Conceptual Issues

“Can you bring a child into being in order to harvest her organs for another? What are the repercussions? What does it do to the child? or to the family?

How might a child born as a result of PGD react later in life after hearing about why they were conceived? How long is a “saviour sibling” obligated to provide transplants for an older sibling? What would happen if the donor sibling chose not to donate later in life or chose to no longer accept the role of “saviour” for which they were originally conceived? Would the donor sibling feel they are around to provide “spare parts”, and not valued for who they are?

These are just some of the moral questions pressing this issue on PGD. A common objection to using preimplantation genetic diagnosis (PGD) to choose an embryo that may produce a child who would provide stem cells for an existing person is that children conceived for the benefits of their siblings are not valued in their own right. Therefore, this prompts an issue on the ethics of saviour siblings or donor babies.

According to Lempert (2002), if one believes that human embryos produced by IVF are human lives that deserve the same respect as babies, it is easy to conclude that a procedure that will produce a number of doomed to be destroyed embryos to save one existing life and to produce another new life cannot be justified. If, on the other hand, one believes that the embryo simply has the potential to grow into human life, it is easy to see great virtue in the procedure that promises both to produce a life and preserve the life of an otherwise doomed living human being. Neither position necessarily shows great respect for human life; they just disagree about what counts as a life.

So even if the baby is loved less, there is no way of refuting the claim that it is better off than if it had never been born or, conversely, of deriving from the claim that it is better to be born than unborn, the conclusion that the procedure and reasons that led to the birth were therefore ethically justifiable. (Boyle &

Savulescu, 2001)

Boyle and Savulescu (2001) added that the uptake of this procedure will have few social consequences and is likely to be a reasonable use of limited health resources. Using PGD to choose a stem cell donor is unlikely to cause harm to anyone and is likely to be beneficial to some. In countries where PGD solely for choosing a Human Leukocyte Antigen or HLA compatible embryo to provide stem cells for treating an existing person should also be permitted.

Turner (2001), apparently, has this to say in response to Boyle and Savulescu's claim that the use of PGD to provide parents with donor babies is ethically acceptable: "Wanting a baby for instrumental reasons alone cannot be acceptable in the civilised world. Parents want a child purely for its characteristics (i.e., its tissue type), indeed tells us that the alternative for the child who was conceived to provide stem cell is not another life in which he or she was conceived in a different way, but non-existence. So the fact that Kant's dictum was "never use people solely as a means" is not a reassurance, because these donor babies are solely means to an end- the successful treatment of the ailing sibling.

However, Kelly (2001) refuting the statement regarding the child being created because it is better for an embryo to live as a tissue donor, than not to exist at all, asserts that bearing children conditionally is unethical based on Kantian moral theory. Using children as commodities fundamentally violates the instinctive natural values and/or natural aspiration of men.

Therefore, the conceptual issue raised based on the literature that were cited is that: Is the use of Preimplantation Genetic Diagnosis (PGD) through IVF to provide Human Leukocyte Antigen (HLA) compatible embryo or a Savior Baby to provide stem cells for treating an elder sibling is an act that violates respect for other human person?

3. Moral Issues

Major ethical principle from Kantian Ethics is that we always act in a way that shows people are valued in themselves and not treated as "things." A child born of PGD as a donor could be considered a means to an end which is a violation of Kantian Principles.

In May of 2004, the Journal of the American Medical Association reported that five families in the United States had used genetically-selective in-vitro fertilization (IVF) to create embryos that would act as perfect-match donors for older siblings with serious medical conditions such as leukemia. Immediately after birth, blood from the umbilical cords of the children was donated in the expectation that this would be enough to cure each of their older siblings' illnesses. Regardless of intention, the implications of these "designer babies" were enormous.

Katherine Arnie of the Washington Post asks, "Is the deliberate selection of an embryo as a tissue match for a terminally ill child ethical? How would a child feel, knowing he was conceived for the sole purpose of saving his sibling's life? What would happen if the ailing sibling required future medical treatments or transplants? Where would a donor's own rights begin and his responsibility end?" (Rounds, 2001)

In thinking about the case from a Moral Rules and duties perspective, the ends may not justify the means when considering the number of embryos that are affected in by this practice. A clinic in Chicago published data showing that in treating nine (9) couples whose children suffered from forms of leukemia and anemia 199 embryos were tested. Of these 199, 45 tissue matching embryos were identified for implantation and 28 of these were used in 12 separate cycles of in vitro fertilization. Only five (5) of these embryos resulted in pregnancies, and 171 embryos were discarded. (Rounds, 2008)

Of what value does man save another life at the expense of other's life? Or of what moral ground can this practice be justified, whether it is morally permissible or impermissible? Is it morally right or wrong for parents to resort to PDG in order to create a savior baby so their elder child may live? Does Kantian's moral principle justify the act of creating Savior Siblings as morally permissible or impermissible?

III. Conclusion

Applying Moral Theories on the Ethics of Saviour Siblings

The ethics of using pre-implantation genetic diagnosis

(PGD) to select stem cell donor for an ailing elder child posed controversies as regards its practice. There have objections as regards this practice as the children conceived for the benefit of their siblings are not valued in their own right. It has been mentioned that donor children or saviour siblings are somehow treated as merely things as their sole purpose of being born is to be the “organ bank” of their ailing siblings. Issues provided in the discussion raised numerous moral questions as to the morality of PGD practice. Although some medical practitioners support this practice with the justification based on bioethical principles, that is, the purpose of the procedure is to prevent harm, still a lot of professionals in the field of medicine view the act to be unethical and unacceptable.

Based on Kantian Moral principles, discussed in the earlier part of this paper, provides that the Moral worth of an action does not depend upon the results expected from it, and that any moral action proceeds from the proper motive, that is the “good will” or “recognition of duty.” Kant believes that the morality of our actions has nothing to do with the results but has everything to do with our intentions. For Kant, “it has everything to do with our intentions and reasons for action, those that are embedded within the principles we live by.” Therefore, the end does not justify the means.

In the case of the Fitzgerald, Sara and Brian, resorting to PGD for the purpose of saving Kate’s life is reasonable. Looking at every possible way to cure their child’s illness is morally permissible but to conceive Anna to be their saviour baby or saviour sibling for Kate is morally impermissible. Based on Kantian’s principle of respect for others, Sara and Brian obviously qualified to the violation of respect for human life. Initially, it is quite convincing that what Sara did was all for the good of Kate and her love for Anna is unquestionable. But Anna finds the act to be a violation of her right as a person, her right to decide for her own body, as she, thereby, sought for medical emancipation.

The Kantian moral theory explicates the value of every human person existing. That respect for others should be of paramount concern of every individual. Our will, our reason should always be the means of our actions and what will justify our actions may only be emanated from our genuine intentions.

Analyzing this case of Anna and Sara, both can be justifiable on the morality of their actions but when assessed as to which act qualifies as a moral act, Anna's law suit for medical emancipation outweighs Sara's intentions and therefore, Anna's act is justifiable and is morally permissible.

Anna has been once an HLA through IVF, with that the principle of autonomy has been violated. Now that she has reasons to decide for her own welfare, her being a Saviour Sibling must come to an end. Yes, Kate needs her but her moral duty to her was decided upon by her parents, and this case, Sara deliberately imposed it. But Sara forgets that it is not Anna who has the moral duty to her sister, but rather, she has! As mother, she is obliged to always ensure the welfare of her children, Kate, Jesse, and Anna. All of them are her children- whether done unintentionally or intentionally- they deserve to be respected as Human persons!

In the final analysis, Kantian's moral principle finds the act of creating Saviour Siblings as morally impermissible since this act does not only respect human life, it also violates the right of a human person to his/her own life. Moreover, this practice is deliberately done as a means to an end; therefore, its intention does not promote goodwill or moral duty. Categorical imperative is violated resorting to the results of the action rather than its cause or reason of the act. In all the major qualifications of a moral act in Kantian principle, the act of creating saviour siblings is not morally permissible.

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