



## The Ethical Dilemmas of Designer Babies

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### ABSTRACT

Designer babies or savior siblings are babies whose genetic makeup has been selected via In Vitro Fertilization (IVF) or Preimplantation Genetic Diagnosis (PGD). They could be devoid of certain genetic diseases or have specific characteristics or traits that have been considered preferred traits. They are also conceived to save their sick sibling. This procedure is hazardous and might have unintended consequences. Despite the fact that it could save lives, this procedure is fraught with danger. Sometimes there may be serious errors and health problems and genetic side effects. There are several ethical concerns surrounding designer babies. So, in this term paper, a few ethical issues concerning savior babies will be covered.

**Keywords:** Preimplantation Diagnosis, Gene Editing, Siblings, Genetic Testing, Bioethics, DNA

### 1. Main text

Gene editing technologies exist for decades but gained significant momentum until the development of engineered nucleases resulting in cost effective, precise and user-friendly editing.<sup>1</sup>

Designer babies or Savior babies are genetically matched babies created through In Vitro Fertilization (IVF) in accordance with a Pre-Implantation Genetic Diagnosis (PGD) which acts as a donor for a sick sibling. In the future, hematopoietic stem cells from bone marrow, umbilical cord, and peripheral blood of the savior sibling will be used in invasive procedures such as multiple bone marrow transplants or even organ transplants.<sup>2</sup> The PGD procedure is usually carried out on day three, where the embryo is around six to ten cells in size and is screened to prevent inherited disorder. One cell is sucked out from the embryo using a thin pipette and screened for the probability of developing a genetic disorder. Genetic testing of the embryo can be done via PGD to find out whether it is affected by a genetic condition. Technologies like tissue typing make it possible to confirm the compatibility of the donor for an existing child and also to select between embryos. PGD avoids abortions if prenatal testing reveals that the fetus is not tissue-compatible in case of using natural conception to attempt to conceive a donor child.<sup>3</sup>

Parents vaccinate their children, monitor what they eat to keep them healthy, teach and discipline them when they disobey/ misbehave in order to carve them in to intellectually curious and better human beings. Gene editing is controlling what our children will be like rather than shaping children to be better individual. Creature a parent shapes a kid, but changing a child's DNA to create a flawless being is undesirable. The primary concern with this technology is the unanticipated and damaging safety concerns.<sup>4</sup>

Few religious institutions and individuals consider this technique as manipulating what is believed to be God's creation—human life. Bioethics is devoid of religious convictions, yet respects people's perceptive. Therefore, whether or not to embrace preimplantation genetic screening or in vitro fertilization is a personal choice.<sup>5</sup>

The savior child is born with a major mission of saving his/her sick sibling which has been predetermined by own parents and doctors. The donor kid's bone marrow will be removed while he or she is quite young for the ailing sibling. If necessary, even the savior child will be asked to donate a kidney. They will be used as organ banks as they are the perfect match for the sick child. They will be coerced into donating against their will by their own parents throughout life. Hence children are being used as commodities.<sup>6</sup>

The first Savior Sibling in the world was Adam Nash born on August 29, 2000, in the U.S to save his sister who was suffering from Fanconi Anemia.<sup>2</sup>

India's first savior sibling was Kavya Solanki, born on October 2018 to save her brother who was suffering from Thalassemia major.<sup>7</sup>

"My Sister's Keeper", a book by Jodi Picoult describes the life of a savior sibling being born for her sister. In 2009, a Cassavetes-directed film based on this novel was released. They narrated the circumstances of the mother, father, sick child, donor child, and brother. They presented the numerous ethical ramifications of gene editing techniques.

In a review by Seldom S et al. (2004), discussed the chances of stepping into a slippery slope if this procedure is permitted. Permitting or accepting new interventions might be less risky at times, but it could lead to major consequences in the future.<sup>8</sup>

Parent's reason for having a second child evolves around the first child. They require a matched tissue-type second child who could save the ailing first child. Prospective parents have several grounds for having a child or a second child. It could be for the sake of family harmony, to protect the firstborn, to produce a kid with desired qualities, or even just to keep the firstborn company. Children have rather be used as commodities. The causes of procreation might be addressed using the right to reproductive autonomy and the non-maleficence principles.<sup>9</sup>

In 2019: The Indian Council of Medical Research, in consultation with the Department of Biotechnology and the country's top drug regulator, the Central Drugs Standard Control Organization, drafted a law banning germline gene editing and prohibiting the use of gene editing to induce "unnatural advantages" like enhanced physical functions or selection of particular traits to create designer babies.<sup>10</sup>

## ***METHODOLOGY***

### **Search Strategy**

A comprehensive literature search was carried out in various electronic databases.

From an initial search of articles from the databases, studies and review articles related to the ethical theories and principles perspectives were identified. From the cross references of those articles, certain key words and their corresponding MeSH terms were identified. Also depending on the study title, its aim and objectives other potential articles were selected. The following are the MeSH terms and keywords selected:

1. Preimplantation Diagnosis
2. Gene Editing
3. Siblings
4. Genetic Testing
5. Bioethics
6. DNA
7. Savior Sibling
8. CRISPR

## ***DISCUSSION***

In this context, we would like to explore and understand designer babies or savior siblings from ethical theories and principles perspectives.

## ***ETHICAL PRINCIPLES***

### **Autonomy**

Self-determination – An autonomous individual is in charge of their thoughts, feelings, and behaviors. The acts, conduct, and inner life of an independent person are within their own control. According to the Kantian principle of respect for persons, every person should be respected and appreciated. Everyone ought to appreciate one another's choices. The right to autonomy is among the fundamental rights where an individual should have the decision-making potential as long as it doesn't harm others. Harm indeed the primary obstacle to autonomy. When autonomy is implied in health care, a competent individuals should be free to accept or refuse any actions that affect their lives.<sup>11</sup>

A review article by Rubeis et al. (2019) states that respect for autonomy is a key concern when it comes to the treatment of the savior sibling and is obtained via informed consent. Informed consent is not feasible due to the child's age. Competence is one of the components of informed consent which implies the capacity to make health-related decisions. In this scenario, it's not possible to consider the child competent enough to make decisions. Parents being legal guardians take decisions, which may or may not align with the child's wishes. Thus, it truly depends on the parents as the child is not competent to make health-related decisions. Understanding medical information is another element of informed consent and it might be challenging for a child to grasp the nature, scope, and consequences of the proposed procedure. Therefore, it is impossible to imply one's autonomy i.e., self-determined decision. Furthermore, voluntariness is crucial to informed consent. The overt or covert pressure exerted on the savior sibling threatens their voluntary decisions. It may be implied that their decision will affect their sibling's life. Their life depends on the decisions that were made before birth by their legal guardians. The therapeutic team falls into a dilemma as to whether to act against the child's will. The child's autonomy is violated as these crucial elements are not provided. The savior sibling's choice of refusal makes the situation controversial even though the legal guardians want the procedure to be performed.<sup>12</sup>

Bennet et al. (2013) in their review article point out that a savior sibling might be treated as a means to an end.<sup>3</sup>The violation of the Kantian ideal of treating individuals with respect and not as objects have been put forward in the review article by Dickens et al.(2005) He emphasizes the fact that not

for this purpose did they hadn't being born and the purpose of their life is entangled with the reason for their birth.<sup>5</sup> Even the savior sibling has the right to live their life to the fullest.

### **Non - maleficence**

Non-maleficence which is defined as doing no harm is a fundamental moral principle although is not always adequate to govern human behavior. An action cannot be deemed moral if it results in harming a person or group. The Hippocratic oath says, "primum non nocere", which means, "First do no harm" The ADHA Code of Ethics states, "We accept our fundamental obligation to provide services in a manner that protects all clients and minimizes harm to them and others involved in their treatments".<sup>11</sup>

Rubeis et al. (2009) in their article bring out the numerous health risks posed by gene editing: like every surgical procedure is supervised by certain anesthetic hazards, risks related to bone marrow extraction, additionally, transfusion risks also exist in this condition. The health hazards of intervention are often acceptable as long as the benefits outweigh the dangers. Other than the psychological or emotional benefits of saving his/her sibling, the child is not benefitted from any of the procedures. The principles of non-maleficence might be regarded as a defense against medical intervention as the emotional satisfaction or benefits don't outweigh the medical risks.<sup>12</sup>

Brokowski et al. (2019) in the review article described the various undivulged health hazards such as limited on-target editing efficiency, inaccurate on- or off-target editing and mosaicism are the possible technical limitations that have already been reported in animal and human-line cell studies. This procedure evolves at an unpredictable pace.<sup>13</sup>

Dicken et al. (2015) in their review article states that adapting the PGD procedure would result in the discarding of several healthy embryos, as they lack particular gene or other necessary traits.<sup>5</sup>

In a review article by Strong K A et al (2011) discussed the psychological harms encountered by savior babies, sick child, and parents. Psychological harms are indeed unforeseen and inevitable. Post-traumatic stress and anxiety are among the psychological problems that the savior sibling has to deal with. They might even fail to understand the role played in sibling's life.<sup>14</sup>

### **Beneficence**

Acting in the patient's best interest is the essence of beneficence.<sup>16</sup> Strong K et al. in the review article (2014) state that it is impossible to consider both the sick child and the donor child's best interest. Choosing the sick child over the donor child or vice-versa would end up with both sufferings severe health issues.<sup>15</sup> Beneficence is not merely avoiding harm but also ensuring all the benefits to patients. There is an assessment of the risk-benefit ratio-thus focused to minimize the former and maximize the latter. They do seek the benefit of the sick child but not the savior child.<sup>2</sup>

A savior child would be a source of spare parts as the grounds for having children are complex and varied. They could also be held accountable for unsuccessful transplantation. Even they lack the right to refuse and their sufferings during the procedures are seldom acknowledged.<sup>9</sup>

The Review article by Dickens et al. (2015) consider gene editing as an extremely riskier and challenging task to create a genetically compatible embryo and proposes the possibility of producing surplus embryos. The extra embryos produced are of no use. The surplus embryos should be used for other beneficial alternatives rather than discarded, thus maximizing the benefit. The couple's consent should be obtained as utilizing them without their consent is unethical.<sup>5</sup>

Sheldon s et al.(2004) claim that we are obliged to the welfare of any child created while deciding on reproductive technologies.<sup>8</sup>

### **Justice**

The review article by Jacob et al. (2022) describes justice in health care as distributive justice where people will be treated equally and fairly. People should be treated equally regardless of who they are in every given situation. Everyone has the right to access all the medical interventions and healthcare nevertheless who they are and where they belong to.<sup>16</sup>

A review article by Ormond et al. (2017) proposes the people's affordability to this technique. Wealthy people could be able to afford the selection of desirable traits in their offspring while those of lower economic standing wouldn't be able to access the same options. As a result, economic divisions may grow into genetic divisions with social distinctions. The currently existing inequalities in society would exaggerate if this procedure succeeds and is clinically implemented.<sup>17</sup>

This procedure is expensive, restricted geographically, and may not be covered by many health systems. It is also not possible to provide this procedure at the Primary health care level. Thus, equality is in doubt in a country with a diverse population like India. Genetic diseases, a condition that used to affect everyone equally could turn into an artifact of class, culture, and geographic location.<sup>17</sup>

The savior child should also be treated equally, fairly, and accepted by the public even if they were born for a reason.

### **ANALYSIS**

Everyone is terrified of losing their loved ones, which results in opting for drastic steps. The ray of hope never dies, but not at the cost of someone's life. Even though the savior sibling's birth was for a purpose, the suffering cannot be neglected. Knowing the truth about their birth would be challenging to

endure, and continuing to live without any autonomy wouldn't be ideal. Despite the fact that birth cannot be chosen, everyone has the right to live as they like.

A slippery slope will undoubtedly result from gene manipulation. Gene editing is the permanent alteration of the gene to prevent occurring of certain disorders in the future. Thus, these alterations were passed on to the next generation. There are a lot of unforeseen dangers entangled with this procedure.

This process is associated with unanticipated and unheralded risks. Numerous medical treatments are physically and emotionally agonizing. There are adverse effects to every procedure. The ill and savior siblings are both predicted to have different health risks. The savior baby is forced to undergo painful surgical procedures. A medical health hazard is accepted if it outweighs the dangers. Thus, violating one of the principles of ethics- non-maleficence.

It also infringes on the child's autonomy. The child may not have the right to decide whether to undergo any medical intervention. Despite that they receive no benefits; instead, struggle with psychological, physical, and mental issues. Parents act paternalistic.

Utilitarianism aims to maximize pleasure and usefulness, concentrating more on the outcome rather than the nature of the action. Despite the unanticipated hazards, gene editing can treat unwell children. Actions are justified based on maximizing happiness in the world. Deontology emphasizes abiding by rules. Despite the favorable results, people should adhere to the rules. Opting for medical intervention should focus on whether it is right or wrong. Gene editing is not an option for everyone since it is a pricey procedure. As a result, there are disparities in accessibility, which will cause a societal divide. Justice is therefore transgressed. Access to all technologies is a right for each person.

## **CONCLUSION**

Every circumstance in which decisions concerning the care of sick children are made on the nature and intensity of parental love as well as the prospect of a loss. Influencing children's traits is not objectionable but rather the means to achieve is, that is choosing their genes. Medical innovations are always acceptable in the interest of a better future, but they should never be used to exploit or exploit others. A great deal of hope and new perspectives are made possible through gene editing techniques. Since it involves significant psychological, ethical, and legal concerns, this technology still remains controversial. The wise words of the bioethicist Jeffery Kahn: "We know people will do anything to save their child. Now we are learning what 'anything' really means" Therefore, legislation should be passed to protect designer babies or savior siblings

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