EMBRYO SELECTION TO SAVE THE LIFE OF AN ALREADY-BORN

Carolina Neiva Domingues Vieira de Rezende
Pontifícia Universidade Católica de São Paulo (PUC-SP)
São Paulo – SP
http://lattes.cnpq.br/9429603493209338
Abstract: When parents are faced with the information that their child is likely to die if they cannot find a compatible donor, considering that the chance of an HLA match between siblings is relatively high (25%), they may decide to have another child in the hope that the child will be able to donate the cell stem or organ for the sibling after birth. However, can they select an embryo to ensure this compatibility? The situation discussed here will examine the ethical aspects of selecting an HLA-compatible embryo with an individual in a debilitating condition so that the individual from the selection is a donor of material that can help in his treatment. The possibility is discussed considering the possible physical and psychological risks involving the selected child. To do so, the possible risks and expected benefits are weighed with the principles of bioethics, especially those of non-maleficence and beneficence.

Keywords: embryo selection; embryo; compatibility; bioethics; law.

DISCUSSION

A set of concerns concerning the selection of an HLA-compatible individual with an existing sibling considers possible distortions that the selection could generate in the relationship between the siblings involved (donor and recipient) and between the selected child and their parents.

Maroja and Lainé (2011) draw attention to the fact that, in psychoanalysis, it is impossible to speak of prediction; thus, it would be more appropriate to speak of possible psychic risks. It could be suggested that the compatible baby is subject to psychopathological risks.

In the case of siblings, the concern is that a relationship of eternal debt could be established between them. So far there seems to be no empirical research in the scientific field that reports the psychological impact on children selected to donate HLA-compatible material to a sick sibling, research related to the psychological impact on non-selected sibling donors (that is, existing ones) will be explored. when the need arose and the impact of this donation on their lives. This way, we can discuss it in a reasoned way.

In research carried out by Oliveira-Cardoso et al. (2010) with twenty bone marrow donors, the reaction when they were informed about the possibility of bone marrow transplantation to their brother due to HLA compatibility emerged as a reassuring factor for 70% of them and as an event that triggered anxiety for the other 30%.

Positive emotions arose from excitement about being compatible and contributing to helping a family member, as well as relief that something was being done (PILLAY et al., 2012). The main causes for anxiety, in turn, are linked to the difficulties inherent to the procedure: nineteen of the twenty donors considered general anesthesia the main source of anxiety, fearing “not coming back” after being induced by the anesthetic.

Respondents also mentioned deaths resulting from transplantation complications for the recipient, even though this is a rare event. In four of the donors interviewed, fanciful answers still emerged regarding the implications arising from the donation process, such as the fear of drying up all the blood, of transmitting personality characteristics to the recipient, or of becoming impotent after the act of donation. Confusion between bone marrow and spinal cord was also found and identified as common, which made some of the donors afraid of becoming paralyzed.

As can be seen, the discomfort with the idea of undergoing the bone marrow donation procedure is related to the lack of knowledge about the procedure and its real risks, which could be solved with the help of qualified professionals, who could explain how it occurs and resolve any doubts that persist.
As demonstrated by Oliveira-Cardoso et al. (2010), the ambivalence between placing trust in the possibility of a cure and considering the outcome fatal permeated the donors’ discourse, making the donor siblings see the treatment as saving and threatening at the same time before the transplant was performed, which generated psychological impact and emotional ambivalence on the patient and his family.

The responsibility of having the burden of “saving the brother” placed upon him and the consequent impossibility of exempting himself from this responsibility proved, in some cases, to be oppressive and with the potential to lead to psychological anguish and anxiety symptoms in the donor. bone marrow (OLIVEIRA-CARDOSO et al., 2010)

Psychological damage to the individual may also occur because of the pressure to which he is subjected regarding the obligation to donate material to his brother – not only at birth but perhaps throughout his life.

According to results presented by Macleod et al. (2003), almost all siblings felt they had no choice in becoming donors. The basis of this perception, however, differs among donors: about a third of donors participating in the survey reported feeling that doctors and family members limited their opportunity to say no, making them perceive that they had a “forced choice”. The remainder of the donors in each group thought they had a “deliberate choice” as they did not see denial as an option due to their own beliefs about morality and death.

In interviews conducted by Oliveira-Cardoso et al. (2010), the embarrassment caused by pressure from the nuclear family and friends also appeared as a reason for accepting the donation charge, especially in those donors who did not have relationship difficulties with the patient. One of the interviewees commented on this: “I thought about not donating, but what was I going to say to my mother? My friends also advised me: your brother needs you... then I had no escape” (p. 6, our translation). Even so, several participants recognized in the interview that, although their decision to be a donor was not completely voluntary, they would probably undergo the procedure for donation purposes even without this pressure (MACLEOD et al., 2003).

One could ask whether these decisions were autonomous since they were influenced or pressured by the opinion of third parties. However, it is commonly accepted that illegitimate behaviors by others that can undermine willingness are force, coercion (threats), and undue inducement (HAWKINS; CHARLAND, 2020). If the case is just one of counseling – and the subject may, even if against the will of friends and family, have refused to undergo the procedure –, it is not considered an offense to the autonomy of the will.

In any case, in addition to prior, informed, free and informed consent, which is already customary for acceptance to submit to any medical procedure (which must, to be valid, respect the rules of veracity, privacy, confidentiality, and fidelity), suggests - even if this is not the central theme of the work - that there is psychological counseling so that the decision can be, in addition to being autonomous, conscious.

After the completion of the hematopoietic stem cell transfusion (HSCT), the donors differed a little regarding their participation. As the health status of the recipient often fluctuates after transplantation, the donor may remain in a situation of continuous stress.

When the transfusion was successful, sibling donors reported a predominantly positive impact on many aspects of their lives – including family relationships, worldview, feelings about themselves, and lessened
helplessness. It was also verified that the brothers reported having a closer relationship after the operation and rarely described any negative aspect in their experience as a donor (BAETENS et al., 2004; MACLEOD et al., 2003).

In cases where the recipient’s brother or sister developed serious and long-lasting complications with the procedure, however, negative emotions were reported, especially regarding the lack of support to deal with them. Although to a lesser extent, positive feelings were also reported; anger and guilt, however, were the most common emotions expressed by these donors.

For some participants, this guilt did not develop immediately but built up over time – especially in cases where they did not find the opportunity to discuss these thoughts with others. Research by Macleod et al. (2013) was conducted with adult individuals who donated as children. These reports have resigned what happened, but remember how, knowing that it was the last chance for their sibling to survive and realizing that all the effort had not worked, they felt guilty.

Pillay et al. (2012) also found similar results in their research with sibling donors between 2007 and 2010 in Melbourne, Australia: guilt and responsibility for the negative result were commonly expressed by participating donors – even if they had the understanding, at an intellectual level, that they did not were responsible for these results.

Although close donors not selected for this purpose may also be under pressure to continue donating (as many reported feeling), in the case of the selected child, parents, siblings, other relatives, and close people can act more incisively, emphasizing that its existence was given for this purpose and that, therefore, it must fulfill it. Thus, this person may feel an oversized responsibility regarding the survival of his brother, especially if he dies before it is possible to remove the organ or stem cells necessary for the treatment. Under these circumstances, agreeing to the donation can lead the individual to take risks that he would not have taken if it were not for the circumstances that preceded his birth.

The competence of children to consent to the donation of bone marrow or stem cells for transplantation has been a subject of some debate (DELANEY et al., 1996; MUMFORD, 2001) which has not yet been pacified. For reasons already explored earlier, however, we are considering here that the donation by an individual selected for HLA compatibility with his brother refers to cells from the umbilical cord, that is, that the situation to which the child is subjected will not cause him any harm. physical, being in consonance, therefore, with the principle of non-maleficence.

In psychological terms, it is not clear what the effects will be of knowing that someone has been selected as a donor. It may be that this knowledge is experienced positively, adding meaning to your life. It is possible that they feel that their existence is worthwhile not only for them, but also for a significant other person in their lives and that of their family members, and that they were able to help maintain their brother’s life – which seems plausible, to compare with experiences reported by unselected sibling donors.

As for the risk of possible psychological consequences arising from the feeling of “lack of alternatives” and the consequent “obligation” of being a donor, Baetens et al. (2004) point out that babies born to act as donors due to their HLA compatibility with siblings do not try them, since the choice was not theirs, but the parents’.

The discussion about this type of selection also raises questions about possible psychological damage to the selected child, due to how his relationship with his parents would develop. One of the arguments usually
advanced on this point is that the child may have a less intimate and loving relationship with the parents, who will be less likely to value him since they want him to save his brother’s life.

Murray (1996) states:

It would be ridiculous to argue that all children born of such arrangements are irreparably damaged, or their relationships with their rearing parents warped. But I do not think it is silly to worry about the net effect such practices have on our intimate relationships more generally, and on parent-child relationships in particular.

Taking advantage of Murray’s provocation, we will analyze a possible breakdown in the relationship between parents and selected children to provide HLA-compatible material for their brother.

Maroja and Lainé (2011) conducted interviews with women who were carrying HLA-compatible children with an existing child and realized that, in the reports of these mothers, pregnancy did not symbolize a moment of pleasure, but rather a passage to obtain a result (a compatible child).

The authors point out that, throughout the interviews, they did not perceive representations of these women as mothers of those children, who were rarely mentioned in themselves, and that the representations regarding the future of the child they were carrying were completely absorbed as a baby planned for healing.

As an example, the response of one of the interviewed mothers is cited, when asked if she had already chosen the name for her son, explained: “Perhaps Emanuel, he will be Emanuel if he is compatible with my daughter, and if he can do anything for her. This is the name of Jesus.”, adding that “if he is compatible, he will be welcome” (MAROJA; LAINÉ, 2011, p. 577, our translation).

Maroja and Lainé (2011) explain that maternal representations since pregnancy, in which the woman imagines and identifies herself as the mother of that child, are extremely important to build the future mother-baby interaction after childbirth. Based on this statement, the authors emphasize a possible disinvestment in the future baby that is not linked to the cure of the disease of the interviewee’s eldest daughter.

Even if it is considered that the motivating factor for having another child was the attempt to help an existing child affected by some serious illness for which the adequate treatment is the transplantation of HLA-compatible stem cells, this reason, by itself, is probably not enough to infer that the new child’s needs will be ignored. After all, people decide to have children for the most varied reasons (to experience pregnancy, to “save” a marriage, to give a child a sibling, etc.), and such reasons do not make parents not love their children or them, love less—nor that it was generated with merely instrumental value, as seen.

In the case of an HLA-compatible individual’s pregnancy with the existing child, there are even more reasons to believe that he will be very loved and cherished — as the already-born child is, to the point that the parents decide to change the family dynamics and plans by/for them established and have one more child — than neglected.

It is difficult to predict in advance how the parents will relate to the child selected to donate HLA-compatible material to his sibling. The fact that these parents put so much effort into saving the life of an existing child and their willingness to go through the process of parental construction entirely new — especially at a delicate moment like the one experienced by the parents at the time —, however, may be reason enough to make us believe that they are and will be extremely committed parents with the life of their new child.
One might think that, in cases where compatibility exists, some parents will doubly invest in that child, creating feelings of love and gratitude that will be linked to their dual role in this family: that of a baby belonging to their affiliation and who saved their brother, contributing to the well-being of the family. This feeling is perceived by some of the living donors, as reported by one of those interviewed by Macleod et al. (2003), who adds that, after donating and transplanting a stem cell to her brother, she felt that her father started to treat him with a kind of admiration.

At the other extreme, Maroja and Lainé (2011) also emphasize that the reason for the conception and birth of the selected child (providing the material that helps in the treatment of his already-born brother) can make the child potentially narcissistic for the mother. This situation, yes, could be, to a certain extent, harmful to the child, who would grow up in an overprotective environment, with parents depositing their fantasies of omnipotence and perfection in them, shielding them from any type of experience of pain or suffering, which it would harm her in the project of ascension to the status of subject and actor in her own life (ARAÚJO, 2010) and would cause the opposite effect to that initially intended. To prevent relationships of this nature, however, psychological support can be encouraged (or required).

The greater risk in psychological terms for the child, however, would reside in the chance that compatibility would not be verified, since, in this case, the frustration of the family, especially the parents, could be transformed into resentment towards the child. The risk, then, is that the family will not be able to appreciate him as a whole child in himself and that there will be regret for not having fulfilled the duty of being “born to save”.

The effects of having an individual born with a trait that differs from the selected one (i.e., HLA mismatch) should also be considered. It is feared that the child may reproach himself for being “another”, who should bring healing to his brother, condemning himself for not being born up to the parents’ desire. However, although in the case of selection by pre-implantation genetic diagnosis, there is a risk of the child being born without HLA compatibility with the sibling, it is negligible – which, compared to pregnancy without the test, can be considered an advantage.

One of the ways to prevent this kind of damage would be to require continued psychological follow-up with the family, to help them from the moment before the parents decided to have a child in these circumstances and even after the procedures (albeit conducted in a satisfactory and achieved the intended purpose).

It is important to make it clear that all these formulations regarding possible psychological damage to the individual selected to be an HLA donor for his brother or sister, however, are just hypotheses, which can be confirmed or discarded after empirical studies are carried out that deal with the behavior of the parents and his interaction with this child. The question of knowing whether the well-being of these children is influenced negatively (or positively, although only the former is a situation to be curbed) can only be answered when a sufficient number of children selected for HLA matching have grown up and are asked whether this fact influenced their lives.

Something that proves indispensable in cases where the individual is a donor for his or her brother or sister – and which would certainly also have to be expanded to eventual planned and selected births to donate material to a sick brother or sister – is the support (including professional support) to overcome feelings of diminished self-esteem and frustration with their role in the family. The assistance of psychologists to families...
with HLA donor babies can be, as highlighted earlier, of paramount importance in coping with the long-term effects, especially if the procedure fails.

As a way of reducing distortions about the responsibility of the selected individual in the healing process of his brother, as well as of the parents with their child, it is also relevant that clear information is made available regarding the risks involved, that there is guidance for families, to reconcile their desires and convictions with reality, and there is psychological follow-up throughout the process with those involved (parents, selected child/sibling and receiving child/sibling).

**CONCLUSION**

From the above, we can conclude that, as a mechanism to prevent the selection of human embryos for implantation in the mother's uterus for reasons of third-party health, it occurs in such a way as to cause damage to the selected child or to treat it in an instrumentalized way – which would conflict with the dignity that is (like everyone else's) inherent and must be guaranteed –, some requirements must be fulfilled. They are:

1. that the condition of the affected child that motivates the selection is serious enough and can be resolved with the existence of this new being.

2. that all other treatment possibilities and tissue sources for the affected child (such as the search for a related HLA-compatible individual and the search for a potential donor in a national and international database) have already been explored, this being the only alternative – or the least harmful.

3. that the selection of an HLA-compatible individual occurs for the donation of material through a non-invasive procedure.

4. that the individual resulting from the selection is not at risk for the condition that affects the existing child or for another limiting disease (otherwise, the individual selected would depend on the parents selecting another embryo that was compatible with it).

5. that there be parental and family counseling through psychologists and the discussion of the subject with a medical group - in which questions can be answered, doubts can all be solved, and curiosities satisfied.

This can avoid the regret of parents for whatever decision is taken, in addition to favoring the raising of the selected child about possible negative feelings in case of non-efficacy of the treatment or regarding its diminished value due to the circumstances that conditioned its birth.

Thus, we suggest that such requirements be present in future guidelines of the Council of Medicine or in a legal device that regulates the subject.
REFERENCES


