Informing patients about emerging treatment options: creating "saviour siblings" for haemopoietic stem cell transplant

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ABSTRACT

- In June 2008, the ABC screened a television documentary involving a couple who decided to have an additional child in the hope of obtaining umbilical cord blood to treat their daughter who had leukaemia.
- The couple conceived naturally, meaning that there was a one in four chance that their child would be suitably matched. They seemed to be unaware of technologies that, if successful, could provide a near certainty that the next child would be a matched "saviour sibling".
- This story raises questions about whether clinicians have an obligation to discuss emerging and morally contentious treatment options.
- Ignorance of technology, assumptions about availability, and medical assessment of burdens and benefits may affect attitudes towards treatment options, but they do not justify non-disclosure of information.

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Last year, ABC Television screened a documentary on *Australian story* about a couple, Nicola and Jim Walker, and their 2-year-old daughter, Abby, who was undergoing chemotherapy for acute leukaemia[1]. Nicola and Jim decided to have another child in the hope that umbilical cord blood collected at birth could provide haemopoietic stem cells for Abby, should she relapse and need a transplant. Well into the pregnancy, Nicola was surprised to learn that there was only a 25% chance that the new child would be a human leukocyte antigen (HLA) match for Abby. Following the birth of their son, cord blood was collected and stored. At the end of the documentary, it was unclear whether the "saviour sibling" was a match for his sister.

The Walkers' experience is not new. Since 1987, there have been reports of parents seeking to conceive a child naturally to secure a suitable donor for an existing child who is seriously ill and who needs (or may need in future) a haemopoietic stem cell transplant.[2] The practice of creating so-called saviour siblings has raised a number of ethical objections. Some argue that it treats the donor child as a commodity, or as a mere means to an end.[3] Others argue that it is unethical because the donor is placed at potential risk of physical and psychosocial harm without enjoying any medical benefit.[4] Furthermore, increasingly burdensome demands may be made of the donor if the transplant is unsuccessful. (The latter possibility was explored in a popular novel, *My sister's keeper*,[5] that will soon be turned into a film.) These objections have been countered by several arguments: parents who try to create saviour siblings may be on higher moral ground than those who procreate for more common, self-interested reasons;[6] it is unlikely that parents will not treat the new child with the same love as an existing child;[7] the harms of donation are not inevitable;[8] and there are potential psychological benefits for the donor and the family.[9]

Another way to look at this case is one that does not call into question the actions of the parents, but raises questions about the obligations of the medical profession to inform parents and patients about their options. It would have been possible, in principle and practice, to assist the Walkers to not only have another child but to have one known to be an HLA match for their daughter. This would have involved the application of three existing technologies: in-vitro fertilisation (IVF), preimplantation genetic diagnosis (PGD) and HLA typing, whereby embryos are tested to exclude a genetic condition (where relevant) and to identify those with an HLA type matching the sick sibling, hence suitable for implantation. The first family reported to proceed with this option was in the United States in 2001.[10] An Australian family was later reported to have pursued the same option.[11] In the ABC documentary, it was unclear whether the Walkers were aware of this option.

Clinicians may choose not to discuss particular therapeutic options with patients or parents for several reasons. They may have moral objections (as is sometimes the case with contraception or termination of pregnancy); they may be unaware of new developments; they may believe their patients are unable to access particular services; or they may feel that it is inappropriate to discuss a particular option, either because it is not clinically indicated or because the burdens outweigh any benefits. For such reasons, some clinicians may also be circumspect about raising the option of creating a saviour sibling through IVF and PGD. Most children in Abby Walker's situation are cured by chemotherapy and never need a transplant.[12] If Abby relapsed and her existing siblings did not match her HLA type, her physician could then search for a donor, safe in the knowledge that an unrelated donor can be found for the vast majority of children in Australia.[12] Her physician would also know that, as a transplant should be performed early in the course of a second remission, it is not possible to defer transplantation for the minimum of 12 months required for parents to undergo IVF, bring a pregnancy to term and collect the umbilical cord blood.[12] IVF and PGD also impose substantial physical, emotional and financial burdens on parents at a time when they may need to focus on providing care and comfort for their ill child. There is no guarantee that IVF will be successful — the average pregnancy rate per embryo transfer is 34% (range, 14.8%–42.7%) and depends on the IVF centre and age of the mother.[13] Although the Australian Government currently provides funding for the search for an unrelated donor, it does not regularly subsidise IVF and PGD for producing a matched sibling donor, so these can be costly processes. Finally, these technologies may not be available in every state and territory, as different jurisdictions have different regulations,[14] so some parents may have to travel interstate to access appropriate services.

Do practitioners have an obligation to inform parents and patients in the Walker family's position about IVF and PGD treatment? Ignorance is difficult to justify, as the technologies involved are established and have been combined successfully in multiple cases around the world involving genetic conditions and

Conditions and indications for discussing preimplantation genetic diagnosis for an HLA-matched sibling

- Sick child has a disease that can be treated with a *non-urgent* haemopoietic stem cell transplant (umbilical cord blood, bone marrow).
- Suitable donor is not available:
  - ➢ No matched sibling donor, and unrelated matched donor is suboptimal for the sick child's condition (eg, Fanconi anaemia)
  - ➢ No matched sibling or unrelated donor (in cases where matched unrelated donor transplants have comparable outcomes to those from matched siblings).
- Both parents are available, of reproductive age, and willing to undergo in-vitro fertilisation to have another child.

HLA = human leukocyte antigen. ◆

haematological malignancies.[15,16] Although clinicians may have concerns about the appropriateness of discussing these technologies, and be justifiably circumspect about raising options that will impose additional psychological, physical and financial burdens on families who are already dealing with serious illness, these concerns do not justify non-disclosure, and non-disclosure is not in line with public preferences.[17] All courses of action carry potential burdens as well as benefits, and these are best assessed by those for whom they are most salient — the patient and the surrogate. In addition, it is difficult to make assumptions about the choices that families may make and their capacity to cope when facing the loss of a child. Parents will generally understand that relapse is unlikely in childhood acute lymphoblastic leukaemia, but may still want to have haemopoietic stems cells available should that happen. Finally, even if a clinician has a moral objection to creating a saviour sibling, then they still have a moral and legal obligation to inform the parents about this option, or refer them to a practitioner who will, as is the case with other forms of conscientious objection in medicine. Conditions and indications for discussing PGD for an HLA-matched sibling are summarised in the Box.

It is not appropriate for medical practitioners to withhold information about available technologies such as PGD for HLA typing. That is not to say that parents should pursue this option, but rather that they should be given all relevant information and allowed to consider all of their options. Although this is a complex issue, it should be raised, just as other complex issues are raised in the course of clinical consultations. Failure to do so is becoming increasingly difficult to justify for this particular combination of technologies and other emerging treatment options that are morally contentious.

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Competing interests

None identified.

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