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Legal and Ethical Discourse of Saviour Sibling: How Should Indonesia Respond to this New Trend?

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Abstract

Thalassemia major *is a genetic condition characterized by an inefficient synthesis of red blood cells which can be cured by bone marrow transplantation surgery. However, getting a matching donor is a challenging task. Therefore, some people have been using the "saviour sibling" procedure wherein a sibling is born to be a donor for their sibling. This procedure, however, has been raising debate, especially concerning bioethics. Indonesia, a country with a high number of people who suffer from such an abnormal genetic condition, needs to be aware of this procedure and its policy framework. This paper conducts a comparative study in identifying and analyzing how saviour sibling is regulated in countries other than Indonesia. Besides, it discusses the legal and ethical implications of saviour sibling procedures in Indonesia. It is a cross-discipline research that combines legal research in the fields of health law, human rights law, and private law and resources from medical science. The analysis is established by using normative, comparative, and ethical approaches. This study found a disparity in the policy framework between countries because such a procedure is in the grey zone between bioethics and technologies. Nevertheless, no rights are violated because the child would live a life of physical and mental well-being. This procedure also plays a critical role in developing medical technology. In bioethics, the saviour sibling procedure begs whether the conceived sibling is just a means to an end, a mere commodity. In Indonesia, the legal framework on health technology involving human subjects is still relatively lax in regulating saviour siblings. Therefore, this study suggests that Indonesia needs to consider the diverse local wisdom as the foundation of its bioethics in regulating saviour sibling in the future.*

Keywords: *Bioethics; Indonesia; Legal framework; Medical technology; Saviour sibling.*

1. INTRODUCTION

The birth of a child with a severe genetic (congenital/hereditary) disease can be prevented by genetic engineering or by preimplantation genetic diagnosis (PGD).[1] Genetic engineering or modification is one of the modern biotechnology techniques that manipulate or modify deoxyribonucleic acid (DNA) molecules to change the characteristics of an organism.[2] This genetic

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[1] A L v. Hammerstein, Matthias Eggel, and Nikola Biller-Andorno, "Is Selecting Better than Modifying? An Investigation of Arguments against Germline Gene Editing as Compared to Preimplantation Genetic Diagnosis," *BMC Medical Ethics* 20, no. 83 (2019): 1–2.

[2] Sutarno, "Rekayasa Genetik Dan Perkembangan Bioteknologi Di Bidang Peternakan," *Proceeding Biology Education Conference* 13, no. 1 (2016): 23.

modification technology uses proteins, called enzymes, to cut through the areas of DNA in an organism's genetic material so that it will compose the organism's genes.[3] Genetic engineering technology is different from PGD, where in the PGD procedure, there is no process of changing genes or DNA.

PGD is a procedure in which the embryo is screened *in vitro.* Based on the data obtained, only embryos with the desired genetic features will be implanted into the mother's womb.[4] PGD is usually conducted to screen embryos that are going to be planted in In Vitro Fertilization (IVF) reproduction.[5] This technique can identify sex and genetic abnormalities that may occur in the embryo.[6] PGD is different from prenatal diagnosis, where a prenatal procedure is performed at the time of pregnancy.[7] PGD assists in identifying the presence or absence of genetic defects by discerning genes or chromosomes in the embryos.[8] The purpose of PGD is to get a healthy baby and prevent diseases in the baby that will be planted in IVF reproduction. The question arises: What if the PGD process shows that none of the embryos can be planted through IVF? In other words, what would happen to the embryos if all the embryos screened were affected by genetic diseases?

PGD has been used in reproduction therapy since the first live birth in 1990 to test for genetic abnormalities in embryos, wherein later HLA Typing (tissue matching for Human Leukocyte Antigen) was included in the procedure to become the saviour sibling procedure in 2000.[9] Therefore, PGD is utilized during an IVF cycle not only to determine genetic conditions but also to match tissue-type, i.e., HLA typing.[10] This is significant compared to the fact that when PGD was first announced, nobody could have predicted its potential. [11] PGD combined with tissue typing allow a saviour sibling where a sibling is born to become a *hematopoietic* stem cell (HSCs)

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[3] Julie Everett-Hincks and Mark Henaghan, "Gene Editing in Aotearoa -- Legal Considerations for Policy Makers," *Victoria University of Wellington Law Review* 50 (2019): 515.

[4] Sandra O Samardžić, "Saviour Siblings - Current Overview, Dilemmas and Possible Solutions?," *Medicine, Law & Society* 12, no. 2 (2019): 90.

[5] Thomas Lemke and Jonas Rüppel, "Social Dimensions of Preimplantation Genetic Diagnosis: A Literature Review," *New Genetics and Society* 38, no. 1 (2019): 88.

[6] Harvey J. Stern, "Preimplantation Genetic Diagnosis: Prenatal Testing for Embryos Finally Achieving Its Potential," *Journal of Clinical Medicine* 3, no. 1 (2014): 281.

[7] Samardžić, *loc.cit.*

[8] Stern, *loc.cit.*

[9] Lisa Cherkassky, "The Wrong Harvest: The Law on Saviour Siblings," *International Journal of Law, Policy and the Family 29*, no. 1 (2015): 37

[10] Malcolm K. Smith, "The Human Fertilisation and Embryology Act 2008: Restrictions on the Creation of 'Saviour Siblings' and the Relevance of the Harm Principle," *New Genetics and Society* 32, no. 2 (2013): 155.

[11] Lisa Cherkassky, "Twenty-Seven Years of Controversy: The Perils of PGD," *International Journal of Pediatrics and Neonatal Health* 1, no. 6 (2017): 141.

donor for their sibling.[12] HSCs are multipotent primordial cells that may grow into all types of blood cells found in various organs, such as the bone marrow and umbilical cord blood.[13] HSCs transplantation is performed by matching the donor's Human Leukocyte Antigen (HLA) and the recipient (HLA-typing) so that relatives with identical HLA can be considered a preferred donor.[14]

The first case of a saviour sibling occurred in the United States in 2000 when a baby named Adam Nash was born to be a donor to his sibling Molly, a rare anemia patient.[15] A similar case occurred in India in 2018, where Kavya Solanki was born to save her brother Abhijit who suffered from *thalassemia major*.[16] *Thalassemia major* is a hereditary (genetic) disease due to decreased and imperfect production of hemoglobin (red blood cells).[17] Patients with *thalassemia* require regular blood transfusions to prevent anemia.[18] Abhijit's parents then tried to find a permanent solution to their son's illness and found out about the saviour sibling procedure.[19] Finally, after the doctor matched and selected the embryos for six months, his sister's embryo was planted in his mother's womb.[20] After the younger sister was born and reached 16-18 months, bone marrow transplantation surgery was performed.[21] To this day, Abhijit no longer needs blood transfusions.[22] Kavya also seems to be doing well and has been mainly staying indoors due to Covid-19 pandemic.[23]

This saviour sibling procedure raises the question of whether babies born to become tissue or cell transplant donors are legally and ethically justified. It is conceded that this saviour sibling procedure can help with medical treatment, however, it is an exploitation of a legal subject. Ethical principles relating to a contravention of technology development are

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[12] Chee Ying Kuek, Sharon Kaur Gurmukh Singh, and Pek San Tay, "The Need to Address Legal Ambiguity on Conceiving Saviour Siblings in Malaysia," *Health Policy and Technology* 8 (2019): 278

[13] Ji Yoon Lee and Seok-Ho Hong, "Hematopoietic Stem Cells and Their Roles in Tissue Regeneration," *International Journal of Stem Cells 13*, no. 1 (2019): 1

[14] Kuek, Singh, and Tay, *loc.cit.* See also Rani Tiyas Budiyanti,"Aspek Etika Pre-implantation Genetic Diagnosis (PGD) pada Teknologi Bayi Tabung," *Cermin Dunia Kedokteran* 42, no. 7 (2015): 543.

[15] Samardžić, *op.cit.*, 91.

[16] British Broadcasting Corporation, "India's First 'saviour Sibling' Cures Brother of Fatal Illness,"

[17] Evy Sari Sutrisnaninfsih, Suharjono, and Bambang Sudarmanto, "Analysis of Deferasirox and Deferipron Use in Children with Pediatric B-Thalassemia Major," *Folia Medica Indonesiana* 52, no. 1 (2016): 42.

[18] *Ibid.*, 43.

[19] British Broadcasting Corporation, *loc.cit.*

[20] *Ibid.*

[21] *Ibid.*

[22] *Ibid.*

[23] The Week, "A Life Made, a Life Saved", https://www.theweek.in/health/cover/2021/02/24/a-life-made-a-life-saved.html .

associated with moral, legal, socioeconomic, and health issues.[24] According to K. Bertens, there is a close relationship between ethics and law. Bertens put forward two reasons to support this. First, the implementation of the law must be accompanied by ethics because the execution of laws that do not meet moral norms is worse than no law. Second, laws often embody and confirm moral ideas. The law is essentially a crystallization of morals[25] and is in line with the maxim *Quid Leges Sine Moribus* (The law is meaningless if it is not accompanied by morality). Therefore, it also implies a relationship between ethics and health law.

In health services, especially medicine, doctors must uphold ethical principles.[26] For example "Hippocratic Oath" as the basis of the first medical ethics. Ethics in health law is also called "bioethics", an interdisciplinary study related to the development of medical and biological sciences both on a micro and macro scale in the present and the future.[27] Issues on bioethics include legal, social, political, economic, religious, cultural, and medical (health) fields. In the medical field, some examples are euthanasia, abortion, artificial reproductive technology, and genetic engineering. According to Beauchamp and Childress, there are four principles in bioethics, namely*:* beneficence, non-maleficence, respect for autonomy, and justice.[28]

The saviour sibling procedure in the Kavya Solanki case is closely related between ethics and law and is currently known as a bioethics problem. PGD technological advancements may enable the savior sibling operation in Indonesia. Adopting such technology seems urgent considering more than 10,531 *thalassemia* patients and an estimated 2,500 babies are born with *thalassemia* yearly in Indonesia.[29] Albeit it is conceded that there is a further discourse on the issue of collective family interest, the saviour sibling procedure allows parents to choose a to-be-child to save the life of a child in their family.[30] Nonetheless, this begs the question of whether the to-be-child is just a mere means to an end. In other words, there are many

[24] The innovation and development of medical technology are so rapid in various health service sectors. Therefore, using newly invented health service technology must always consider ethical aspects to anticipate malpractice, fraud, and moral hazard. See Ambar Dwi Erawati, and Hargianti Dini Iswandari,"Ownership of Medical Records in Indonesia: Discourse on Legal Certainty and Justice," *Udayana Journal of Law and Culture* 6, no. 2 (2022): 197.

[25] K Bertens, *Sekitar Bioetika* (Yogyakarta: Kanisius, 2018), 116.

[26] Hardisman, "Opini Publik Tentang Malpraktek Kedokteran," *Jurnal Pendidikan Kedokteran Indonesia* 2, no. 1 (2013): 17.

[27] M Jusuf Hanafiah and Amri Amir. *Etika Kedokteran Dan Hukum Kesehatan* (Jakarta: EGC, 2009), 3.

[28] H Widdows, *Global Ethics: An Introduction* (Durham: Acumen, 2011), 94.

[29] Kementerian Kesehatan Republik Indonesia, "Angka Pembawa Sifat Talasemia Tergolong Tinggi." https://www.kemkes.go.id/article/view/19052100003/angka-pembawa-sifat-talasemia-tergolong-tinggi.html

[30] Michelle Taylor-Sands, "Saviour Siblings And Collective Family Interests," *Monash Bioethics Review* 29, no. 2 (2010): 11.

opposing interests and these concerns are what make regulation in this issue so challenging.[31] Many debates then have been centered on whether it is acceptable to choose embryos in order to ensure that the eventual kid would be a suitable tissue match for a sick older sibling.[32] In other words, a bioethical issue has not been addressed comprehensively.[33] Recent work in bioethics suggests the need to advance health and social justice globally and to advance justice to be in line with foundational moral commitments for public health research, practice, and policy.[34]

In Indonesia, the issue of Health Technology and Health Technology Products is regulated in Law No. 36 of 2009 concerning Health (Health Law).[35] In particular, Article 44 of the Health Law regulates the possibility of developing technology and technological products by testing humans and animals, so the question arises whether it is permissible to select or test embryos *in vitro* to be used as "factories" for organs to be donated to others in Indonesia. Nonetheless, the Government Regulation supposed further to regulate the implementation of human trials in Indonesia has yet to be formed. In other words, it is argued that the PGD and saviour sibling regulations need to be clarified in Indonesia. Therefore, this paper seeks to answer two research questions. First, how is Saviour Sibling regulated in various countries other than Indonesia? This question aims to assess the legality of savior sibling practice in countries other than Indonesia in a comparative means. Second, what are the legal and ethical implications of saviour sibling procedures in Indonesia? This question aims to discuss and evaluate the consequences of savior sibling procures from the perspectives of law and ethics.

This article implies cross-discipline research. It is primarily legal research that has a basis in the field of health law, human rights law, and private law. However, non-legal sources and science-based analysis generally come from medical and health perspectives. The analysis is established by using normative, comparative, and ethical approaches. The normative approach explains how legal principles and existing regulations govern pre-implantation genetic diagnosis in Indonesia, especially regarding children's protection. The comparative approach explains how saviour sibling is regulated in other countries, particularly regarding whether

[31] Madeleine Whelan, "Saviour Siblings: The Role of the Welfare Principle within the Law of Assisted Reproductive Technology in England and Wales (Part 2)," *Family Law*, no. 2 (2021): 252–260.

[32] Heather Zierhut et al., "More than 10 Years After the First 'Savior Siblings': Parental Experiences Surrounding Preimplantation Genetic Diagnosis," *Journal of Genetic Counseling* 22, no. 5 (2013): 600.

[33] Barbara Pfeffer-Billauer. "Savior Siblings, Protective Progeny, And Parental Determinism in The Age of CRISPR-CAS." *Chicago-Kent Law Review* 96, no. 1 (2022): 177.

[34] Bridge Pratt, et.al, " Justice: A Key Consideration in Health Policy and Systems Research Ethics" *BMJ Global Health* 5, no.4 (2020): 2.

[35] Law No. 36 of 2009 concerning Health, Arts. 42-45.

countries generally allow or prohibit pre-implantation genetic diagnosis combined with HLA-typing for saviour sibling procedures. The ethical approach concerns the importance of regulating the ethical aspects of technological progress used in savior siblings. The third approach is the social science and the health law approach.

2. RESULT AND ANALYSIS

2.1. Comparison of Saviour Sibling Regulation in Various Countries

Indonesia is a developing country based on the World Economic Situation and Prospects (WESP) 2021 published by the United Nations.[36] Thus, the comparison should start by looking at how saviour siblings are regulated in developing countries and countries neighboring Indonesia. Next, a comparison of saviour sibling regulation in developed countries will be carried out to see how they differ from developing countries.

2.1.1. Developing Countries

This research chooses Malaysia, India, and Serbia as examples of how developing countries[37] regulate the issue of savior siblings. Malaysia and India would serve as examples of the neighboring countries of Indonesia. Malaysia, in particular, has a pretty similar culture to Indonesia while India is acknowledged as one of the most high-technology countries in developing countries. Serbia was designated as an example of a non-neighboring country.

a. Malaysia

Malaysia does not have legislation specifically regulating assisted reproductive technology (ART).[38] The saviour sibling procedure or more specifically the use of PGD and HLA-typing technology is regulated in the Guideline on Assisted Reproduction established by the Malaysian Medical Council (MMC).[39] This guideline contains two specific articles on PGD and saviour siblings. Article 14 of the guideline states that PGD is used mainly for the diagnosis of many diseases and to determine the sex of the embryo. Next, Article 15 stipulates prohibited/unacceptable practices such as the prohibition of producing clones. Therefore, although these two articles indicate that experiments have been carried out to select embryos to match

[36] United Nations. "World Economic Situation and Prospects 2021" (New York: United Nations, 2021), 126.

[37] The three countries are classified as developing countries by some indexes. See for example World Data, "Developing Countries," https://www.worlddata.info/developing-countries.php and Department of Foreign Affairs and Trade of Australia, List of Developing Countries as declared by the Minister for Foreign Affairs, March 2022, https://www.dfat.gov.au/about-us/publications/list-of-developing-countries-as-declared-by-the-minister-for-foreign-affairs

[38] Kuek, Singh, and Tay, *op.cit.,* 279.

[39] Guideline on Assisted Reproduction 2006, Arts, 14-15.

HLA with children who need hematopoietic stem cell transplantation, this regulation does not explicitly regulate whether it is permissible to give birth to rescue siblings.[40] So it can be concluded that Malaysia does not expressly allow or prohibit the procedure of saviour sibling. Kuek, Singh, and Tay argue that Article 14 and Article 15 of the MMC are ambiguous, which makes the health industry in Malaysia assume that the saviour sibling procedure is prohibited because the testing and selection of embryos are not intended for the health of the prospective child himself.[41]

b. India

India adopted a Pre-conception and Pre-natal Diagnostic Techniques ("Prohibition of Sex Selection") Act 1994 that specifically covers the PGD. This Act was created basically as a prohibition on choosing the sex of the future child before or after conception. The Pre-Natal Diagnostic (PND), according to this Act, also includes the diagnosis before conception.[42] Thus PND includes PGD for this purpose. The Prohibition of Sex Selection Act provides that PND is prohibited unless it is intended to detect the presence of chromosomal abnormalities, metabolic genetic diseases, hemoglobinopathy, genetic diseases related to the genitals, congenital anomalies, and other abnormalities or diseases mentioned by the Central Supervisory Board.[43] Therefore, India allows the PGD because saviour sibling procedure in the PGD stage utilizes PGD for detecting genetic diseases, i..e, *thalassemia major.* Furthermore, the Prohibition of Sex Selection Act provides requirements for PND, one of which is when a woman is pregnant or whose partner has a family history of mental retardation or physical abnormalities, or other genetic diseases.[44] In conclusion, India expressly allows the saviour sibling procedure.

c. Serbia

Serbia regulates assisted reproduction in the Law on Bio-Medically Assisted Fertilisation (LBMAF). Although Serbian law allows the use of PGD technology, Article 25 and Article 47 of the LBMAF provide that the use of PGD is only intended for couples who need assistance due to their infertility.[45] Thus, it can be concluded that the use of PGD for saviour sibling procedures has not been allowed in Serbian law.[46] Although it is not yet allowed, Samardžić argues that the process of donating tissues or cells

[40] Kuek, Singh, and Tay, *loc.cit.*
[41] *Ibid.*, 281.
[42] Pre-Conception and Pre-Natal Diagnostic Techniques Act 1994, Section 2.
[43] *Ibid.*, Art. 4 (2).
[44] Ibid., Art. 4 (3).
[45] Samardžić, *op.cit.,* 96; Law on Bio-Medically Assisted Fertilisation 2017, Art. 25 and Art. 47.
[46] *Ibid.*, 104.

does not violate the child's right to health, since by law stem cells should only be taken from the umbilical cord or bone marrow.[47]

2.1.2. Developed Countries

This paper chose the United Kingdom of Great Britain and Northern Ireland (UK), the United States of America (USA), Australia, and Spain as examples of developed countries. The UK is known as one of the progressive pioneers in regulating saviour sibling while the USA is leading in both health law and health technology. Australia is mainly chosen due to its geography, which is the neighbor of Indonesia. The choosing of Spain was by considering its valuable contributions to the Oviedo Convention 1997, including as the host country for the conference that resulted in this convention.

a. The United Kingdom of Great Britain and Northern Ireland

For a long time, the UK has regulated medical procedures and has incorporated the creation of saviour siblings with government involvement[48] and court ruling.[49] The UK permits embryo testing (PGD) if a child is suffering from a serious medical condition that can be cured by the administration of stem cells derived from the umbilical cord, bone marrow, or other tissues belonging to the prospective child.[50] This implies that the UK allows the saviour sibling procedure that has an implication not only to test whether their embryos contain genetic diseases but also allowed solely for tissue typing.[51] Based on this, it can be concluded that the UK is very progressive regarding PGD.

b. The United States of America

The USA has no regulations established by the government or specific legal guidelines on saviour siblings, so the use of PGD technology for saviour siblings procedures is left to discretion and consensus between health care providers and patients.[52] Some organizations that establish guidelines on IVF, PGD, and reproductive medicine such as the American Society for

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[47] *Ibid.*, 102.

[48] Nonduduzo Penelope Gumede, "The Rights and Regulation of Saviour Siblings in South Africa: An Ethical and Jurisdictional Comparative" (Master Thesis, Masters in Law, University of Kwazulu-Natal, January 2020), 75.

[49] See Dyer C. Law, "Lords Give the Go Ahead for Creation of "Saviour Siblings". *BMJ 3*30 (2005):1041.

[50] Human Fertilisation and Embryology Act 2008, para. 1ZA (1) (d).

[51] Madeleine Whelan, "Saviour Siblings: The Role of the Welfare Principle within the Law of Assisted Reproductive Technology in England and Wales (Part 1)," *Family Law*, no. 1 (2021): 83.

[52] Zachary E. Shapiro, "Savior Siblings in the United States: EthicalConundrums, Legal and Regulatory Void," *Washington and Lee Journal of Civil Rights and Social Justice* 24, no. 2 (2018): 443–444.

Reproductive Medicine, the American Congress of Obstetricians and Gynecologists, and the American College of Medical Genetics do not provide strict arrangements on saviour siblings.[53] Moreover, these organizations do not provide official statements or attitudes towards saviour siblings procedures, so their guidelines do not address saviour siblings comprehensively.[54] In conclusion, the arrangement in America related to the saviour sibling is still in the grey zone.

c. Australia

Australia is a federal country with different states and does not have uniform legislation for reproductive technologies.[55] The Commonwealth of Australia (Federation) Parliament does not have a constitutional authority to regulate assisted reproductive technology in Australia.[56] Thus, the authority is left to the authority of the state. Nonetheless, the National Health and Medical Research Council (NHMRC), a commonwealth legal authority, has published non-legislative guidelines on assisted reproductive technology which are "voluntary" arrangements for states, i.e., no binding force for states to implement them.[57] The NHMRC directive is titled Ethical Guidelines on the Use of Assisted Reproductive Technology in Clinical Practice and Research 2017 (ART Guidelines). It should be noted that state legislation, national professional standards, and ethical principles govern Assisted Reproductive Technology in Australia.[58]

Article 8.15.1 of the ART Guidelines provides that preimplantation genetic testing (PGT), which consists of preimplantation genetic diagnosis (PGD) and preimplantation genetic screening (PGS), should only be used to: fight genetic conditions, diseases, or abnormalities that may significantly limit the quality of life of the person to be born; choose embryos with tissue suitable for stem cell treatment intended for parents, siblings or other siblings; or increase the probability of being born.

States in Australia, on the other hand, have different approaches regarding assisted reproductive technology.[59] Although the settings vary, their general policy is that PGD is only allowed to obtain genetic

[53] *Ibid.*, 447.
[54] *Ibid.*
[55] Gumede, *op.cit.*, 72.
[56] Australian Constitution 1901, Section 51.
[57] Michelle Taylor-Sands, "Selecting 'Saviour Siblings': Reconsidering the Regulation in Australia of Pre-Implantation Genetic Diagnosis in Conjunction with Tissue Typing," *Journal of Law and Medicine* 14 (2007): 552.
[58] Michelle Taylor-Sands et al., "Non-Medical Sex Selection in Australia: Public Views and Bioethical Concerns," *QUT Law Review* 18, no. 2 (2019): 44–76.
[59] Malcolm K Smith. *Saviour Siblings and the Regulation of Assisted Reproductive Technology* (New York: Routledge, 2016), 10–11.

compatibility with sick relatives and also to prevent "real risks in the future, where the embryo will suffer from severe genetic diseases".[60]

d. Spain

The regulation on assisted reproductive technology in Spain is provided for in the Assisted Reproductive Technology Act 2016 (*Ley de Técnicas de Reproducción Humana Asistida* 2016) in which Article 12.2 of the Act provides that there are only certain conditions under which the embryo can be examined to attempt *histocompatibility* with third parties.[61] At the international level, the Oviedo Convention 1997, a convention for the protection of human rights and dignity concerning the application of biology and medicine established in Spain, provides that the taking of regenerative tissues of a person, who has no capacity to give consent can be allowed if these conditions are met, namely:[62] First, no suitable donor has the ability to give consent. Second, the recipient is the brother or sister of the donor. Third, tissue donations should have the potential to save the life of the recipient. Fourth, the granting of permission as referred to in Article 6 paragraphs 2 and 3 has been given specifically and in writing, following existing law and with approval from the competent body. Fifth, potential donor recipients did not refuse.

Therefore, it can be concluded that Spain generally allows saviour siblings with several caveats. Next, after providing a comparison of the arrangement of saviour sibling procedures in other countries, the question then is how to regulate saviour siblings in Indonesia and its ethical implications.

2.2. Legal and Ethical Implications of Saviour Sibling Procedures in Indonesia

2.2.1. Preimplantation Genetic Diagnosis Policy Framework

Article 28H paragraph (1) of the 1945 Constitution of the Republic of Indonesia guarantees that everyone has the right to live a life of physical and mental well-being. This constitutional provision is one of the bases for the establishment of the Health Law besides Article 27H paragraph (1) and Article 34 paragraph (3). The Health Law regulates various aspects of the health sector, one of which is the Technology and Technology Product section which is in Chapter V on Resources in the Health Sector. This section regulates, for one, the technological trials of humans. Article 44 of the Health Law provides for the possibility of developing technology and technological products with human trials.

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[60] Alejandra Zúñiga Fajuri, "Born to Donate: Proposals for 'Savior Sibling' Regulation in Latin America," *Colombia Médica* 49, no. 3 (2018): 230.

[61] Zúñiga Fajuri, *loc.cit.*

[62] Oviedo Convention 1997, Art. 20.

While research in health sciences and the medical field is growing in Indonesia, the quality and ethical standards for research still need to be developed appropriately. Developing quality and ethical standards through international collaborative research activities become necessary. It would avoid conflicts of interest, scientific misconduct, poor informed consent, unethical use of subjects (human, animal, plantation, without a material transfer agreement (MTA), and the occurrence of ethics imperialism. [63] Therefore, research should pay attention to the humanities, ethics, legal and professional (HELP).

The European Union has developed standards for researchers, namely Ethics for Researchers.[64] One of the provisions in the Ethics for Researchers stipulates that research related to adult stem cells and embryonic stem cells will not be allowed and financed by the government if it does not pay attention to or heed the ethical provisions for researchers of the European Commission and the provisions on human rights.[65]

Regulations on research and development of health in humans are regulated in Government Regulation No. 39 of 1995 concerning Health Research and Development (GR 39 of 1995). GR 39 of 1995 regulates research not only on humans but also regulates research and development of health in animals, plants, mechanical remains, and the environment. Thus, it is the general regulation of health research and development for humans, animals, and plants.[66]

In research for humans, families, and communities, there must be written permission and consent from the person concerned or it can also be given by his parents if the person concerned is not legally capable or because his health and physique are in no way possible to give his consent or the person concerned has passed away and his body will be used as an object for health research and development. The written consent must also be given by the head of the family if the object of the research is the family and the written consent of the regent if the object of research is the community. Furthermore, GR 39 of 1995 determines that the information that must be provided to humans, families, and the community as the object of research includes: a) the purpose of health research and development and the use of the results; b) guarantees of confidentiality about identity and personal data; c) the methods used; d) risks that may occur, and; e) things

[63] See Soenarto Sastrowijoto et al. *Buku Putih Universitas Gadjah Mada: Inspirasi UGM Untuk Indonesia "Bioetika": Meneguhkan Kembali Etika Kehidupan Berbangsa Dan Bernegara* (Yogyakarta: Pusat kajian Bioetik dan Humaniora Kedokteran, 2014), 17.

[64] Directorate-General for Research and Innovation (European Commission), Ethics for Researchers: Facilitating Research Excellence in FP7 (LU: Publications Office of the European Union, 2013), https://data.europa.eu/doi/10.2777/7491

[65] *Ibid.*, 16.

[66] Government Regulation No. 39 of 1995 Concerning Health Research and Development, Art. 5.

that need to be known by the person concerned in the context of health research and development.[67]

In Indonesia, regulations on service and research ethics need to be developed by considering diverse local wisdom. Local wisdom is required since ethics may be readily adopted if the local community believes in its implementation. [68] Culture in Indonesia with thousands of tribes from Sabang to Merauke, of course, there is a lot of local wisdom that can be used as the basis for the preparation of ethical regulations.[69] Local wisdom must also be maintained to avoid moral imperialism and to prevent other nations from forcing the use of their moral values or changing a nation's moral values according to their interests.[70] Various tribes in Indonesia are also influenced by their religions (Islam, Christianity, Catholicism, Hinduism, Buddhism, and Kong Hu Chu).[71]

In Indonesia, regulations on reproductive health are regulated in Government Regulation No. 61 of 2014 concerning Reproduction Health which includes: [72] a) maternal health services; b) indications of medical emergencies and rape as exceptions to the prohibition of abortion; c) assisted reproduction or pregnancy outside the natural way. Specifically reproductive health services with the help of birth outside the natural way, it is further regulated in Ministry of Health Regulation No. 43 of 2015 concerning the Implementation of Reproductive Services with Assistance or Pregnancy Outside the Natural Way (MoH Regulation 43 of 2015). According to this ministerial regulation, Assisted Reproductive Technology Services is an effort to obtain a pregnancy outside the natural way without going through the process of conjugal relationship (copulation) if the natural way does not obtain results, by bringing together the husband's spermatozoa with the wife's egg in the tube.[73] MoH Regulation 43 of 2015 also determined that there are only two ways to provide assisted reproductive technology, namely, conventional and Intra Cytoplasmic Sperm Injection (ICSI). It also regulated the need for counselling in advance and the existence of informed consent before the assisted reproductive technology service action is carried out. However, MoH Regulation 43 of 2015 does not cover the implementation of reproduction with the aim of a saviour sibling.

A weak legal framework on health technology with human subjects is indicated by the abstention of either a government regulation that explicitly regulates the implementation of human trials or a government Regulation

[67] *Ibid.,* Art. 10.
[68] Sastrowijoto et al., *op.cit.,* 13.
[69] *Ibid.*
[70] *Ibid.*
[71] *Ibid.*
[72] Government Regulation No. 61 of 2014 Concerning Reproduction Health, Art 2.
[73] Ministry of Health Regulation No. 43 of 2015 concerning the Implementation of Reproductive Services with Assistance or Pregnancy Outside the Natural Way, Art.1.1

that establishes a supervisory agency for the use of technology and technological products in health. It is foreseen that lack of supervision of the use of PGD technology is a current problem that can cause other new problems in the future.

Research on stem cells and human embryos is an issue of concern in bioethics. The explanation of Article 44 (2) of the Health Law stipulates that trials of human subjects must refer to four principles of bioethics: (1) respect for persons; (2) beneficence; (3) nonmaleficence; and (4) justice.[74] This shows that the principles used by the Government of Indonesia in trials with human research subjects above follow the principles of bioethics proposed by Beauchamp and Childress.

2.2.2 The Concern on Children Whose Embryos Have Been Tested Through Pre-Implantation Genetic Diagnosis

The question that arises is whether the saviour sibling procedure through PGD and tissue typing violates human rights. In answering this question, it is necessary to ascertain in advance the legal status of the embryo itself.

Human beings are the subject of law from birth to death.[75] However, even before being born, man can become the subject of law. From a private law perspective, the Indonesian Civil Code states that a child in the womb will be considered as having been born if he has an interest, for example as an heir.[76] However, if the child dies at birth, it is considered that it never existed. This provision is in line with the maxim "*nasciturus pro iam nata habetur quatiens de cammadis eius agitur*" which means that an unborn child is considered to have been born if it has an interest.

The embryo is formed from the confluence between the sperm and the ovum/egg which initially forms a zygote and then the implantation of a fertilized egg in the uterine wall occurs.[77] The zygote divides into two, four, eight and so on until it forms an embryo.[78] In PGD, the meeting of sperm and ovum (insemination) is carried out outside the uterus, namely in the petri dish.[79] The embryos resulting from the confluence of the ovum and

[74] Amru Hydari Nazif, "Isu Nasional Dalam Bioetika Di Indonesia" (Prosiding Seminar Nasional Bioetika Pertanian, 2009), 4–5, http://repository.pertanian.go.id/handle/123456789/11768

[75] SHH Davis, "The Legal Personality of the Commonwealth of Australia," *Federal Law Review* 47, no. 1 (2019): 5.

[76] Indonesian Civil Code, Art.2.

[77] Antonietta Rosa Silini et al., "Perinatal Derivatives: Where Do We Stand? A Roadmap of the Human Placenta and Consensus for Tissue and Cell Nomenclature," *Frontiers in Bioengineering and Biotechnology* 8 (2020): 4.

[78] *Ibid.*

[79] Judith Daar, "A Clash at the Petri Dish: Transferring Embryos with Known Genetic Anomalies," *Journal of Law and the Biosciences* 5, no. 2 (2018): 228–229.

sperm will then be selected as the best to implant in the uterus.[80] Embryos implanted in the womb will develop or live until they become fetuses.[81] The development of the zygote to form an embryo because cell division occurs indicates the existence of life in the embryo.

Based on this, it becomes a question whether embryos that are being matched outside the womb can be considered legal subjects. The subject of law is everything that can obtain rights and obligations from the law.[82] Legal subjects other than human beings as individuals are also legal entities. Human as a subject of law means a person as a person with rights and obligations from birth to death. However, the position of man as a subject of law can begin earlier, that is, from the time in the womb of his mother if his interests require it, for example in the case of inheritance where the child in the womb must appear as an heir. Although the baby in the womb is already considered a legal subject if his interests require it, in carrying out legal acts, he still has to be represented by his mother who lives longer. In addition, Article 2 of the Civil Code further stipulates that, although the child in the womb can be considered a legal subject, on condition that he is born alive. Born dead then the baby in the womb is considered to have never existed. This rule is an exception to the rights called legal fiction. It is called legal fiction because there is currently no more detailed arrangement on the subject.

It is important to determine the position of humans as a subject of law because every human being is a person with rights and obligations from birth to death. This means that every human being has legal authority but does not necessarily have the authority to act to exercise his rights and obligations. Humans as a subject of law are not always capable of performing legal acts. Article 1329 of the Indonesian Civil Code provides that everyone is considered capable. Capable, according to J. Satrio is if a person can account for and understand the consequences of his actions, in other words, he can do a legal act himself with rare legal consequences. *A Contrario*, the subjects of law who are considered capable according to the Civil Code are adults and not those who are placed under guardianship. If it is connected with Articles 2, 836, and 899 of the Indonesian Civil Code, then the embryo can already be referred to as a subject of law because if the interests of the baby are in need, then they can be considered as heirs and can obtain inheritance through a will.

In the PGD procedure where the saviour sibling is made, the process begins with bringing together the father's sperm and the mother's ovum in vitro in a Petri tube/dish. Sperm and ovum meet and form a genome which is a new identity, and this identity will be carried throughout life.

[80] *Ibid.*
[81] Antonietta Rosa Silini et al., *loc. cit.*
[82] Soedikno Mertokusumo. *Mengenal Hukum* (Yogyakarta: UGM, 2010), 110.

Fertilization between the ovum and sperm then forms a zygote that develops into an embryo. The thousands of embryos that are formed are then selected in a certain way and only embryos with the desired genetic features will be implanted into the mother's womb. Residual embryos that are free from genetic problems will be frozen for future use, while those that are not selected will be destroyed. The question that arises is, is the extermination of embryos right according to bioethics rules?

K. Bertens argued that embryos already have a genetic identity and personal identity.[83] Therefore, it has a moral status, just like a person who has been born, alive. Based on the aforesaid opinion, the embryo already deserves a respect to develop. Embryos can also be categorized as vulnerable human beings. In 2005, the United Nations Educational, Scientific and Cultural Organization (UNESCO) issued a document regulating groups with vulnerabilities, namely the Universal Declaration on Bioethics and Human Rights (UDBHR). It is a non-binding instrument that has core principles that can apply to saviour siblings i.e., human dignity and the best interests of the child.[84] During the drafting of UDBHR, International Bioethics Committee conducted a series of consultations with national bioethics experts in various countries, including Indonesia.[85] Indonesia recognizes and upholds human rights and basic human freedoms as rights that are naturally inherent in and inseparable from human beings, which must be protected, respected, and enforced for the sake of increasing the dignity of humanity, welfare, happiness, intelligence, and justice.[86] Moreover, the practice of medicine in Indonesia is carried out based on the philosophy of *Pancasila*[87] and is based on scientific values, benefits, justice, humanity, balance, as well as patient protection and safety.[88] Therefore, every doctor in Indonesia is also obliged to respect human dignity in every one of their practices.[89]

The UDBHR underlines respect for human vulnerability and personal integrity.[90] It stipulates that human vulnerability should be taken into account in applying and advancing scientific knowledge, medical practice, and associated technologies. Further, individuals and groups of special

[83] K Bertens. *Sekitar Bioetika* (Yogyakarta: Kanisius, 2018), 194.
[84] Gumede, *op.cit.*, 46-47.
[85] Michael Kirby, "Human Rights and Bioethics: The Universal Declaration of Human Rights and UNESCO Universal Declaration of Bioethics and Human Rights," *Journal of Contemporary Health Law and Policy* 25 (2009): 321.
[86] Law No. 39 of 1999 concerning Human Rights, Art. 2.
[87] Pancasila is a state ideological values of the Republic of Indonesia that consist of five precepts. See I Gusti Agung Ika Laksmi Mahadewi, Ni Komang Tari Padmawati, and I Gusti Agung Mas Rwa Jayantiari," Notary in Indonesia: How Are State Fundamental Values Reflected in Law and Professional Ethics?" *Udayana Journal of Law and Culture* 6, no. 2 (2022): 205, 214.
[88] Law No. 29 of 2004 concerning Medical Practice, Art. 2.
[89] Code of Ethics of Doctor, Art 8.
[90] Universal Declaration on Bioethics and Human Rights, Art. 8.

vulnerability should be protected and the personal integrity of such individuals respected".[91] Again, referring to Indonesian Civil Code and UDBHR, the embryo is a persona and a vulnerable human being.

In the saviour sibling, the embryo will be screened with DNA so that later it will become a healthy baby without carrying bad genes. So that when he is born after he is over six months old, his stem cells can be transplanted into his brother. Based on the discussion before the purpose of the saviour sibling process that uses PGD technology is for health issues and not for non-medical reasons. In addition, stem cells would only be taken from the umbilical cord or bone marrow which brings no harm to the child. Lastly, this PGD process gives the future child a healthy life without disease. As a result, no human rights are infringed because the kid would have a life of physical and mental well-being if they did not have anything against the process of saviour sibling.

3. CONCLUSION

The comparison analysis suggests that the national policy of various countries indicates disparities in the saviour sibling procedure using PGD technology. The arrangement for this procedure is still in the grey zone, reflecting a dilemma between bioethics and technological advances. Developed countries, as discussed in this paper, allow saviour sibling procedures (with their caveats) expressly, while others only allow PGD technology for assisted reproduction or the future child's health. However, questions regarding the bioethics of the process are always remaining. It is paramount that saviour sibling procedure is utilized only for health issues and not for non-medical reasons. Otherwise, the PGD technology may be utilized for other purposes, choosing the gender, skin colour, or hair colour of the baby. In Indonesia, however, aside from the lack of a Government Regulation that mainly controls the implementation of human trials, there is also a need for a Government Regulation that establishes a supervisory agency for the use of technology and technical goods concerning health. The implication is that only some organizations in Indonesia can oversee the application of PGD technology. Based on this, Indonesian regulations on health technology involving human subjects need to be revised. Regarding ethical implications, further regulations on service and research ethics, in this case, saviour siblings, need to be developed by considering diverse local wisdom. Local wisdom is required because ethics will be easier to adopt if the local community believes in its execution. In advancing the content of this article, further research may be carried out on the protection of embryos, PGD procedures in Indonesia, and the need for collaboration

[91] *Ibid.*

between medical, legal, and cultural experts to resolve the case of *thalassemia* in Indonesia.

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