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Protection for Saviour Sibling Children Reviewed from, Medical Bioethics and Indonesian Positive Law

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Abstract: The development of assisted reproductive technologies such as In Vitro Fertilization (IVF) and Preimplantation Genetic Diagnosis (PGD) currently allows the birth of a child for the purpose of saving a sick sibling through a stem cell transplant or better known as saviour sibling. This practice was first successfully carried out in 2000 and continues to grow to this day around the world. This article aims to examine the bioethical aspects and legal arrangements related to the practice of saviour sibling in Indonesia, which until now has no specific regulations despite the continuous development of related technologies. The research method used is normative legal research, with qualitative analysis of primary, secondary, and tertiary legal materials. This article compares the arrangements of saviour sibling practices in several countries to identify the principles relevant to the regulation in Indonesia. The results of the study showed that this practice has significant benefits, such as saving the lives of patients with hematopoietic disorders, but also poses physical and psychological risks to children born as saviour sibling. This article recommends the need for special arrangements in Indonesia that cover aspects of ethics, law, and child welfare to ensure their implementation responsibly.

Keyword: Medical Bioethics, Positive Law, Protection, Saviour Sibling.

INTRODUCTION

Current advances in science and technology, especially in medicine, have given rise to a new technology known as Assisted Reproductive Technology (ART). This technology aims to help infertile couples who want to have offspring to realize their desire. The ART method that is widely used today is invitro fertilization (IVF). Although IVF has been widely used and helped many couples with infertility, the practice of IVF often raises debates in society regarding bioethical aspects. The IVF process raises dilemmas and ethical considerations, for example, the selection of genetic characteristics (Putra & Abrar, 2022).

The selection of genetic characteristics in IVF is possible with the Preimplantation Genetic Diagnosis (PGD) method. Embryos obtained through IVF will be screened using two methods, namely Polymer Chain Reaction (PCR) and Fluoresence In Situ Hybridization (FISH). This method was developed to determine the genetic profile of the embryo so that

selection can be carried out before implantation. This technique is often aimed at avoiding the birth of a defective child from at-risk parents in IVF programs (Budiyanti, 2015).

In addition to providing benefits, PGD has the potential to cause ethical problems, one of which is its use for the purpose of saviour siblings (savior of brothers) in which in this case children are deliberately born to provide stem cells to be transplanted to their siblings who suffer from blood disorders such as thalassemia-β, diamond-blackfan anemia, or Fanconi anemia (Human Fertilisation & Embryology Authority, n.d.). In transplantation, the match of human leucocyte antigen (HLA) between the donor and the recipient is important so that there is no body's rejection reaction after transplantation, while in siblings the HLA match is greater (Asplund, 2020). HLA has been known since it is still in embryonic form. PGD can select embryos that have the same HLA as the recipient and are free from genetic diseases. Embryos are made in vitro from the mother's egg and the sperm of the biological father. Furthermore, the corresponding embryo will be implanted in the uterus until the moment of birth. After the birth of this savior brother, the stem cell-rich cord blood is harvested and infused into the sibling to restore normal blood cell formation (Wilkinson, 2008).

Some examples of the use of PGD for the purpose of saviour siblings that have occurred in the United Kingdom are Jamie Whitaker who was born in 2003 to save his older brother Charlie who suffers from Diamond Blackfan Anemia (DBA) disease (BBC News, 2006). Another case is Adam Nash who was the first baby in the United States to be born through saviour siblings technology to save his older sister Molly who suffers from Fanconi anemia (Lahl, 2009). In Malaysia, there is a health service that provides a Saviour Sibling Programe (SSP) that offers couples who have a child with Thalassemia to conceive another child who has HLA tissue compatibility with a sick sibling (Malaysia, n.d.).

The debate about children born for the purpose of saviour siblings is feared to have an impact on the physical related to the medical procedures carried out and psychological disorders related to their existence in the world that is intended only as a savior, not as a child to be raised in the true sense. Ideally, this child, although born with the intention of saving others, does not have to bear the risks mentioned above.

Until now in Indonesia, there have been no cases of saviour siblings, but it is possible that in the future this saviour sibling program will be needed to overcome health problems, especially children born with blood disorders. Therefore, special arrangements are needed regarding the use of this saviour sibling method so as not to cause physical and psychological disturbances for the child born in terms of bioethics and law. The problems that will be discussed in this article are:

1. How is the use of the saviour sibling method so as not to cause physical and psychological disturbances to the child born is reviewed from a bioethical perspective in Indonesia?
2. How is the use of the saviour sibling method so as not to cause physical and psychological disturbances to the child born is reviewed from a legal perspective in Indonesia?

METHOD

The type of research in this study is a normative legal research method, namely researching law as what is written in laws and regulations. Law is conceptualized as a rule or norm that is a guideline for human behavior that is considered appropriate. The data sources used in this study come from secondary legal data, which consists of primary legal materials, secondary legal materials or tertiary data (Salim HS & Erlies Septiana Nurbani, 2016). The analysis of legal materials was carried out qualitatively to draw conclusions, aiming to find out about the legal and bioethical aspects of the practice of saviour siblings in Indonesia.

RESULTS AND DISCUSSION

The Use of the Saviour Sibling Method to Avoid Physical and Psychological Disorders for Children Born Is Reviewed from a Bioethical Perspective in Indonesia

Saviour sibling or "rescue brother" is the designation given by bioethicists to a child who from the beginning of his birth plan was to become a donor for his sick brother (Mary Anne Bobinski, David Orentlicher, I. Glenn Cohen, 2018). Thus the purpose of the birth of a saviour sibling child is to save the life of his brother. The pregnancy process of a saviour sibling child is carried out through the Invitro Fertilization (IVF) method. Some ovum and sperm cells from the child's parents are fertilized into embryos which are then genetically identified through the Preimplantation Genetic Diagnosis (PGD) method (Marianne Talbot, 2012). After obtaining an embryo that is immunologically and genetically in accordance with its sick sibling, then the selected embryo is implanted into the mother's uterus to be conceived until the moment of birth. Then, as soon as the child is born, stem cells from cord blood are harvested and transplanted to their sick siblings (Tamparo, 2007).

Research on the use of IVF and PGD technology for sibling saviour purposes was first conducted in the United States in 2000 for the case of a child suffering from Fanconi Anemia. With the consent of the parents, the researchers sought to obtain healthy embryos that had the characteristics of Human Leukocyte Antigen (HLA) that were identical to those of the sick child. After a series of screening and embryo selection, a child is born who will be a donor for his brother. Three weeks later, his brother who suffered from Fanconi Anemia was given an infusion of stem cells taken from the placental blood of the saviour sibling child. The patient showed bone marrow recovery within four weeks. Three years later, based on the results of the medical examination, his hematopoietic and immunological systems became normal (BBC News Online, 2000).

After the success and publicity of this first case, many parents who had children with diseases that required a hematopoietic stem cell transplant, sought to find PGD facilities for HLA matching in order to save their sick child. Until now, there have been many saviour sibling children born in various countries. The benefits of the saviour sibling method have also been widely felt by parents, sick children and the development of medical technology itself. Some of the benefits of saviour sibling are:

1. Saving patients' lives.

Some genetic diseases such as Thalassemia-β, Diamond-Blackfan Anemia, or Fanconi Anemia cannot be cured through medical therapy. Treatment of patients so far only aims to overcome the symptoms that arise due to their disease. Patients undergo regular blood transfusions that will probably be done for the rest of their lives. Hematopoietic stem cell transplantation is the only therapeutic approach that has been shown to be successful in curing patients. However, the difficulty of finding a suitable donor for patients is a challenge in itself. Therefore, saviour siblings are a new hope for patients to save their lives. In addition, tissue donation from a saviour sibling child to his sibling has a high success rate thanks to the genetic compatibility between the donor and the recipient (Ailsa Taylor, 2008).

2. Giving new hope to families.

Parents who are at risk of losing their children to a genetic blood disorder that is difficult to cure often feel they have new hope through the saviour sibling program.

3. Medical technology development.

The implementation of saviour siblings encourages advances in assisted reproductive technologies such as In Vitro Fertilization (IVF) and Preimplantation Genetic Diagnosis (PGD). It can also be used to avoid genetic abnormalities in the child to be born.

In addition to having benefits, saviour siblings also have an impact that is still debated by experts. Concerns about medical intervention will have a physical impact on the growth and development of the embryo, as well as the psychological impact in the future that may be felt by the child.

1. Physical impact

The physical impact on the child of the saviour sibling is related to the methods used, namely IVF and PGD (Althorpe & Finneron-Burns, 2023). An editorial in The Lancet stated

that embryo biopsies during PGD do not show adverse physical effects in the short term (Sheldon & Wilkinson, 2004). Likewise, there was no finding of impact on babies whose umbilical cord was used as stem cell donors to save their siblings. Cord blood collection is noninvasive and painless. Studies have shown that this blood draw poses no risk to newborns. However, there are several studies that show that babies born from IVF are more prone to being born prematurely and have low birth weight (Ailsa Taylor, 2008). The biggest concern arises if there is a failure of a cord blood stem cell transplant for several reasons, such as an inadequate dose of cord blood cells, or the recipient's child has a recurrence after transplantation. If the cord blood transplant fails, the next possible step is to retrieve and transplant the bone marrow (Whelan, 2021). Although the risk of death caused by bone marrow removal surgery is not known for sure, the probability is no more than 1/10000, the bone marrow removal procedure can cause physical impacts for the donor such as side effects of anesthesia, the risk of infection due to invasive procedures or the pain response felt by the donor after the procedure (Mary Anne Bobinski, David Orentlicher, I. Glenn Cohen, 2018). After a bone marrow transplant is performed, there will be a possibility of the need for a solid organ transplant. Toxicity associated with chemotherapy and radiation or immunosuppressive drugs can lead to organ failure involving the kidneys, liver, or other organs. Makes it possible for conceived children to be genetically matched to face potential donation requests throughout their lives.

2. Psychological impact

The psychological impact on children born through the saviour sibling method should be a concern. They may feel distressed by the notion that their purpose was born only as a savior for their sick sibling, not as the birth of a child that would normally be expected. In addition to developing unwanted feelings, the attitude of parents who may pay less attention to it and focus more on the sick sibling will put psychological pressure on the child. This can lead to feelings of insecurity, inferiority, and even anger towards their parents. In addition, these children may also experience trauma due to medical procedures they undergo early on. According to a study at Wake Forest University in the United States in 2013, children of saviour siblings feel lower self-esteem than their peers and one in three people experience severe post-traumatic stress disorder. Being a rescue sibling can lead to profound psychological repercussions and can develop into a larger psychological problem as they grow into adulthood (Ahona Haque, 2023).

Until now, there has been no use of the saviour sibling method in Indonesia. But in the future this method may be needed to overcome diseases of genetic blood disorders that cannot be cured, for example thalassaemia. Currently, Indonesia has a high percentage of Thalassemia disease. The number of Thalassemia patients continues to increase year by year. Based on data from the Indonesian Thalassemia Foundation, the number of thalassemia cases in Indonesia in 2012 was 4,896 cases, which increased to June 2021 by 10,973 cases. In terms of financing, according to BPJS Kesehatan data in 2020, Thalassemia occupies the 5th position as the highest user of the National Health Insurance (JKN) budget among non-communicable diseases after heart disease, kidney failure, cancer and stroke, which is as much as Rp. 2.78 trillion (Widyawati, 2022).

The possibility of developing the saviour sibling method in Indonesia is also supported by the development of IVF and PGD technology in Indonesia. Based on data from PERFITRI (Indonesian In Vitro Fertilization Association), the total cycle of IVF programs in Indonesia in 2021 is estimated to reach more than 10,000 cycles (programs). In addition, the number of clinics or hospitals that can perform IVF procedures is also increasing (Mia Chitra Dinisari, 2022). Most of them also have PGD technology combined with IVF.

Until now, in Indonesia there is no code of ethics or special guidelines that explicitly regulate the practice of saviour siblings. For this reason, in the future, it is necessary to make special guidelines that regulate the practice of saviour siblings in Indonesia so that its implementation can be accounted for. Its preparation could involve the government represented by the ministry of health as the main regulator in health services, medical professional

organizations, bioethicists, and child protection commissions. Things that need to be regulated in the guidelines include who can carry out the saviour sibling method based on medical competence, informed consent, how the standards are implemented, what actions are allowed, and the treatment of children born to avoid physical and psychological impacts.

Some general ethical principles in assisted reproductive health and services can be used as basic guidelines in the preparation of guidelines for the practice of saviour siblings in Indonesia. The four principles (basic principles) of bioethics that are the basis of ethical norms in the health sector, namely respect for autonomy, nonmaleficence, beneficence, and justice. These four bioethical principles are the benchmark in ethical decision-making in the case of saviour siblings.

The Indonesian Medical Code of Ethics (KODEKI) in general has also regulated the limits on the use of technology in assisted reproduction. Article 11 of the Code of Civil Code requires every doctor to always remember his or her obligation to protect the life of human beings. In paragraph 3 it is stated that a doctor must be careful, consider various aspects of diagnosis, treatment/treatment and prognosis in the context of reproductive life in general and use various advancements/sophistications of any reproductive technology that can eliminate or degrade human dignity and human dignity. What is meant by reproductive life includes starting from the beginning of conception/pregnancy, birth, sterilization/prevention of pregnancy, sectio caesaria, procreation (artificial insemination), stem cells, cloning and others to the end of life/at the time of death and other reproductive technologies, especially those driven by the will of the patient/their family as well as genetic and molecular medicine with or without nanotechnology and other types of technology.

The Use of the Saviour Sibling Method to Avoid Physical and Psychological Disturbances for Children Born Reviewed from a Legal Perspective in Indonesia

Although there is no special regulation that explicitly regulates the use of the saviour sibling method in Indonesia, several provisions in laws and regulations can be used as a legal basis for its implementation. In general, regulations in the health sector are regulated in Law Number 17 of 2023 concerning Health. Regulations regarding the protection of infants and children are regulated in Article 46 which states that every infant and child has the right to be protected from all forms of discrimination and acts of violence that can endanger the health of the baby and child. Meanwhile, the regulation on reproductive health is listed in Part Six, which covers Articles 54 to 62. Article 57 states that every reproductive health service, including assisted reproduction, must be carried out safely and of high quality and does not contradict religious values and the provisions of the law. Furthermore, Article 58 stipulates that assisted reproduction can only be carried out by a legal married couple, and the process of implanting an ovum must be carried out in the womb of the wife from which the ovum originated. Furthermore, Article 135 states that cell-based and/or stem cell-based therapy can be carried out if it has been proven to be safe and beneficial for disease healing and health recovery. However, the therapy is prohibited from being used for reproductive purposes and must not originate from embryonic stem cells.

The provisions in Article 135 are further described in Government Regulation Number 28 of 2024, especially Article 384 which states that the collection of cells and/or stem cells must be based on the written consent of the patient and/or donor, in accordance with professional standards and standard operating procedures, and must pay attention to professional ethics and the safety of patients and/or donors. This PP also regulates in Article 20 the obligation to protect infants and children to avoid all forms of discrimination and acts of violence that can interfere with their health.

Comparison of Saviour Sibling Arrangements in Multiple Countries

The practice of saviour siblings is known and carried out in many countries in the world. Several countries such as the United States, the United Kingdom, France, Australia, and India have also regulated the practice of saviour siblings. The table below summarizes the arrangements for saviour sibling practices in several countries.

Table 1. Saviour Sibling Settings in Some Countries

Country	Arrangement
1. United kingdom	Human Fertilisation and Embryology Act 2008 : a. A person should not conceive a child to perform an unethical procedure if it is performed on a child who has already been born; b. Siblings are in a serious or life-threatening condition; c. All other treatment options have been tried but have not provided a cure; d. Parents must undergo counseling; e. Donor giving is limited to cord blood or spinal cord. Solid organ harvesting is not allowed (Jonathan Herring, 2015).
2. United States	a. The sibling is in a life-threatening condition or causing serious disability and is likely to be saved through a saviour sibling; b. There should be a psychological examination of the parents to ensure that they will have the right attitude towards the children and be able to raise them in a loving environment; c. Restrictions on donors who can be given by the rescuer siblings before adulthood (e.g. no solid organ transplants) (Zúñiga-Fajuri, 2018).
3. Spanish	a. If there is no suitable donor who is able to give consent; b. If the donor recipient is the donor's brother or sister; c. If the donation is made to save the life of the donor; d. If special written authorization has been granted by the case representative and the ethics committee (Anniek Corveleyn, Eleni Zika, Michael Morris et al., 2007).
4. Australia	a. Sick siblings have serious or life-threatening medical conditions and have no effective alternative treatment; b. The planned transplant is expected to significantly improve the patient's prognosis; c. The request must be approved by the Human Research Ethics Committee (HREC) which ensures that this procedure is conducted ethically and for a legitimate reason; d. Decision-making must consider the welfare of the child conceived as a saviour sibling, including the physical and psychological risks that may arise from the donation process (Samardžić, 2019).
5. India	a. Saviour siblings are only allowed if their siblings have serious or life-threatening illnesses or other genetic diseases that require a hematopoietic stem cell transplant; b. The procedure should be aimed at helping to save or prolong the life of the sick sibling; c. Each procedure must obtain approval from the ART (Assisted Reproductive Technology Ethics Committee) ethics committee, which ensures that this procedure is carried out for legitimate reasons and does not violate the rights of the unborn child; d. This process must consider the welfare of the saviour sibling child. There should be no significant risk to the physical or psychological health of the child to be born (Ansari et al., 2024).

Based on the arrangement of saviour siblings in several countries, there are similarities in terms of the conditions that allow saviour siblings to be carried out, namely :

1. The rescued child was in a life-threatening condition and there were no other therapeutic options available;
2. The entire procedure must pay attention to the welfare of the child saviour sibling, there should be no physical or psychological risk to the child to be born.

CONCLUSION

Based on the description above, it can be concluded that:

The use of the saviour sibling method so as not to cause physical and psychological disturbances for children born in terms of bioethics in Indonesia needs to be regulated by paying attention to the basic principles of bioethics, namely respect for autonomy, beneficence, nonmaleficence, and justice. Bioethical guidelines should emphasize the well-being of the child being born, including ensuring that medical procedures such as IVF and PGD are performed to strict standards to minimize physical risks. In addition, there should be efforts to avoid psychological impact on the child by ensuring that his or her birth is valued not only as a donor but as an individual of value. The preparation of guidelines should involve the Ministry of Health, bioethicists, medical professional organizations, and child protection commissions.

Regulations regarding the use of this saviour sibling method so as not to cause physical and psychological disturbances for the child born legally in Indonesia must include clear restrictions related to the use of assisted reproductive technology and PGD in accordance with Law Number 17 of 2023 concerning Health. This regulation must ensure that the practice of saviour siblings is carried out safely, in quality, and does not contradict religious values and societal norms. It is important to create a legal framework that includes informed consent, oversight by an ethics committee, and restrictions on the types of medical procedures that are allowed to safeguard the welfare of children. Comparisons with regulations in other countries can be a reference for adopting best practices in reproductive health law.

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