Having Children to Save Children

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Introduction

Preimplantation genetic diagnosis (PGD) is a technique that involves removing a few cells from the early embryo, genetically screening them, and then deciding if the embryo should be discarded or placed in a uterus to progress into a pregnancy. The process has been available since 1990 and since then more than 1,000 children have been born as a result (Robertson, 2003). Prospective parents may choose to use preimplantation genetic diagnosis for several reasons: to select specific characteristics of their baby-to-be (such as gender, hair color, and even intelligence), to screen for genetic mutations, and in combination with human leukocyte antigen (HLA) tissue typing to create a donor for an existing child with a life-threatening condition whose only chance of survival is a tissue or organ donation. The use of preimplantation genetic diagnosis and human leukocyte antigen typing has ignited worldwide debates over the ethical concerns that surround them. Some individuals oppose preimplantation genetic diagnosis (and by default human leukocyte antigen typing, too); others accept preimplantation genetic diagnosis in certain circumstances, but not solely for human leukocyte antigen typing; yet others permit the use of preimplantation genetic diagnosis specifically for human leukocyte antigen typing. The purpose of this paper is to examine the ethical arguments for and against preimplantation genetic diagnosis and human leukocyte antigen typing for the purpose of creating a donor for an existing child.

Review of Literature

One reason people oppose preimplantation genetic diagnosis is that it discriminates against individuals with disabilities because it implies that their lives are not as valuable as the lives of individuals who do not have disabilities. However, Cameron and Williamson (2003)

cited the International Sub-Committee of the British Counsel of Disabled People which stresses that there are more people living with disabilities as a result of traffic accidents and work accidents than there are as a result of genetics. As a society, we do not encourage environmental accidents which cause disability, but rather allot significant resources to avoid such accidents. "As an example, resources aimed at reducing road accidents, including media campaigns and police resources are significant. This allocation of resources would not be regarded as discriminatory" (Cameron & Williamson, 2003, p. 91).

Critics object to the use of oppose preimplantation genetic diagnosis and human leukocyte antigen typing because of the 'slippery slope' it creates. According to this argument,

> If you permit an exception to the guideline that preimplantation genetic diagnosis may only be used to select for characteristics related to the health of the future child […] and accept preimplantation genetic diagnosis / human leukocyte antigen-tying, then you no longer have any convincing arguments for the rejection of the 'designer' model, which allows parents to select embryos however they please, including selection for non-medical characteristics such as a predispositions for special talents' (de Wart, 2005, p. 3263).

Proponents argue that those who choose to use preimplantation genetic diagnosis and human leukocyte antigen typing are not seeking to create a perfect child; they simply want a child free of genetic diseases and who can serve as a donor for an existing child. In addition,

> As is usually the case with slippery slope arguments, if the possibility of unwelcome future events were a sufficient reason to prohibit new technology, there would be little innovation, since new technology almost always has undesirable consequences. Allowing

> the acceptable use of technology is not incompatible with prohibiting unacceptable use (Frost, 2004, p. 2125).

Those who oppose preimplantation genetic diagnosis / human leukocyte antigen-tying for human leukocyte antigen typing do so because they believe

> […] donor children, or so called 'saviour siblings', are created merely for instrumental reasons-to serve as a donor for the sick sibling-and not for their own sake […] (as cited by Devolder) Nicholson says: 'We are not creating this saviour sibling to be a child in its own right. We have created it-designed it-to be a source of spare parts for an existing child' (Devolder, 2005, p. 583).

Others refer to these children as "spare part sisters" or "bred to order brothers." Devolder (2005) cited "The Value of Children Project" as showing that in reality parents choose to have children for all kinds of instrumental reasons, such as to enhance the husband/wife relationship, continuity of the family name, and the financial and psychological benefits that children offer when their parents get old.

Some say that parents should only be able to create a donor child if they had already planned to have another child. They believe that if a child is created simply to be a donor, the child will not be loved and cared for the way the child should be. Others say that these arguments are not valid because it is difficult, if not impossible, to determine why parents choose to have children. A couple's plans to have children often change, depending on a variety of circumstances. In addition, these parents choose to go through so much to save an older child suggesting that they are loving and caring parents making it unlikely they will treat the younger child as a "saviour sibling," but will provide it with all the love and support that a child deserves

and needs. Preliminary evidence supports this argument, although more follow-up studies with these families are needed (Devolder, 2005).

Others would permit the use of preimplantation genetic diagnosis and human leukocyte antigen typing only if the cells being screened are tested for illness. In 2002, a couple living in the U.K. requested permission to use preimplantation genetic diagnosis and human leukocyte antigen typing from the UK's Human Fertilisation and Embryology Authority. Their existing child was suffering from Diamond-Blackfan anemia, a rare condition that requires frequent blood transfusions and daily injections. Currently, the only cure for it is a transplant of stem cells from a perfect match donor. The UK's Human Fertilisation and Embryology Authority rejected the couple's request because no genetic test exists for Diamond-Blackfan anaemia. This would mean the only one to benefit from the procedures would be the existing child and not the embryo/child-to-be. As there are fewer regulations on PGD and HLA typing in the United States, the couple sought treatment here and successfully had a baby who was a perfect genetic match for their existing child (Spriggs, 2005).

Among those who support the use of preimplantation genetic diagnosis and human leukocyte antigen typing, there is still disagreement regarding what can be done to the embryo/child-to-be and who qualifies to be a recipient. Currently, a common standard of practice is what would be done to the donor if it already existed (Devolder, 2005). Harvesting blood from the umbilical cord is one practice that is widely accepted because it is neither invasive nor painful to the mother or newborn. Bone marrow donations from the newborn to a sibling are common because the pain from the procedure can be well managed and the psychological effects can be minimal provided adequate care is given to the donor.

Organ donations from a newborn are not accepted because of the risks to the donor. Kidney donation is a borderline type of case because an individual can live with only one kidney. Many argue that riskier and more inconvenient procedures should be limited to cases in which the donor and recipient are very closely related. Thus, a kidney transplant may be permitted, but only if the donor and recipient are siblings. The reasoning behind this is the possible psychological benefits to the donor child. A young child may experience gratification at being able to donate, or guilt when they are not allowed to donate. In addition, they will have the advantage of growing up in a more stable environment than if the sick sibling had died (Devolder, 2005).

Currently some countries, such as the Netherlands, permit preimplantation genetic diagnosis and human leukocyte antigen typing in cases where the recipient is a parent or a sibling. However, the U.K. and other countries only allow human leukocyte antigen typing if the intended recipient is a sibling for several reasons. Most simply, if the intended recipient is a parent the chances of having a tissue match are extremely small (.005%) and thus the use of preimplantation genetic diagnosis and human leukocyte antigen typing may be pointless. In addition, umbilical cord blood typically does not provide enough stem cells to treat an adult. A conflict of interest may also arise if the intended recipient is an adult because parents typically grant consent for their children. As already stated, if the intended recipient is a child or another loved one, the parents are unlikely to mistreat the new child (Devolder, 2005).

Conclusion

There are numerous ethical dilemmas regarding the uses of preimplantation genetic diagnosis and human leukocyte antigen typing. Each individual has his/her own reasons for proposing or opposing the issues, although it seems that everyone has the same desire to protect the interest of

the embryo/child-to-be. As nurses, it is essential that we are aware of these ethical dilemmas because we may care for a patient who has chosen to use of preimplantation genetic diagnosis and/or human leukocyte antigen typing. In such a situation it is important that we give these patients the same quality care that we give to all of our patients, regardless of whether or not our beliefs are the same.

References

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