Embryo screening for tissue matching

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Parents with children who need a hematopoietic stem cell transplant are increasingly using preimplantation genetic diagnosis to have a well-matched sibling donor. Preimplantation genetic diagnosis may ethically be used for this purpose even if the resulting child is not at risk of inheritable disease. (Fertil Steril® 2004;82:290–1. ©2004 by American Society for Reproductive Medicine.)

Preimplantation genetic diagnosis (PGD) to screen embryos before transfer is now being considered for several indications beyond its original use to avoid transmission of severe genetic diseases to children. One proposed expansion receiving wide attention is a couple’s use of PGD to have a healthy child who would be a suitable human leukocyte antigen (HLA) match for tissue donation to an existing child.

Such requests are a last resort for parents with a child with thalassemia, Fanconi anemia, leukemia, and other inherited and sporadic diseases. A child has been diagnosed with a serious illness and is in danger of dying unless he or she receives a hematopoietic stem cell transplant to rejuvenate the immune or blood system. The threat of graft vs. host disease, a prime cause of mortality and morbidity in such transplants, can be minimized by the use of a matched donor. Matched sibling donors are the best candidates, but none might be available. If so, parents in this situation often consider having another child, with the hope that it will also be a suitable donor for their existing child.

The most effective way to ensure that another child would be a close match would be to undergo IVF, screen resulting embryos, and then transfer only those that seem to be healthy and a suitable match. Preimplantation genetic diagnosis gives greater certainty of a matched sibling than birth after coital conception and is more easily tolerated than prenatal diagnosis and abortion. As a result, parents in this situation are increasingly turning to PGD for this purpose and are likely to do so in greater numbers in the future (1, 2).

The parents’ actions are ethically defensible on several grounds. They are having a second child for a beneficial purpose. Nothing in the circumstances suggests that they will not be as loving and caring of the second child as they have been of the first. How a child is treated after it is born, not the motivation in conceiving it, determines whether reproduction is ethical. The charge that the parents’ conduct is unethical because it treats the second child as a “mere means” simply does not describe what is going on.

Nor should it matter whether the embryo that is transferred had also been at risk for inheriting the same disease as afflicts the first child. In either case, one is creating and selecting embryos for an important, non-trivial purpose. Nor are the parents likely to be less committed to and caring of the second child because PGD does not provide a direct medical benefit to that child. If PGD for HLA is acceptable in cases of inherited diseases, such as Fanconi’s anemia, then it should also be acceptable for diseases that are not inherited (3).

The distinction between the two cases has not yet posed legal problems in the United States, but it has in the United Kingdom. The Human Fertilisation and Embryology Authority (HFEA), which regulates all assisted reproduction in the United Kingdom, ruled in 2001 that PGD for HLA matching was permissible in cases in which the second child was at risk of inheriting the genetic disease that its sibling had but not when the affected child had a sporadic
disease (4). This policy has created serious problems for parents with such children. If they have the funds, they might travel to the United States or other countries that permit PGD in such cases. If they lack the funds, they might try coital conception and take the chance that a subsequently born child will be a correct tissue match. If not, their first child might die for want of a matched donation.

Affected families in the United Kingdom find the government’s policy especially frustrating because PGD for HLA matching in cases in which a child is suffering from an inherited disease is permitted, and the reasons for treating the two cases differently are not persuasive. The physician for one family with a child with a rare sporadic blood condition, Diamond Blackfan anemia, has threatened to sue to invalidate the ban because of the arbitrariness of the distinction drawn (5). Whether or not legal action occurs, the HFEA should change its policy, and United States programs should not follow it.

The HFEA’s reasons for its position seem to be based on concerns about the appearance or risk of using a subsequent child as a mere means when its own health is not at risk from the sibling’s disease. Although the HEFA recognizes that embryos are too rudimentary in development to have rights or interests and can be created and screened by PGD to avoid severe genetic disease, it requires that “the embryos conceived in course of treatment should themselves be at risk from the condition by which the existing child is affected”(5). The rationale is not fully explained but seems to be that because screening embryos for characteristics that are not directly medically relevant to the well-being of the subsequent child provides no direct benefit to it, such a practice risks using that embryo and child as a means for the good of another.

Such a rationale, however, is not convincing. Whether the first child’s disease is inherited or sporadic, embryos will be deliberately created and then, if they have a particular genome, not be transferred. It is hard to believe that parents who resort to PGD to match a second child’s tissue with an existing child will be any less committed to the welfare of the second child merely because that child was not at risk of inheriting the disease affecting the sick child. Indeed, from the second child’s perspective once it is born, PGD for HLA matching in the case of sporadic disease was directly beneficial for it because it led to it being selected for transfer and birth.

A deeper, lurking fear of a “slippery slope” might help explain the HFEA’s position or that of others who might agree with the HFEA’s position (6). With PGD suddenly being used in new ways, there is some nervousness as to whether it will be used wisely or abused. Because these uses deviate from previous uses of prenatal and preimplantation testing to prevent the birth of children with serious genetic disease, the HFEA might be reluctant to cross that threshold out of fear that it could pave the way to other nonmedical uses that are not directly beneficial in health terms to the resulting child, such as PGD for nonmedical gender selection or enhancement.

But the fear of a slippery slope is not a good reason for holding to such a position. The embryos chosen for transfer in the case of inherited disease are also being chosen because of their HLA type. Moreover, the HFEA has already taken the position that no use of assisted reproduction for nonmedical gender selection is acceptable (7). Nor, because of the multifactorial basis of most nonmedical traits, are simple genetic tests for such traits usable for PGD likely soon to be available, if ever.

Fears that the welfare of HLA-matched children will suffer or that society will tumble down a slippery slope to nonmedical uses of PGD are not good reasons to deny families the chance to have a child who would also serve as a cordblood donor for an existing sick child who has no other feasible medical alternative. Loving families in desperate straits choose PGD regardless of whether the first child’s disease is inherited or sporadic. Society should not block them from doing so.

References
4. Human Fertilisation and Embryology Authority. HFEA confirms that HLA tissue typing may only take place when preimplantation genetic diagnosis is required to avoid a serious genetic disorder [press release issued August 1, 2002]. Available at: http://www.hfea.gov.uk/PressOffice/Archive/43575563. Accessed April 15, 2004.