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Bilimsel Çalışmalar

Born to Keep Alive: The Moral Dimension of Savior Children

Anıl Öztürk¹

I call heaven and earth to witness against you today, that I have set before you life and death, blessing and curse. Therefore choose life, so that you and your offspring may live.²

To choose and protect life is arguably the only moral rubric that all members of the human race hold, despite all the differences stemming from national, cultural, political, philosophical, or religious identities. This immemorial principle not only creates a basic value standard but also imposes the duties to heal, to rehabilitate, and to save to the utmost. The fulfillment of these duties gets easier as diagnosis and treatment methods become more successful and effective day by day, one of the most important milestones in this direction being the possibility of curing a number of severe health impairments via tissue transplantation. In this context, the difficulties of finding matching tissue, together with the relative inefficiency of the transplants from unrelated donors compared to transplants from related donors for some of the said impairments,³ have directed parents to have another child, often referred as the savior sibling (or child), to provide the matching tissue for the treatment of their sick child. 4 While the success of such an attempt was entirely dependent on luck in the past decades, with the evolving prenatal genetic diagnosis (PGD) technology, it became possible to almost certainly ensure that the savior child would have matching tissue.⁵ Despite providing the only successful treatment option in some cases, the moral dimension of the subject of deliberate creation of savior children through PGD is far from reconciled and agreed upon. Therefore, in this work, ascertainment of the moral dimension (and boundaries) of the creation of savior children and what can be done to him/her is aimed through a survey of the arguments wholly against the deliberate creation of savior children and evaluation of the status of savior child in different contingencies.

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² Deuteronomy 30:19-20 English Standard Version (ESV).

³ Susan M. Wolf, Jeffrey P. Kahn and John E. Wagner, 'Using Preimplantation Genetic Diagnosis To Create A Stem Cell Donor: Issues, Guidelines & Limits' (2003) 31 The Journal of Law, Medicine & Ethics 327, 328.

⁴ Whitney Fasbender, 'The Savior Child: Having A Child To Save A Sibling...Is This Right?' (2009) 3 The Journal of Undergraduate Nursing Writing 18, 19.

⁵ Robert Sparrow and David Cram, 'Saviour Embryos? Preimplantation Genetic Diagnosis As A Therapeutic Technology' (2010) 20 Reproductive BioMedicine Online 667, 670.

Behind the 'Making' of the Savior Children: PGD Technique

PGD is a method developed alongside in vitro fertilization (IVF).¹ In the procedure of PGD, biopsies are taken from the embryos that have been fertilized in the laboratory environment and screened to identify genetic markers of the presence or absence of certain characteristics, to implant a selected embryo and discard the others.² The first use of this method was in 1989, ten years after the emergence of IVF, to preclude implantation of an embryo with serious illness genes.³ Over time, PGD has also been used for purposes such as sex selection of the baby in addition to the purpose of avoiding the implantation of embryos with the genetic code of a particular disease or disability.⁴ Ultimately, in 2000, for the first time, PGD has also been used to determine and subsequently implant a healthy embryo with matching-tissue type with an existing ailing child, with the intention to procure and transplant some of the tissues of child-to-be to the malfunctioning child.⁵

Debunking the Arguments of Inherent Immorality

There are a number of arguments opposed to deliberate creation of savior children, all assessing that the said phenomenon is inherently contrary to morality; but basing it on different grounds.

The first argument claims that a savior child is conceived as a means to cure another child, rather than as a person to his or her own ends.⁶ Proponents of this argument predicate it on the moral principle of Kant, 'Act so that you treat humanity, whether in your own person or in that of another, always as an end and never as a means only'.⁷ To them, procreating a savior child connotes bringing forth a tool to rehabilitate the ailing child and hence opens a new door into instrumentalizing a person to achieve the purposes of others.⁸ This argument is erroneous for three reasons. Firstly, Kant attributes personhood to rational beings.⁹ That being the case, as neither the embryos nor the newborns-to-be are capable of

⁴ Shenfield (n 5) 313.

¹ Françoise Shenfield, 'Ethical Aspects Of Preimplantation Genetic Diagnosis' (2008) 18 Obstetrics, Gynaecology And Reproductive Medicine 312, 312.

² Marian D. Damewood, 'Ethical Implications Of A New Application Of Preimplantation Diagnosis' (2001) 285 JAMA 3143, 3143.

³ ibid.

⁵ Amy T. Y. Lai, 'To Be Or Not To Be My Sister's Keeper?' (2011) 32 Journal of Legal Medicine 261-293 261.

⁶ Natalie R. Ram, 'Britain's New Preimplantation Tissue Typing Policy: An Ethical Defence' (2006) 32 Journal of Medical Ethics 278, 279.

⁷ James Rachels, *Elements Of Moral Philosophy* (Random House 1986) 114.

⁸ Ram (n 10) 279.

⁹ 'free agents capable of making their own decision, setting their own goals, and guiding their conduct by reason' Rachels, (n 11) 116.

reason, it is possible to assert that conceiving a savior child lies outside the scope of the moral principle of Kant. Secondly, even when conceiving a savior child is regarded within the scope of the said moral principle, it is not possible to allege that the (s)he is solely a means to end. On the contrary, it can be suggested that as the parents go all out to cure their sick child, they would have a 'caring and loving' attitude; rendering it almost impossible to claim that the savior child sibling would be treated solely as a means to end and would not be valued for his or her own sake. 1 As a matter of fact, a number of anecdotes confirm that savior siblings do receive 'necessary love and care' and are valued for their own sake.² Thirdly, even outside the context of savior siblings, many parents have babies partly with other intentions, such as 'continuity of the family name's, 'inheriting the family business',4 'economic and psychological benefits at the old age'5 and 'benefits for the relationship between parents'.6 Indeed, it is not possible to ensure that the child is conceived for his or her own sake and without any other intention for any birth. Therewithal, the attitude towards the child, not the intention behind having one, is acknowledged as a moral measure for the births outside the scope of savior siblings. 7 Thus, concentrating on the intention in regards to the procreation of savior siblings would be conclusory and unfair. To sum up, arguing that procreating savior siblings would be immoral as the savior child is conceived to be an instrument seems to be without merit.

The second argument is about the moral status of the embryo, stemming from the fact that the PGD process includes the creation of multiple embryos and the destruction of them except for the selected embryo. To this argument, from the moment of fertilization the embryo has a moral value and thus no embryo should be deliberately destroyed. Those who advocate this view can be divided into two. The first group claims that 'the embryo should be entitled to full moral status from the moment of fertilization'; basing this claim on the postulation that embryo has the potential to become a human being from the moment of fertilization. The claim of this group can easily be debunked, since the underlying postulation is flimsy: The embryo indeed has the potential to develop into a human being,

¹ Katrien Devolder, 'Preimplantation HLA Typing: Having Children To Save Our Loved Ones' (2005) 31 Journal of Medical Ethics 582, 584.

² ibid.

³ ibid 585.

⁴ M Spriggs, "Saviour Siblings" (2002) 28 Journal of Medical Ethics 289, 289.

⁵ Devolder (n 14) 584.

⁶ ibid.

⁷ ibid 586.

⁸ Bartha M. Knoppers, Sylvie Bordet and Rosario M. Isasi, 'Preimplantation Genetic Diagnosis: An Overview Of Socio-Ethical And Legal Considerations' (2006) 7 Annual Review of Genomics and Human Genetics 201, 203. ⁹ ibid.

but only when it is in the mother's womb. Until its implantation into the womb, it is just a group of cells on a petri dish and it cannot show any differentiation or development apart from, maybe, mitotic division. If an indispensible condition for development into an human being such as implantation in the mother's womb could be neglected when attributing the potential to develop into a complete human being, then there is no obstacle to ignore another condition, such as fertilization and to attribute full moral status to the reproductive cells, and even to the organic molecules which have the potential to develop into reproductive cells and eventually into complete human beings. The second group propounds that 'the embryo has some moral status from fertilization, but to a lesser extent than a born human being, and gradually acquires full moral status during development. Since employment of the PGD/IVF for the creation of a savior child provides for the enhanced likelihood of the survival of the ailing child (who has full moral status), destruction of the embryos (which have lower moral status) during these processes should be admissible in reference to the argument of this group. In conclusion, as attribution of the full moral status of the non-implanted embryo is absurd, and attributing any lower moral status renders its interests dispensable in the face of the ailing child's interest in survival, the argument about the moral status of embryo are not able to preclude deliberate creation of savior siblings.

The third argument is that allowing creation of savior siblings through PGD would lead up to the creation of 'designer babies'. Advocates of this argument assert that allowing preference of the embryo with matching tissue to be implanted is the first step onto a 'slippery slope' to the preference of embryos for non-therapeutic reasons, which, in turn would appall social diversity and lead to stigmatization of people with disabilities or any minority whatsoever, endangering the future of mankind and entailing irreversible damage to the society in the long run. It is worth noting here that some of them even hold the predetermined creation of savior babies through PGD technique equal with the creation of designer babies and condemn it as a method of 'reproductive discrimination'. This argument is not very strong as well. To begin with, it is an extreme and faulty generalization to evaluate the use of PGD for the detection of embryo with matching tissue under the same category with its non-therapeutic uses such

¹ Kristie Lauren Trifiolis, *Savior Siblings: The Ethical Debate* (Seton Hall University 2014) http://scholarship.shu.edu/student_scholarship/432> accessed 24 April 2017 3.

² Knoppers (n 21) 203.

³ To clarify, 'designer babies' imply the human embryos that have been genetically engineered to have preferred characteristics, such as sex, cosmetic traits like eye color, or abilities. Lai (n 9) 266.

⁴ Ram (n 10) 281.

⁵ Lai (n 9) 267.

⁶ Spriggs (n 17) 289

as determining the baby's hair or eye color (or any cosmetic character). Although both purposes involve the selection of an embryo among others, it is fairly easy to avoid the use of PGD for non-therapeutic purposes by the implementation of well-prepared regulations and functioning control mechanisms. ¹ In the second place, in terms of risks related to social harm and the future of mankind, it is obvious that choosing an embryo that does not carry a certain disease or has a compatible tissue is not the same as a custom-design baby. In the case of using PGD for therapeutic purposes, as the selection would be made on solely basis of tissue-compatibility, it is not likely to prejudice social diversity. ² On the contrary, the therapeutic use of PGD is even of social benefit due to the decrease in child mortality rates and positive effects on general health it entails. In the last place, since PGD is ultimately only a technique of screening and selection, it is not a suitable technique to create 'designer babies' in a real sense; with PGD, one of the possible babies is selected from amongst others, and no 'design' is made. Thus, the technology used to determine savior babies is not suitable for realizing the fear of 'designer babies'. ³ In sum, this argument is weak as it is based on a misunderstanding of how PGD works and what it is capable of. The concern posed by this argument can be overcome by limiting the use of technology to therapeutic uses and it is not sufficient to interpose the creation of savior babies.

Thereupon, since all of these arguments that claim the inherent immorality of deliberate creation of savior children are invalidated in the face of simple analysis, and as the said practice pursues the high moral objective of saving a human life along with providing a strong likelihood for the realization of this objective, it should be established that the deliberate creation of savior siblings is not per se immoral, and quite the contrary, has a moral worth.

Situating Moral Boundaries

Although the deliberate creation of savior children is not inherently contrary to morality; its moral conformity and moral worth is not unlimited, as the moral rubric 'to choose and protect life also includes not to purposively harm other human lives. For this reason, when the moral boundaries of practice are

¹ In this respect, it is possible to observe relatively successful practices in Australia and the UK. Trifiolis (n 23) 16-17

² M Spriggs, 'Is Conceiving A Child To Benefit Another Against The Interests Of The New Child?' (2005) 31 Journal of Medical Ethics 341- 341.

³ The situation that can lead to this fear may be overuse of gene-editing (CRISPR, etc.) technology; however, since the gene-editing technology has not yet been used on human embryos, and the capabilities and dangers it entails are yet unknown, speculations over gene-editing technologies are out of the context of this work. Aparna Vidyasagar, 'What Is CRISPR?' (Live Science, 2017) http://www.livescience.com/58790-crispr-explained.html accessed 24 April 2017.

being situated, it must be ensured that another human life would not be subjected to potential danger of any irreversible and/or serious damage. Considerations regarding the sick child's situation such as the psychological burden (the feelings of debt) can be ignored, as the benefit obtained from such a process is survival. Likewise, the situation of the parents and other siblings are irrelevant as their situation cannot be worse than the situation of not having a savior child, even if the transplant fails. Therefore, it is evaluated that only the situation of the savior child should be considered when determining the mentioned boundaries. In this respect, in this part of the study, firstly the situation of the savior child will be examined in various possibilities and the moral boundaries of the process will be drawn on these possibilities.

The first question in terms of the savior child's state is that whether the PGD damages the selected embryo. The worry here is the effects of the embryo biopsy and subsequent implantation, on the health of the savior child to be born. These effects can be examined in two dimensions, birth defects and long-term risks. With regard to birth defects, recent studies express that neither embryo biopsy nor implantation presents a greater risk than normal pregnancy in terms of birth defects. When it comes to the long-term risks, there is no scientific data as the relevant technologies are still too new for surveillance of their long-term effects. Although some authors suggest that it should be acknowledged that long-term risks might be present, as the children born through these methods have not yet shown any health problems that can be associated with the use of them, and since there is no scientific data pointing such a possibility; there is no justification for accepting that these methods can be harmful in the long run. Thus, the worry that the savior siblings may be exposed to a birth defect or a risk in long-term due to the technology used for his or her conception can be overlooked.

The second question is that whether the harvest of the tissue from the savior child damages or endangers the child's health. This question can be analyzed separately for the invasive and non-invasive harvesting, assessing the effects on the child's physical and psychological health of each. To begin with; non-invasive harvesting can be defined as harvesting the tissue without any interference to the body of the child; connoting stem cell transplant from umbilical cord blood or transplant from placenta.⁵ As the harvesting

¹ Ram (n 10) 278.

² Devolder (n 14) 583.

³ ibid 584.

⁴ Devolder (n 14) 583; Ram (n 10) 279.

⁵ Wolf (n 2) 334.

is made from the umbilical cord or placenta (which are otherwise considered as waste),¹ without even touching hair of the child, it is not possible for the child to suffer any physical harm from it. ²Moreover, as the perceptive abilities of a newborn are minimal, it is not expected that the savior child would be psychologically affected by the non-invasive harvesting procedure alone.³ To continue, if an invasion to the body of the child is required for harvesting the tissue, that can be identified as invasive harvesting, such drawing blood from the child, or harvesting bone marrow or an organ.⁴ In order to analyze the effects of invasive harvesting on the health of the savior child it is necessary to examine its different parameters. First, it should be assessed that which tissue would be harvested. In this context, drawing blood from the savior child is regarded to pose negligible physical and psychological risks. Bone marrow transplant, however, carries some non-ignorable risks, both physical and psychological. Physical risks involved with bone marrow transplantation can be exemplified as 'infection, risks associated with general anesthesia, pain and discomfort'. Furthermore, studies have identified a number of psychological effects of bone marrow transplant on the donor child, namely feelings of 'guilt and a sense of responsibility for saving the sibling's life'.6 In respect of solid organ harvesting from the savior child, as solid organs are generally not regenerative, both physical and psychological risks are identified to be even more substantial.⁷ Hence, it can be suggested that in invasive harvesting; the physical and psychological impacts on the child's health differentiate with regard to the tissue harvested and the complexity of invasive surgery. The likelihood of damaging the child's health and consequently wellbeing increases from drawing blood to the solid organ harvest. Secondly, whether the invasive harvesting would occur for once only or repeatedly should be taken into consideration. The abovementioned adverse effects and risks of invasive harvesting are expected to increase exponentially with the repetition of invasive harvesting of the relevant tissue.8 In addition, it is suggested that the savior child would feel more vulnerable, stressed and under pressure in repeated harvesting.⁹ Thirdly, the age at which the child is exposed to invasive surgery should also be considered. Here, it is suggested that as the child grows older, the physical risks would remain unchanged while the psychological impacts would

¹ Ram (n 10) 280.

² Spriggs (n 30) 342.

³ Wolf (n 2) 334.

⁴ Ram (n 10) 280; Wolf (n 2) 334.

⁵ Wolf (n 2) 334.

⁶ ibid.

⁷ ibid.

⁸ ibid 335.

⁹ ibid 336.

increase, as the bodily awareness and emotional perception of the child develops with age.¹ Accordingly, in invasive harvests from older children, it is determined that the child would feel more anxiety and fear before the surgery in comparison to harvests made from younger children.² Additionally, the child might feel coerced, under pressure, and even abused or used when the harvest is made at an older age, potentially affecting the self-worth of the child.³ Thus, it must be acknowledged that the risk of irreparable psychological trauma in the savior child increases with the age of surgery. To sum up, then, it is necessary to recognize that invasive harvesting procedure alone may cause adverse physical and/or psychological effects on the savior siblings depending on the parameters such as the type of the tissue harvested, the number of invasive surgeries and the age of the child.

The third question is that whether the sick sibling is recovering, or, in other words, whether the treatment has been successful or not. Whether the ailing sibling's condition improves or not is likely to affect the wellbeing of the savior sibling in terms of psychological health. If the treatment has been successful, it is suggested that the savior child would be positively affected as (s)he would have 'the chance to grow up in an intact family, with a sibling, and (s)he has contributed to saving a life.' Indeed, several studies point out that, where the treatment has been successful, savior children feel pride and contentment.⁵ That being said, it is also suggested by some authors that successful treatment can also lead to rivalry or jealousy between savior child and non-donor siblings.⁶ Nevertheless, it should be concluded that a successful treatment would generally affect the savior child's psychology positively and will not cause any traumatic negative effect. On the other hand, however, if the treatment fails and the ailing sibling dies, the psychology of the savior sibling is very likely to be negatively affected. For this scenario, it has been reported that the feelings of stress due to the inability to help and powerlessness may harm the child's psychology in addition to the psychological burden of growing up in a family that is experiencing the perpetual grief of losing a child.⁷ In some cases it has been determined that the psychological trauma of the unsuccessful savior child has reached the extent of 'complete loss of sense of self and purpose in life'.8 Hereunder, it should be noted that one of the strongest factors in the

¹ ibid 333.

² P Baetens and others, 'HLA-Matched Embryos Selected For Siblings Requiring Haematopoietic Stem Cell Transplantation: A Psychological Perspective' (2005) 10 Reproductive BioMedicine Online 154, 160.

³ ibid 161.

⁴ Knoppers (n 21) 213.

⁵ Lai (n 9) 268.

⁶ ibid 269.

⁷ Baetens (n 47) 159.

⁸ Lai (n 9) 269.

probability of unsuccessful treatment has been eliminated by the ability of selecting and implanting the embryo with matching tissue, provided by the PGD technique; although a treatment might still fail for other reasons than tissue mismatch. In brief, it can be concluded that the success of the treatment is a decisive factor for the psychological wellbeing of the savior child.

The fourth question is the family's attitude. This question can be discussed in two contexts. First, it should be assessed that whether the serious illness of the first child disrupts the functioning of the family, as it is not unexpected that parents can concentrate on the condition of the sick child and neglect the needs of the other siblings. This might lead to a lack of expression of necessary care and love for the other siblings, thus causing some psychological problems for them.² This possibility, of course, is also the case for the savior sibling, especially when the transplant from umbilical cord blood has not been successful and subsequent transplants are required. Although a report suggests that such a problem is not experienced in the majority of affected families, there is a significant minority that cannot be ignored.³ Secondly, it should be considered how the parents behave with the savior child. The concern in this regard is that the savior sibling might be told that (s)he is spare parts or insurance, or might be treated as such.4 To elaborate, it is feared that the savior child might be subjected to harvesting procedures that are likely to harm the child, (s)he might be manipulated into donation, forced against his/her will, or (s)he might be exploited in any way. 5 There is no scientific or anecdotal evidence to confirm this concern, and moreover, it is not reasonable to think that parents who face any difficulty to save a child will exploit another child, or even act to their detriment in any way. In that case, it can be claimed that although the fears about exploitation of the savior child are unwarranted, the concerns about (s)he might be neglected are not quite so.

From this analysis, it is possible to situate the moral boundaries of the process of deliberate creation of savior siblings and what could be done to them. Although some authors suggested that all kinds of interventions can be made other than those pose deadly risks to savior child because (s)he has the great benefit of being in existence,⁶ it is not possible to agree with them due to the injustice and inequality

¹ Baetens (n 47) 160.

² ibid.

³ ibid.

⁴ Wolf (n 2) 334.

⁵ ibid.

⁶ Robert Boyle and Julian Savulescu, 'Ethics Of Using Preimplantation Genetic Diagnosis To Select A Stem Cell Donor For An Existing Person' (2001) 323 BMJ 1241, 1242.

their claim gives rise to, and furthermore as it is not possible to ascertain whether existence is better than non-existence. Then, the moral boundaries of practice should be the situations that pose extraordinary risks to the savior child. In this regard, first of all, it is outside the moral boundaries to have a savior child in cases where the possibility of the death of the sick child, despite the treatment, is very high. In addition, it is not also moral to have a savior child where a solid organ donation is absolutely necessary for the sick child, because of its high risks for the savior child. Secondly, for the moral conduct after the birth of savior child, invasive harvesting from the savior child should be limited to harvesting of regenerative tissues, (eg bone marrow) and experts must evaluate the effects on the child's health and psychology before any harvesting. Since the will of the child is at least emotionally under pressure, even if not for any other reason, no determinative influence should be given to the consent or assent of the child in any case. Thirdly, before the savior child is made the functioning of the family should be corrected and both the savior child and family should receive psychological support throughout the whole process to minimize the risks of psychological harm.\(^1\) Apart from these, it would be appropriate to encourage the creation of a savior child through PGD, instead of natural conception, as to eliminate the potential psychological harms of the creation of a non-matching tissue type savior child.

Conclusion

In conclusion, it can be stated that there is nothing inherently immoral in the deliberate creation of savior children through PGD, and furthermore, it is morally preferable for some cases over its alternatives like natural conception. On the other hand, it is clear that for the moral conduct of the process, there are some boundaries, especially considering the situation of savior child and social concerns. Some of these boundaries require the limitation of the use of PGD to therapeutic purposes and perhaps to allow it for the creation of savior child only when treatment is likely to be successful, whereas the others necessitate the measures to be taken to ensure the physical and psychological wellbeing of the child is maintained. In this context, neither the lack of regulation regarding the use of PGD in the United States,² nor the entire ban on it in Germany, Switzerland, Ireland, Western Australia, and Austria is acceptable.³ On the other hand, the regulation and control mechanisms in Australia and the United Kingdom, specifically the guidelines of HFEA and ITA are in line with the moral boundaries

¹ Baetens (n 47) 160; Wolf (n 2) 334.

² Trifiolis (n 23) 17.

³ ibid 15.

outlined here as for the limits of harvesting,¹ and the focus on the wellbeing of the savior child, and not permitting the use of PGD for non-therapeutic purposes.

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¹ Wolf (n 2) 329.

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