Altruism by proxy: volunteering children for bone marrow donation

Should children ever be allowed to donate bone marrow to help treat their sisters or brothers? Can their parents give informed consent to an invasive procedure that is not in the child's own best interests? Linda Delany, an academic lawyer, suggests that such donations are legally questionable. We invited a range of interested professionals to give their opinions.

Protecting children from forced altruism: the legal approach

Linda Delany

The case of *R v Cambridge Health Authority ex parte B*, decided in March this year,¹ highlights the lack of legal concern for children who become bone marrow donors. While the proceedings against Cambridge Health Authority chiefly aimed to secure further aggressive treatment for 10 year old B, who suffered from acute myeloid leukaemia, the case also reflected how uncontroversial bone marrow donation by young children is in Britain. The judgments recited without adverse comment the fact that last year B received bone marrow from her younger sister.

Nevertheless, it is by no means clear that harvesting bone marrow from a child is legal. Neither statute nor case law specifically sanctions bone marrow donation by a child. Whether the practice is lawful or not must therefore be deduced from general principles of medical law.

Two quite distinct legal approaches to medical interventions involving children can be identified. The first, adopted by the House of Lords in *Gillick*² and consistent with the philosophy of the Children Act 1989, permits a medical procedure only if it serves the best interests of the child who undergoes it. In other words, unless parents and medical staff are guided by the best interests of the child they have no legal right to make treatment decisions on his or her behalf. When a child's carers disagree on the best course of action the conflict should be referred to court. The second approach accepts that parents can give valid consent to treatments which are "not against the interests of the child." This approach was developed in order to permit the taking of blood samples from children whose legitimacy or parentage was at issue.³ Skegg has argued that the approach is relevant to any medical intervention carried out on children purely for other people's benefit.⁴

Is bone marrow donation by a child lawful under either approach? To answer this we need to review the clinical aspects of bone marrow harvesting. The child will be subjected to tests to check whether his or her bone marrow is a suitable "match." If it is he or she may be admitted to hospital for up to two nights, and a general anaesthetic (with its attendant risks) will be administered. On regaining consciousness the child may suffer pain or severe discomfort as a result of the bone marrow extraction. For the child donor the only positive aspects of the intervention are likely to be psychological. There may be pleasure at helping the recipient and at basking in the approval of parents and medical staff. Potential donors, on the other hand, may be exposed to unfair pressures and threats and fear of disapproval if they do not cooperate.

Assessments based on factors such as these may show that bone marrow donation is not "in the best interests" of the donor. Indeed, they may conclude

that a donation is against the child's interests. When the proposed donor is too young to have established an emotional bond with the proposed recipient of the bone marrow the factors favouring the medical intervention appear to be outweighed by those against it. If, as happened in the United States, a baby is conceived because the parents wanted to procure a supply of bone marrow for their 17 year old daughter,⁵ how can the subsequent graft to the much older sibling be said to serve the interests of the baby?

How should donation of bone marrow by children be regulated? New legislation should prohibit unauthorised donations. Only donations found to be in the child donor's best interests as determined by reference to a statutory checklist of factors (which would include the ascertainable wishes of the child) should be permitted. A forum, independent of the parents and medical advisers, should vet each proposed graft. An informal tribunal or independent medical social worker, rather than a court, might be used for this purpose.

Such an approach would reflect the strategy developed by the Law Commission in a recent report for safeguarding adults suffering mental incapacity from being inappropriately "volunteered" for bone marrow extraction.⁶ It would at last confer some legal protection on children forced to display altruism.

1 *R v Cambridge Health Authority, ex p B* [1995] 2 All ER 129.

2 *Gillick v West Norfolk and Wisbech Area Health Authority* [1985] 3 All ER 402.

3 *S v S, W v Official Solicitor* [1970] 3 All ER 107.

4 Skegg PDG. Consent to medical procedures on minors. 36 MLR 370-381 at 381.

5 McBride G. Keeping bone marrow donation in the family. *BMJ* 1990;300:1224-5.

6 Law Commission. *Mental incapacity*. London: HMSO, 1995. (Law Commission report No 231.)

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Preventing children from donating may not be in their interests

Stacy Month

Ms Delany proposes putting more constraints on bone marrow donations by siblings. She wants all such donations to be unauthorised unless a specific forum agrees that it is in the child's best interests. I heartily disagree with this approach. Delany drastically understates the positive aspects to the child donor. We are not simply talking about a few days of feeling good because one helped out. We're talking about probably saving the life of one's brother or sister.

The donor could benefit immensely from many years of a "whole" family. The death of a sibling is an overwhelmingly tragic event with severe psychological repercussions on all family members for the rest of their lives. If a child donates bone marrow to a sibling who eventually dies, of course that child would feel guilt. This guilt can, however, be overcome with good psychosocial support before and after bone marrow

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