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Saviour Siblings: Genetic Screening and Policy

Sarah Levitt

In the field of medicine, new technological advances and procedures require reform in health policy. During this process, ethical issues need to be examined from a variety of different points of view. For example, Pre-implantation Genetic Diagnosis (PGD) and Human Leukocyte Antigen Tissue Typing (HLA typing) are new techniques that allow for the creation of "saviour siblings," which are embryos that are a tissue match for existing children. While certain parameters have been set up in different countries, such as the United Kingdom, these regulations are not always ethically consistent with other health policy. These new advances in medicine need to be carefully considered before they can be implemented on a broader scale.

Ethical issues are intertwined with health care, as clinicians have always had to make difficult decisions surrounding patient care. Today, moral dilemmas are increasingly complex due to advances in medical technologies. The new technology that has come from reform in health policy raises ethical issues and requires legislation for regulation purposes. This process involves multiple interest groups such as government, specialists, and citizens; therefore, the writing of health policy becomes extremely difficult. Pre-implantation Genetic Diagnosis (PGD) and Human Leukocyte Antigen Tissue Typing (HLA typing) for the use of creating "saviour siblings" are examples of healthcare-related ethical issues that we must address. Currently, the United Kingdom has a controversial policy regarding these technologies. This article will address the ethical implications of this legislature, as well as assess how consistent these laws are with other UK biomedical policies.

> "a 'saviour sibling' may only be conceived for a child whose condition is the result of a hereditary disorder"

PGD and HLA typing are used to screen embryos for genetic diseases that will affect their quality of life. This enables couples to carry a healthy baby despite a pre-disposition to a genetic disorder. These technologies can also be used to screen embryos for the benefit of a relative by testing if a person is a tissue match even before birth (Boyle and Savulescu 2004). For example, if a child has a serious blood disease for which a blood transfusion is needed, and there are no appropriate donors, the parents may choose to conceive a second child with the ability to donate blood. Parents like Raj and Shahana Hashmi have attempted to use this procedure to save another child. In the Hashmi's case, their son Zain had the blood disorder β-thalassaemia and they created 14 embryos in an effort to find a blood transfusion match (Sheldon and Wilkinson, 2004). PGD and HLA typing technology create much controversy among policy-makers.

The Human Fertilisation and Embryology Authority (HFEA) in the UK has outlined parameters under which this procedure is permissible. In this criteria, it is stated that "the embryos conceived in the course of this treatment should themselves be at risk from the condition by which the existing child is affected" (HFEA, 2001). This stipulation means that a "saviour sibling" may only be conceived for a child whose condition is the result of a hereditary disorder.

The HFEA's 2001 legislation was developed to ensure that an embryo will not be exposed to unnecessary risks from PGD and HLA typing if the child does not stand to directly benefit from such tests. If PGD and HLA typing are performed on embryos that are believed to be at risk for genetic disorders, the procedures are justified. If the disease is hereditary, one would employ PGD and HLA typing not just to select for a saviour sibling, but also to ensure that the couple's next child does not suffer from the same condition. Therefore one can almost ignore the fact that the child will become a "saviour sibling"—an appealing thought for those who consider this issue morally compromising. This requirement ensures that the future child derives some benefit from PGD and HLA typing instead of being subjected to these technologies solely for his

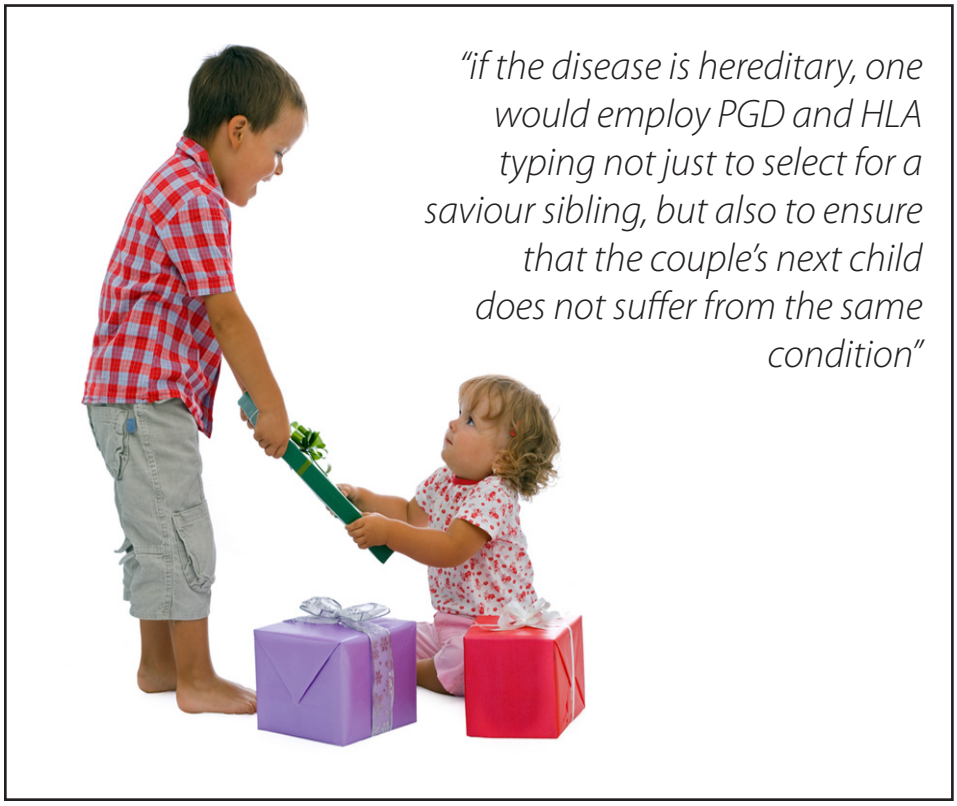
or her older sibling.

Sheldon and Wilkinson (2001) believe "the underlying principle here is that an embryo should be exposed to the risks of PGD only if it (or the person it becomes) is likely to derive enough benefit to outweigh those risks… the potential child is thought to be like an existing patient." Since the embryo is viewed as a potential child, proponents of this reasoning afford the embryo the same moral status as that of a born child (Charo, 2001). It appears the HFEA also supports this argument because it has this condition in its guidelines for "saviour siblings".

Those who argue for "potential" consider the embryo sacred since it will develop into a human being. Thus, they believe many acts like abortion and human embryo stem-cell research to be unethical. The HFEA's policy is founded on a similar principle whereby PGD may only be performed on an embryo that may "benefit" from it by determining whether or not it is healthy. Since it is considered a 'healthy child,' it is not just viewed as a 'healthy embryo'. The embryo itself is neither sick nor healthy, but it does contain genetic information that will determine the well-being of the future child.

"Health policy is constantly within ethical grey areas due to the fact that there is not necessarily a right answer"

When the HFEA makes policy based on this principle, proponents for the "potential" argument will be able to appeal to this organization's practices when discussing other embryo-related issues. Definitions of biological entities cannot change depending on the policy that is being written. If there is a precedent of viewing the embryo as a future child when making embryo-related policy, it must be used in all subsequent policies in order to remain ethically consistent. In this respect, however, the UK falls short as the country passed legislature allowing human embryonic stem cell research to be performed. This decision faces disapproval from those who argue for "potential" (Deckers, 2005).



"if the disease is hereditary, one would employ PGD and HLA typing not just to select for a saviour sibling, but also to ensure that the couple's next child does not suffer from the same condition"

One might argue that the UK legislature regarding "saviour siblings" and the regulations regarding stem cell research differ. With "saviour siblings", the argument from "potential" may be used because, ultimately, one is concerned with the person that results from the embryo. In stem cell research, however, one wishes to use a blastocyte, the developmental predecessor to the embryo[1]. By this logic, the embryos tested by PGD and HLA typing analysis may also be used for research (Boyle & Savulescu, 2001). Using these technologies in the creation of a "saviour sibling" requires the creation of numerous embryos, but only one is implanted (Figure 1). Thus, there is an excess of embryos which couples are encouraged to donate to human embryonic stem cell research.

Under UK law, the parents may donate their embryos to research, which contradicts the present embryo policy. Furthermore, the only reason why one healthy embryo is chosen over another is based on tissue type. In essence, this means that the only distinguishing factor between embryos is their relation to an existing person. Therefore, the HFEA cannot truly say it is operating solely for the benefit of the embryo as this sentiment disproves the very nature of the process. If the HFEA is allowing PGD and HLA typing for the creation of a "saviour sibling," a life that is

[1] That stem cell research uses a blastocyte, not an embryo, is irrelevant to those who argue from potential because the blastocyte is a just a step in the process of creating a child.

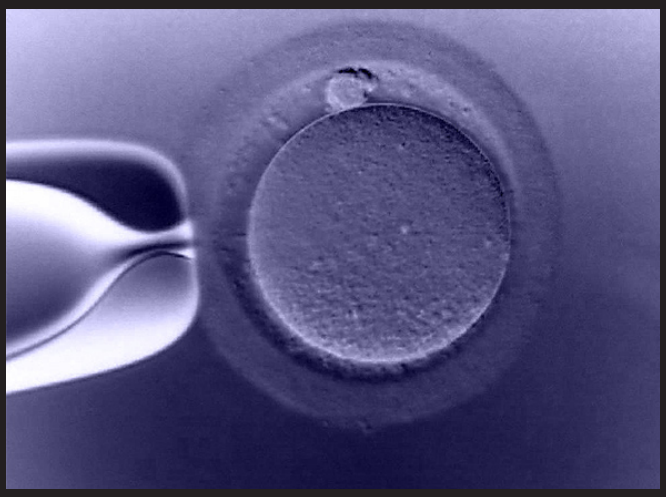


Figure 1 In-vitro fertilization. The embryo is implanted into the mother after genetic modification.

inextricably linked to the well-being of its sibling, this view should be standard in all related situations. The organization cannot shield itself by stating that the procedure may only be performed with embryos who are themselves at high risk of genetic disorder.

There is little reason to believe that PGD and HLA typing will have negative consequences for the embryo (Boyle & Savulescu, 2001). Moreover, the HFEA is not protecting the embryo with this stipulation in its policy. When the egg is fertilized, the hereditary condition may or may not be present in the subsequent embryo. PGD and HLA typing do not cure the condition but merely indicate its presence. Thus, this policy still subjects a healthy embryo to the hypothetical dangers of PGD and HLA typing (Sheldon & Wilkinson, 2001). As has been demonstrated, the HFEA's argument is full of inconsistencies.

It is interesting to note that advocates of the argument for "potential" would disapprove of PGD and HLA typing for "saviour siblings" because it involves both the manipulation and discarding of embryos. In order to remain logically consistent, the UK, through the HFEA, must reconsider their parameters for allowing PGD and HLA typing procedures for "saviour siblings". There should be no distinction between testing embryos that have a higher likelihood of genetic disorder than those that are being tested solely because the embryo is meant to be a donor for his or her sibling (Sheldon & Wilkinson, 2001). Once this distinction is in place, it increases the strength of those who believe the argument for "potential" has a place in policy making — a principle which the UK has shown to disregard in certain cases.

This situation in the UK can help us to explore and maintain ethical consistency within health policy. Those who see the embryo as a potential person will be quick to condemn acts such as abortion and human embryonic stem cell research. This is where consistency becomes important. In order to have a stable policy, the legislation must maintain an unvarying opinion. The government may be swayed by one differing opinion or another, but all related policy must subsequently be rewritten in the wake of such changes in perspective.

Kurt Darr (1991) writes, "it is imperative that managers solving ethical problems, whether administrative or biomedical, be mindful of the organization's philosophy, as well as their personal ethic… to ignore or apply these constraints arbitrarily creates inconsistencies and discontinuities that eventually cause major problems for the organization and for the manager." In this case, the manager is the UK government and it must remain mindful of the policy it has previously put forth. If it chooses to view the embryo as a potential child, legislation must be written to reflect this sentiment. Inconsistent legislation is vulnerable to attacks. For example, Jan Deckers' (2005) article states that, "current UK legislation on embryo research is immoral," thus showing one such assault based on the HFEA's parameters.

Health policy is constantly within ethical grey areas due to the fact that there is not necessarily a 'right answer'. In such cases, it is important for the government to take a firm and consistent stance towards the issue. The regulations on PGD and HLA typing for "saviour siblings" are an example of health policy that must be reconsidered and revised in order to achieve logical consistency. If this is neglected, all of the UK's legislation concerning embryos is vulnerable to attack, which will create an unstable environment in their health care sector.

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