The Savior Child: Having a Child to Save a Sibling…Is this Right?

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Imagine you are a parent of a sick child who is dying from a severe medical condition and whose only chance of living is to find a near perfectly-matched donor for blood or marrow transplantation. Now, imagine you've been told there is a procedure which will allow you, as parents, to conceive another child that will be a perfect blood match to your sick child and will ultimately be able to save your child's life. Ethically, is this right?

Preimplantation genetic diagnosis (PGD) is a procedure that gives hope to desperate parents in the midst of losing a dying child. However, there are several ethical and moral issues concerning whether or not parents should be allowed to use PGD in order to create a child merely on the basis of saving the life of another child. This paper will examine the ethical issues surrounding using PGD in order to conceive a matched-donor child to save the life of a sibling.

Review of Literature

What is Preimplantation Genetic Diagnosis?

Preimplantation genetic diagnosis (PGD) is an early form of pre-natal diagnosis (Hashiloni-Dolev & Shkedi, 2007). It is a procedure in which a biopsy is taken from an embryo previously fertilized outside of a woman's womb to determine different characteristics about that embryo prior to in vetro fertilization and implantation. Its first reported successful use was in 1989, in a case in which it was used to avoid the implantation of an embryo that was "affected by a mutation or chromosomal abnormality associated with serious illness" (Wolf, Kahn, & Wagner, 2003, p. 327). Since then, PGD has controversially been developed and used for "family balancing" based on choosing the sex of a child and, most controversially, to "create a child who is Human Leukocyte Antigen (HLA)-matched with a preexisting sibling in need of stem cell transplants" (Wolf et al., 2003, p. 327). Using PGD in this fashion "allows a parent to

select an embryo free from serious genetic disease and simultaneously select for a tissue match so that the umbilical cord blood of the resulting baby can provide stem cells to treat a seriously ill sibling" (Spriggs, 2005, p. 341). Future marrow and tissue donation may also be expected from the donor child, which further intensifies the ethical debate.

Ethical Controversies Concerning PGD and the "Savior Child"

Wolf et al state that "PGD to avoid serious and early-onset illness in a child-to-be is widely accepted" (2003, p. 327). This is because the screening of an embryo will reduce the chances of parents having a child affected by a genetic or chromosomal disorder in which the parents may be faced with the decision of having to abort the child or live with the challenges associated with raising an ill or disabled child (Wolf et al., 2003). However, a controversy arises when using PGD solely for HLA typing because "when PGD is used to test for genetic diseases, that testing is done in the *best interest* of the embryo or the person it will become, whereas when PGD is used solely for tissue typing, the only benefit is for the existing sick child" (Devolder, 2005, p. 583). However, Devolder (2005, p. 583) believes, "PGD is not a cure, it is a selection procedure. An embryo is selected because of genetic characteristics it already had."

The basis of creating a child to save the life of another child is that "transplantation from an HLA identical sibling is associated with a much higher success rate than a transplant from alternative donors" (Devolder, 2005, p. 582). The ethical debate regarding this issue incorporates the extent to which a child can be expected to be a "life long donor subject to repeated tests and procedures" (Wolf et al., 2005, p. 330), as well as the risks associated with procedures and the extent of bodily invasion. According to Devolder (2005, p. 584),

> "…the standard employed is what would be acceptable if the donor child already existed. Umbilical cord blood harvest is widely accepted since it entails no physical intrusion. Bone marrow donations from young children to siblings are also widely accepted.

> Harvesting vital organs from children is not acceptable in view of the risks involved for the donor child."

To some, PGD to create a "Savior Child" is merely conceiving a child as an instrument to cure another child (Knoppers, Bordet, & Isasi, 2006). In today's society though, parents have children for all different sorts of instrumental reasons. Some of these reasons include benefits to the couple's marriage, continuity of the family name, economic and psychological benefits to the parents upon aging and providing a playmate for an existing child (Devolder, 2005). According to Knoppers et al. (2006, p. 212),

> "…most parents have a broad range of reasons and expectations when they decide to have children, which also instrumentalizes them to a degree, leading some authors to conclude that, as long as the tissue donation would be ethical if performed on an existing child, bringing a child into the world to serve as a tissue donor is ethical if the child is also valued for him or herself."

Those in favor of this practice ascertain it is acceptable "as long as the parents intend to rear and love the donor child" (Wolf et al., 2003, p. 330). "The fact that these parents make so much effort to try to save their child suggests they are caring and loving parents and makes it very unlikely they will treat the new baby as a 'bred to order child" (Devolder, 2005, p. 584).

Another ethical dilemma that has yet to be thoroughly investigated is the psychological ramifications to the donor child knowing he or she had been selected for the purpose of saving a life. Other psychological factors include "whether the child's welfare is subordinated to that of the sick sibling, whether initial tissue donation is successful or further donations are required, and whether the sick child ultimately is cured or dies" (Knoppers et al., 2006, p. 212-213).

The Moral Issues

Because PGD involves the process of picking viable embryos and discarding unacceptable embryos, the question of abortion is ultimately raised in whether or not it is an

acceptable procedure. According to Knoppers et al. (2006, p. 203), two main points of view are debated. They are:

(a) the embryo is a new human life entitled to full moral status from the time of fertilization, because from that time it holds the potential to develop into a complete human being, or

(b) 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.

Wolf et al. (2003, p. 330) asserts that "creating and discarding healthy embryos for lack of HLA-compatibility with the affected sibling is consistent with currently accepted embryo practices".

Hashiloni-Dolev and Shkedi (2007) believe there are three main objectionable moral issues concerning PGD. The first is from those people who think embryos are people and should have human rights at the earliest point of conception. These people oppose the selection and discarding of embryos as a whole. The second objection pertains to the act of "selecting" an embryo. Some people feel this process is unnatural and produces a "manufactured good". The third objection deals with the future rights of the unborn child and how all children, once again, should "always be treated as an end in itself and never merely as a means" (p. 2082).

In defense to the abortion issue, Hashiloni-Dolev and Shkedi (2007, p. 2082) reported two arguments that "failure to implant a pre-embryo is morally preferable to killing a more developed fetus" and "since pre-natal diagnosis in general is widely accepted, there is no reason to single out PGD and ban it."

Conclusion

Preimplantation genetic diagnosis is a procedure that, while associated with many ethical and moral controversies, could potentially be the future in changing the way certain fatal medical

conditions are treated where the life of a sibling is concerned. The positive aspects of allowing PGD to be used to ensure that a perfectly-matched embryo is implanted into the mother would have life altering effects for the parents and the child involved, including the possibility of curing the disease. However, ethical issues concerning the well being of the conceived child would always be at stake, including risks associated with the harvesting procedures, the future psychological health of the child, as well as the ethical and moral issues involving the procedure itself.

The intent of this paper was not to decide whether or not using PGD in hopes of producing a "savior child" is right or wrong, but was to make one aware of the controversies surrounding PGD and having a child to save the life of another child. I would like to see future research done on the psychological effects on the donor child when they become of age to fully understand the intentions of their parents when they were conceived. I, however, do believe that Spriggs (2005, p.341) stated a good point when he reported that the British Medical Association said, "As doctors, we believe that where technology exists that could help a dying or seriously ill child, without involving major risks for others, then it can only be right that it is used for this purpose."

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