

CREATING SAVIOR SIBLINGS: MORAL OR IMMORAL?

Nabeel Althabhwani¹, Siti Fatimah Azzahra Bt Safe'e², Lee Hui Yi³

¹ Faculty of law, Universiti Kebangsaan Malaysia (UKM) 43600 Bangi, Selangor Malaysia. (correspondent author)

² Faculty of law, Universiti Kebangsaan Malaysia (UKM) 43600 Bangi, Selangor Malaysia

³ Faculty of law, Universiti Kebangsaan Malaysia (UKM) 43600 Bangi, Selangor Malaysia

ABSTRACT

A savior sibling is a child conceived through in-vitro fertilization for the purposes of saving a sibling, who needs an organ or cell transplant because of a fatal genetic disorder. The procedure involves pre-implantation genetic diagnosis (PGD), which analyzes the embryos to detect potential genetic disorders prior to implantation. This is to reduce the possibility of passing such disorders to offspring. However, the creation of savior siblings also raises issues of morality. The idea that a child is born for the sole purpose of saving the lives of others, even if siblings, is not acceptable to some sections of society. This is because such a child is being born not for the sake of having it, but merely to be used as an instrument by the parents to save their sick child. Different countries, such as Malaysia, the UK, U.S. and Australia take various positions on whether or not to permit PGD. This article examines the rationale for the conduct of PGD, and, specifically, whether or not the act of creating a savior child can be considered as immoral. Importantly, the examination is undertaken with a focus on Immanuel Kant's moral theory. The notion of the end in itself by Immanuel Kant demands that we always treat humanity not only as a means to an end, but also as an end in itself. Impliedly, parents should not conceive a child solely for the purposes of serving as a donor to a sick sibling, but should also genuinely desire that child. In other words, they should also respect the savior sibling and recognize its inherent value. In this way, the savior sibling is treated not merely as a means, but also as an end. By implication, the creation of savior siblings is not unethical as such, and should be permitted. A more significant factor that should be considered is how they are treated by parents after birth. This article uses a qualitative research methodology and relies on scholarly writings, such as books, journal articles, as well as laws and decided cases.

KEYWORDS: Savior sibling, morality, Immanuel Kant.

1. Introduction

According to the Collins English Dictionary, a saviour sibling is "a child conceived through IVF and screened for compatibility with a terminally or seriously ill sibling in order to provide organ or cell donations as a form of treatment."¹ Basically, the saviour sibling is a child that was conceived by parents who have another child afflicted with a serious illness and in need of someone who is Human Leukocyte Antigen (HLA) compatible with him. This is usually done where the parents are unable to find a donor for their child who needs stem cell transplant. During the birth of the saviour sibling, blood from the umbilical cord serves as a source of stem cells that can be transplanted into the sick child to save his life. A key challenge is that the possibility of getting a savior sibling having an HLA that exactly matches that of

the sick child is quite low, standing at about 25%. This means that the process of getting a saviour sibling is not as straightforward. Additionally, if the sick child has a hereditary disease, it is important to ensure that the saviour sibling does not inherit that particular gene.²

Hence, in trying to have a saviour sibling, the process that the parents must undergo is preimplantation genetic diagnosis (PGD). The PGD is basically an alternative to prenatal diagnosis. In PGD, one or two cells are removed from an embryo produced in vitro, during 6- to 10-cell stage.³ That particular cell will then be taken for a genetic diagnosis. The PGD technique can usefully be applied in cases involving couples, who are at the risk of getting a child with single-gene disorders or for the purposes of screening

chromosomal disorders. Therefore, it can help in reducing the possibility of having a child with sex-linked or other genetic disorders and abnormalities. This is important in producing a saviour sibling as there is a need to ensure that it will not have any genetic disorder. Parents who plan to create a saviour child will undergo PGD as a step towards reducing the need for abortion due to infection of the conceived fetus with a genetic disease.⁴

The PGD will involve HLA typing,⁵ that is, Preimplantation Tissue Typing (PTT). This genetic test requires tissue sample. The tissue sample usually will be taken from blood sample drawn from your arm's vein or it will be taken on the inside of your cheek by using a swab. The HLA typing is necessary to identify certain individual variations in a person's immune system. It is important to determine whether a person can safely donate his cord blood, bone marrow or an organ to another person who is in need of a transplant. In other words, HLA typing helps in identifying a suitable candidate to donate his tissue so that the sick child or person can receive it successfully. This shows that HLA typing plays a crucial role in the human immune system. If the immune system identifies the donated tissue as foreign, it sends an alarm and may then attack and destroy it. That is why it is necessary for the donor to have HLA that is as closely matched as possible to that of the prospective recipient to reduce the prospect of post-transplantation complications.⁶

2. Law and Cases

In Malaysia, PGD is already in use. Despite that, there is yet to be any specific law for its regulation, even though calls have made for the introduction of one. For the time being, the Malaysian Medical Council (MMC) has issued a Guideline on Assisted Reproduction, which cover the application of PGD⁷, although they are silent on PTT. Under the Guidelines, the application of PGD is only permitted

for serious medical conditions. Section 14 of the Guideline prohibits the use of PGD to select the inherited characteristics of an embryo, for example, hair and eye color; any social or psychological characteristics; or any other condition which is not associated with disability or a serious medical condition. Section 15 enumerates other practices that are prohibited and ethically unacceptable. One of them is 'developing embryos for purposes other than for their use in an approved ART programme.' In this regard, ART means assisted reproductive technology. The screening of embryos other than for medical reasons is prohibited by the Guidelines. Therefore, it could be concluded that the creation of an embryo that is a tissue match does not fall within the meaning of 'approved ART programme' and is, hence, prohibited based on Section 15 of the Guidelines.⁸

Different approaches to PGD can be observed in Western countries, such as the UK, U.S. and Australia, where PTT is permitted. In the UK, PGD, including tissue typing, is regulated through the Human Fertilisation and Embryology Act (HFEA) of 1990. The HFEA, together with a licence from the Human Fertilisation and Embryology (HFE) Authority allows the application of PTT to produce a child whose tissue matches that of a sick sibling. In the U.S., on the other hand, the application of PGD, including tissue typing, is unregulated.⁹ Nevertheless, PGD service providers must comply with the guidelines of the American Society for Reproductive Medicine and the American Medical Association.

The American Medical Association permits the use of PGD for the purposes of curing or preventing genetic diseases, but not for the selection of non-disease related traits, while the American Society for Reproductive Medicine regulates the general use of PGD.¹⁰ In the UK, two requirements must be met to obtain authorization for the creation of saviour siblings. The application must have a therapeutic

objective and conform to the best interest principle. In the U.S., the grant of such authorization is based only on the best interest requirement. In Australia, the general rule is that PGD would only be permitted when it is meant to protect the future embryo from the risk of suffering a genetic disease, rather than producing genetic compatibility with a sick sibling, although regulations may differ among states in the country.¹¹

Adam, whose successful transplant saved his sister's life, is the world's first saviour sibling born in the U.S. on 29 August 2000.¹² In 1994, Molly Nash was born to parents, Jack, and Lisa Nash. A serious defect was found in Molly's immune system when she was six years old. Her parents found that she was suffering from Fanconi anemia, a deadly genetic disorder characterized by the failure of bone marrow production. The only choice open to them for the salvation of their daughter was to conceive another child to serve as a donor to her. This led to the birth of Adam. A stem cell transplantation was performed immediately upon his birth and the cells were infused into Molly's circulatory system. After four weeks, Molly's bone marrow showed signs of recovery. Her immune system normalized after three years.¹³ The successful experience of the Nash family resulted in a dramatic rise in the demand for PGD to transplant stem cells from saviour children to sick siblings, a trend that would likely continue.¹⁴

Also, in the U.S. case of *Strunk v. Strunk*,¹⁵ Arthur and Ava Strunk were the parents of two sons, Tommy and Jerry. Tommy who, at that time, was twenty-eight years old, suffered from a fatal kidney disease. Jerry, who was twenty-seven years old, was deemed incompetent and put in the mental age category of a healthy six-year old. Tommy needed kidney transplant from Jerry. The court found the operation was necessary as Jerry would be dependent on Tommy and, therefore, would likely be in a more

detrimental situation, if he lost his brother, than if his kidney was removed.

In the case of *Hart v. Brown*,¹⁶ Peter and Eleanor Hart were the parents of Kathleen Hart and Margaret Hart, identical seven-year old twins. Kathleen needed a kidney transplant from Margaret. The parents consented to the kidney transplant, but the physicians and the hospital refused to carry out the operation, unless there was a court order affirming the rights of the parents to give consent on behalf of their child. If the operation proceeded successfully, Kathleen would be able to perform all the normal activities of life. Nonetheless, there was the danger of trauma being caused to Margaret's remaining kidney. Thus, the issue became how to reconcile the right of the parents with the right of the donor child. After extensive deliberation on the matter, the court affirmed that the parents had the right to give consent on behalf of their child. The court also cited *Strunk*, noting that, in that case, the risk to the donee was even higher, compared to the one involved in the instant case. Accordingly, it decided that the parents had the right to give consent for the PGD operation on behalf of the minor.¹⁷

In the UK, there was a case involving the Hashmi family. They requested authorization for the creation of a saviour sibling to enable the treatment of their child, Zain, who had a severe genetic disorder in his blood. Due to this condition, Zain was in need of regular blood transfusion and medication. It was hoped that the transfusion of stem cells from a saviour sibling's umbilical cord could cure this condition and save Zain's life. Similar to that of the Nash family, the present case was motivated by the need to conceive a child that was both free of genetic disease and suitable to be a donor for Zain. The HFE Authority granted the required authorization because the case met the basic requirement for the permission of PGD, as it was therapeutic in that they would be

choosing an embryo free of inherited genetic disease.¹⁸

Some countries, however, do not permit the performance of PGD. These include Austria, Germany, Ireland and Switzerland, as well as the Australian territory of Western Australia. These jurisdictions have placed a statutory ban on PGD based on moral, ethical and other social grounds. In Germany, for example, PGD is presently prohibited because of the belief that an embryo has the right to life, whereas PGD might lead to the destruction of embryos that carry disease-linked genes.¹⁹

It does not seem appropriate though for countries to place a ban on the use of PGD when a family has a child that is suffering from a serious ailment. It is not right to focus on one single ethical perspective on this issue to the utter disregard of other equally compelling ones. Moreover, each case is different and with varying levels of importance. It can also be argued that non-regulation, as seen in the case of the US, is inappropriate. This might give PGD clinics leeway in formulating their own policies regarding performance of PGD. This could lead to a slippery path since the discretion to perform PGD operations will rest with providers. Perhaps, a preferable option is statutory mandatory licensing, as practiced in the UK. The existence of the HFEA combined with control by the HFE Authority means that all clinics are under the same set of rules and guidelines. They must all apply for a license before an embryo can legally be tested for each new disease.²⁰

The strict nature of regulation in a jurisdiction, such as the UK, precludes the use of PGD for sex selection. This is conceivably right as it helps to prevent the abuse of the freedom by misdirecting it, for example, to choose the sex of the child. There might, however, be some serious sex-related hereditary disorders with a possibility of occurrence that is as high as eighty percent in males, but only ten percent in females. In

such situations, it would be better to harness modern technologies to avoid the birthing of a child that has only a twenty percent prospect of being in good health. What all this implies is that, as far as the issue of PGD is concerned, a case-by-case, rather than a one-size-fits-all approach, also known as self-regulation by professional organizations, accompanied by formal regulation, is the best option.²¹

3. Issues Concerning Saviour Siblings

As previously pointed out in this article, preimplantation genetic diagnosis and tissue typing allow the birth of a child, often called a saviour sibling, who is meant to be a perfect donor for an existing diseased child through a process involving the selection of a human embryo for implantation in vitro fertilization. While this practice may benefit sick children, it also raises a lot of bioethical concerns. The main question is whether creating a child to save a sick sibling is morally or ethically justifiable. Many arguments have been advanced against the practice of creating saviour siblings. A common objection is that a child born through such a practice would be treated as a commodity or wrongfully instrumentalized. This is because he is treated as a means to an end, which suggests that he is born simply to save the life of an existing sick child. For some, it is improper to bring a child into existence 'conditionally' as it violates Kant's morality theory, particularly, his dictum of 'never use people as a means but always treat them as an end.' The practice of PGD is in opposition to this dictum because the saviour sibling is treated as a means to an end. He is conceived merely for the purposes of being²² used as a tool to cure another child, rather than being treated as an end in himself, which means, being born for his own worth and treated as a person.

Thus, the concerns focus on the idea of having children for the wrong reasons and how they are subsequently treated by their parents.²³ Ideally, a

child should be wanted for his own worth and not for the benefit of others. It is ethically objectionable to use children as a means to satisfy the ends of other people by being capable of donating critical tissues needed by them. According to Lord Winston, in such situations, children are born with completely wrong expectations, or as Nicolson puts it, they are treated as not having equal worth as other human beings.²⁴ Consequently, opponents maintain that, based on the Kantian dictum, PGD is unethical because a child is conceived for the singular objective of serving as a tissue donor to an existing sick child and is, thus, used as a means an end, which is to further the parents' motive of saving the sick child.²⁵ This amounts to treating him as a commodity. This charge is another way of saying that the use of ART to provide treatment for sick children through the creation of compatible sibling donors is immoral and in breach of Kant's theory of morality.

4. The Theory of Morality by Immanuel Kant

Immanuel Kant was a German philosopher, who is widely renowned for his work in ethics, the philosophical study of moral actions. This greatly contributed to moral's philosophy, deontology, on which judges base their actions whether to follow a valid rule or the outcome of an action. Kant reflected that, the understanding that human beings are autonomous, rational agents, who deserve respect as such beings, is the foundation for man's sense of what is right or wrong, or what is good or bad. In the Groundwork, Kant wrote that, 'the only thing that is unconditionally good is good.' This means that when people act out of a feeling of moral obligation or act out of goodwill, it is because they believe they have to do so. Morality, he believed, must be founded on reason. This is because only reason can supply the unconditional necessity that allows morality to triumph over individual preferences. Man's basic nature, as an intrinsically rational being with 'free

will', was Kant's starting point as it gives man the ability to decide how to achieve his goals and which ones to pursue.²⁶

The fundamental concepts of morality espoused by Kant are the hypothetical imperative and the categorical imperative. A hypothetical imperative is a moral obligation that applies only to the pursuit of a given goal, which has nothing to do with morality. This type of imperative cannot serve as a principle for determining the intent and will of unconditional goodwill, as they are conditioned by the desire for action and the intended consequences.²⁷ Kant believed that the fundamental principle for our moral obligations is the categorical imperative where we are bound by it unconditionally, regardless of our personal goals and inhibitions. In his moral philosophy, Kant argued that the moral value of an act is determined based on the motive and not the consequences of such an action. As the moral value of an act is determined by its compliance to moral responsibilities, rather than the consequences that result from it, Kant's Categorical imperative forbids one from treating people as commodities, including creating a child as a commodity or instrument to serve other people's end.

In one of the formulations of Kant's categorical imperative, which is the humanity formulation, Kant wrote that, '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.' This formulation means that we should never treat humanity as a means only, but also always as an end in itself. In other words, we should not treat other people merely as an object or an instrument with no other value. One general principle of morality is that one should 'always treat people as ends in themselves, never merely as a means to one's own ends.' This means that a person should be treated as a being that has intrinsic value. Rather than

as a means to an end, treating someone as a rational individual with his own set of values implies treating him as an end in himself.

Since we are rational and free human beings, to treat others as a means to our own objectives would amount to being disrespectful of their ability to make free rational decisions. This can be likened to the idea of mutual respect for each other. We should be able to engage in self-directed rational behaviour in pursuing what we want to achieve. The humanity in ourselves and in others limits what we are morally permitted to do in pursuing our goals.²⁸ However, we always tend to treat people as means for our own purposes in a way that is often not morally problematic. Indeed, there is nothing wrong with using other people as a means to an end. Nonetheless, it is morally impermissible to use a person only as a means to an end. Hence, to act morally means one should never treat others merely as means to an end, but to treat them as persons who are able to determine their ends. This moral imperative, however, is frequently misinterpreted to indicate that one should never utilize other people to achieve one's goals whereas what it rules out is treating other people solely as a means to an end. The implication is that the humanity formula excludes us from engaging in the use of humanity in such a way that we treat it as mere means for achieving our purposes.²⁹ According to Kant's formulation, it envisages that people can be used as a means, if they are also treated as an end; therefore, the act is acceptable as long as you do not lose sight of the fact that the other person is also an end in himself.³⁰ This suggests that human beings must be respected simply because they are human beings, who need a certain level of regard.³¹

Therefore, one may use the other for his own ends as long as he also respects the absolute worth of persons who are affected by his actions. In effect, under Kant's formula, our actions fall into one of two categories:

either we act in such a manner that humanity is never seen simply as means or act in such a way that humanity is always treated as an end.³² This means that one treats humanity simply as a means if and only if one treats it as a means but not also as an end.³³ It can, therefore, be surmised that one is said to respect the other person's agency by treating humanity as an end in itself and not simply as means to an end. Thus, if one fails to do so, it means that he is treating humanity simply as a means, but not as an end in itself.

Applying Kant's principle to the practice of creating a saviour sibling means that parents cannot treat the child as a means for realizing their specified objective of saving the life of their existing sick child and solely for that purpose. Some commentators argue that a child conceived through PGD with tissue typing is not merely a means to advance further ends, but is also regarded as a person and treated as an end in himself. As in Kant's view, a child also has absolute worth and, therefore, personhood right from the beginning, although the parents have the right to treat their child similar to how they treat other objects in view of the child's immaturity.³⁴ The application of PGD with tissue typing does not violate Kant's dictum on treating one merely as an end, provided that the parents also desire the child for his own worth, rather than solely conceiving him to be the donor for the sick sibling. Since Kant's key concept of morality under the humanity formula is that human beings must be treated with respect, it means that, if the parents want to conceive a child in his own right as well as for the benefit of their existing sick child, then the creation of that child would not violate Kant's moral requirement. Therefore, what is relevant to consider is the parents' motive for wanting the child. This is to ensure that they do not want the child simply for the purposes of serving as a donor for the sick sibling, but also in his right and for his own

worth. This means respecting him as a person and as an end in himself.

One cannot simply object to the practice of PGD simply because the child is born with the stated objective of creating a perfect donor for the existing sick child. This is because parents usually have a variety of practical reasons for conceiving a child, including the desire to continue the family line, have the child inherit the family business, provide companion for an existing child, or salvage a failing marriage.³⁵ This, to a certain degree, can appear as though the child is instrumentalized or treated as a commodity to serve other people's end. While it may be objectionable, if the child was created simply as a means to cater to other's wellbeing and nothing more, it may be morally permissible, if he is also valued in himself, taking into account the fact that the parents have also made effort to save their child's life, making it unlikely for them to treat him merely as a tool for saving another's life.³⁶ As other commentators also insist, the saviour sibling is not used merely as a means because he will not be discarded, but rather treated as a human being.³⁷ Others add that after being born, the child will be loved, even more so for saving the life of his sick sibling, such that it can be concluded that he will be treated as an end in himself.³⁸ Therefore, a child born from PGD with tissue typing is morally permissible as it does not violate Kant's principle, which is against treating a child as a commodity. Moreover, the fact that parents may have preferences for certain types of children does not prevent them from loving a child, who is born for his own worth.

More importantly, the real issue to be addressed is how a child born as a saviour sibling would be treated after birth. Parental motivation to conceive a child not as a mere means to an end may be difficult to determine. Nevertheless, whether or not a child is being treated as such can be gleaned from the action

of the parents towards him after birth. The fact that the child was conceived for a particular purpose is irrelevant, provided there is parental love, care and protection of his interest.³⁹ This suggests that the focus of attention should be the conduct of the parents, rather than the purpose for which the child was created.⁴⁰ If the child is neglected fulfilling his function as a donor of the critical tissue needed to treat the existing sick sibling, then the parents can be considered to have failed to respect the child as a person. Instead, they have only treated his humanity merely as a means, but not also as an end. Everything put together, it can be argued that the conception of saviour siblings, who have great potential to save the lives of many other children with serious illnesses ought to be permitted and not prohibited based solely on the motivation of the parents for conceiving them.

5. Conclusion

To sum up, PGD is the process by which a child, often referred to as a saviour sibling, is conceived by parents through in vitro fertilization for the purposes of providing an organ, bone marrow or cell transplant to a sibling suffering from a serious illness. The process involves the genetic testing of the embryo, as well as HLA typing, that is, preimplantation tissue typing (PTT). Through the PTT process, cell from an embryo is screened to see if it is compatible and hence suitable to donate bone marrow or stem cells from the umbilical cord to an existing sick sibling, before being implanted into the mother. There is still no regulation for the application of PGD in Malaysia, although there are guidelines issued by the MMC. However, other than for severe medical conditions, PGD cannot be applied in Malaysia under the said guidelines, which are also silent on the use of PTT. In other countries where PGD and PTT are available, there are different regulatory approaches. In the UK, for example, there is the HFEA of 1990, whereas, in the U.S., the application of PGD, including tissue typing,

is unregulated. Other countries, such as Germany, Switzerland and Ireland, however, do not allow the practice of PGD based on moral, ethical and social considerations.

The application of PGD for the birth of a child meant to be a donor for his sick sibling has raised many ethical concerns from opponents. Debates continue over the moral permissibility of saviour siblings. One of the most common objections raised concerns the instrumentalization or commodification of the child born through the practice of PGD. This is because it is wrong to conceive a child not for his own sake, but simply as a means to further the ends of other people. This is considered to violate the Kantian ethics of treating people with respect as rational agents. The humanity formulation of Kant's categorical imperative requires us to treat humanity as an end in itself. Since Kant's moral value of an act is based on the motivation of the person doing it, parents, should not conceive a child simply as a means to obtain tissue for the cure of a sick sibling, after which he is discarded. Rather, the parents should also genuinely desire the child in his own right, treat him as an end in himself and regard him as a person, who deserves to be respected. Overall, the act of creating saviour siblings to save the lives of sick children should be morally permissible, given the great benefit it offers. The more important issue to consider is the conduct of the parents; precisely how they treat such children after birth.

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