Gillick, bone marrow and teenagers

Lisa Cherkassky

Original Article

Abstract
The Human Tissue Authority can authorise a bone marrow harvest on a child of any age if a person with parental responsibility consents to the procedure. Older children have the legal capacity to consent to medical procedures under Gillick, but it is unclear if Gillick can be applied to non-therapeutic medical procedures. The relevant donation guidelines state that the High Court shall be consulted in the event of a disagreement, but what is in the best interests of the teenage donor under s.1 of the Children Act 1989? There are no legal authorities on child bone marrow harvests in the United Kingdom. This article considers the best interests of the older saviour sibling and questions whether, for the purposes of welfare, the speculative benefits could outweigh the physical burdens.

Keywords
Bone marrow donation, Gillick, child welfare, minors

Introduction
It is settled law that if an older child is Gillick competent she can consent to a medical procedure. There is an assumption, however, that the medical procedure is in her best interests. Bone marrow harvests pose a unique legal problem in that they provide no therapy to the donor. Babies and toddlers cannot experience physical or psychological benefits making their harvests questionable in law (outside the ambit of this article), but older children may glean a psychological benefit by acting as a saviour sibling (the term “saviour sibling” refers to a child who is harvested to save its brother or sister from a debilitating disease). The saviour sibling may, therefore, be born naturally and found to be a match later, or created specifically for harvest using Preimplantation Genetic Diagnosis under the Human Fertilisation and Embryology Act 1990 (as amended). The Human Tissue Authority (HT Authority) recommends that the inherent jurisdiction of the High Court is sought only if there is a disagreement, bestowing maximum discretion upon parents and transplant teams.1–3

There are three potential legal routes to consent for older child donors: (i) Gillick consent may be applicable to non-therapeutic medical procedures; (ii) a parental consent may override a teenage refusal to validate the procedure (subjective), or (iii) the High Court may decide what is in the best interests of the child (objective). There has not been a test case in the UK yet. In the United States, however, the leading authority of Curran v Bosze (1990) 566 N.E.2d 1319 confirms that the saviour sibling must have a loving connection to the sick sibling and awareness in the present of a benefit, per Calvo J at pages 1343–4.4 Re Y (Mental Patient: Bone Marrow Donation) [1997] Fam 110 did accept psychological benefits but the case concerned an incompetent adult, making the outcome in a child case highly speculative.

This article examines the donation guidelines under the HT Authority, the reach of Gillick, and the inherent jurisdiction of the High Court. It will be concluded that the harvest of bone marrow from older children may not be supported under the current law.5

The HT Authority
The current rules for bone marrow harvests upon children are published by the HT Authority. A child is anyone under the age of 18 according to its Code of Practice 2014.6 Donations from children who are not competent to give consent must be approved by the HT Authority but competent children can be “approved
locally'', placing a significant burden on the transplant unit to correctly diagnose Gillick competence (at paragraphs 27 and 26). The HT Authority advise the following:

Paragraph 75: The assessment of “competence” of the potential child donor should be determined by the bone marrow transplant unit. Children competent to give consent are considered “Gillick competent”.

Paragraph 76: In the Gillick case, the court held that a child was considered competent to give valid consent to a proposed intervention if they had sufficient intelligence and understanding to enable them to fully understand what was involved.

It is perfectly conceivable that teenage donors have sufficient intelligence to fully understand what is involved in a bone marrow donation. These mature characteristics help them to form psychological benefits in the guise of altruism, pride, or happiness. It is advised by the HT Authority, to prevent undue influence, that older donors are interviewed alone (at paragraph 79).

Interestingly, refusals are not mentioned by the guidelines. A parent can only consent on behalf of a competent child if that child “fails to reach” a decision (at paragraph 81). In the event that the child issues a competent refusal, it may be classified as a “dispute”:

Paragraph 85: Where there is any dispute between people with parental responsibility or any doubt as to the child’s best interests, the matter should be referred to the court for approval.

Paragraph 109: If the court is asked to consider the matter, the welfare of the prospective donor child will be the court’s paramount consideration and not the welfare of the recipient. The “welfare checklist” which is set out in the Children Act 1989 will be considered by the court in determining the application.

It appears that if a competent child refuses a bone marrow harvest, the High Court can apply the welfare test:

Children Act 1989
Section 1: Welfare of the child.
(1) When a court determines any question with respect to:
   (a) the upbringing of a child; or
   (b) the administration of a child’s property or the application of any income from it, the child’s welfare shall be the court’s paramount consideration.

(3) A court shall have regard in particular to:
   (a) the ascertainable wishes and feelings of the child concerned (considered in the light of his age and understanding);
   (b) his physical, emotional and educational needs;
   (c) the likely effect on him of any change in his circumstances;
   (d) his age, sex, background and any characteristics of which the court considers relevant;
   (e) any harm which he has suffered or is at risk of suffering;
   (f) how capable each of his parents, and any other person in relation to whom the court considers the question to be relevant, is of meeting his needs.

This raises a host of important legal issues not discussed by the courts before: is a non-therapeutic bone marrow harvest in the best interests of a child? Can the plight of a sick sibling be incorporated into the welfare test? Is a speculative psychological benefit enough to authorise the procedure in law?

The HT Authority statistics on child donations show the following (these statistics were requested from the HT Authority by the writer under the Data Protection Act in January 2015 and delivered via email):

<table>
<thead>
<tr>
<th>Year</th>
<th>Child bone marrow/blood stem cell cases approved</th>
<th>Cases rejected</th>
</tr>
</thead>
<tbody>
<tr>
<td>2007–2008</td>
<td>71</td>
<td>0</td>
</tr>
<tr>
<td>2008–2009</td>
<td>57</td>
<td>0</td>
</tr>
<tr>
<td>2009–2010</td>
<td>78</td>
<td>0</td>
</tr>
<tr>
<td>2010–2011</td>
<td>67</td>
<td>0</td>
</tr>
<tr>
<td>2011–2012</td>
<td>68</td>
<td>0</td>
</tr>
<tr>
<td>2012–2013</td>
<td>69</td>
<td>0</td>
</tr>
<tr>
<td>2013–2014</td>
<td>78</td>
<td>0</td>
</tr>
</tbody>
</table>

It is unclear how many of these bone marrow donations are from children old enough to experience a speculative psychological benefit, but the consistent zeros are a cause for concern.

*Gillick competence*

A child aged 16 cannot consent to blood and organ donations under the Family Law Reform Act 1959 as a result of the judgment in Re W(A Minor) (Medical Treatment: Court’s Jurisdiction) [1993] Fam 64:

Lord Donaldson: “The section [8] extends not only to treatment, but also to diagnostic procedures; see subsection (2). It does not, however, extend to the
donation of organs or blood since, so far as the donor is concerned, these do not constitute either treatment or diagnosis” (at page 78).

Nolan LJ: “The section does not cover, for example, the giving of blood… the jurisdiction of the court should always be invoked. I would say the same of a case in which a child of any age consented to donate an organ: such a case is not, of course, covered by section 8 of the Family Law Reform Act 1969” (at pages 92 and 94).

The only alternative is a common law consent under Gillick v West Norfolk and Wisbech Area Health Authority [1986] AC 112, as explained by Lord Scarman:

 “…the parental right to determine whether or not their minor child below the age of 16 will have medical treatment terminates if and when the child achieves a sufficient understanding and intelligence to enable him or her to understand fully what is proposed…” (at pages 188–189).

The HT Authority guidelines (above) state that a Gillick competent child can consent to a bone marrow donation, but this is not necessarily true. The courts have frequently overruled the opinions of teenagers because their competent decisions often lead to more burdens than benefits: Re R [1992] Fam 11; Re E (A Minor) (Wardship: Medical Treatment) [1992] 2 FCR 219; Re W (A Minor) (Medical Treatment: Court’s Jurisdiction) [1993] Fam 64; Re E (A Minor) (Wardship: Medical Treatment) [1994] 5 Med LR 73, and Re P (Minor) [2003] EWHC 2327.

The opinion of the child is not even considered in some cases. In Re P (A Minor) [1986] 1 FLR 272 for example, Butler-Sloss LJ stated that the child’s wishes should not be given “such paramount importance” as to be conclusive (at page 279). In Re E (unreported) 21 September 1990, Ward J directly addressed the issue when he stated: “whether or not he is of sufficient understanding to have given consent or to withhold consent is not the issue for me” (this case is taken from the judgment of Strouton LJ in Re R (A Minor) (Wardship: Consent to Treatment) [1992] Fam 11 at page 28). Therefore, parents of older saviour siblings (and the HT Authority) should not necessarily rely on Gillick competence to validate a bone marrow harvest in law. The lack of therapy distinguishes the harvest from other medical treatments, and a speculative psychological benefit has never been confirmed as an acceptable key to the lock of consent for a bone marrow harvest on a child (per Lord Donaldson MR in Re R [1992] Fam 11 at page 22: “consent itself creates no obligation to treat. It is merely a key which unlocks a door”).

Parental consent

The High Court has no problem in overruling parents who do not put the needs of the child before their own. The “reasonable and responsible parent” test was laid down in Re J (A Minor) (Wardship: Medical Treatment) [1991] Fam 33, confirming that parents can often be subjective in their views, per Balcombe LJ at pages 50 and 52. A starker warning was delivered by Wilson J in the now iconic judgment of Re C (A Child) (HIV Test) [2000] Fam 48 where a mother refused to test her baby for HIV:

“This case is not at its heart about the rights of the parents. And if, as he in effect suggested in his evidence, the father regards the rights of a tiny baby as subsumed within the rights of the parents, he is wrong. This baby has rights of her own. They can be considered nationally or internationally. Under our national law I must determine the case by reference to her welfare” (at page 61).

This decision is clear: the objective rights of the child are not to be subsumed into the subjective ideals of the parents. The most recent case to confirm that the best interests of the child are to be completely separated from the “emotions and wishes” of the parents is An NHS Trust v MB [2006] EWHC 507 (per Holman J at paragraph 16), consolidating a passage from Wyatt v Portsmouth Hospital NHS Trust [2005] EWCA Civ 1811. In support of this, a small group of cases has developed whereby court approval must be sought before the non-therapeutic medical procedure is carried out (this was confirmed by Dame Elizabeth Butler-Sloss in Re J (Specific Orders: Child’s Religious Upbringing and Circumcision) [2000] 1 FLR 571, at paragraphs 31–32). Re W (A Minor) [1993] Fam 64 concerned a refusal from a competent minor, and Nolan LJ was of the opinion that court intervention was necessary:

“Where major surgery or other procedures (such as abortion) were proposed, and where the parents were prepared to give consent but the child (having sufficient understanding to make an informed decision) was not, the jurisdiction of the court should always be invoked. I would say the same of a case in which a child of any age consented to donate an organ” (at page 94).

A bone marrow harvest would probably qualify for the “small group of important decisions” because it involves an internal interference with the body under
a general anaesthetic. Immunisations are to be added to the group too; per Thorpe LJ in *B (Child)* [2003] EWCA Civ 1148, at paragraph 17. However, according to the HT Authority guidelines, a harvest can be authorised on a competent child “locally” (at paragraph 26). In light of the dubiousness surrounding *Gillick* competence and non-therapeutic medical procedures, and the judicial approach to subjective parents, it is submitted that High Court approval should be sought in *every* child donation case to ensure the objective best interests of the child.

**The High Court**

In the event that the case does reach court for approval, what is the likely outcome after an application of the welfare test under s.1 of the Children Act 1989? The risks of donation are significant, including artery rupture, transfusion, scarring, and anaemia. Therefore, any psychological benefit must “leave the account in significant credit” confirmed by Thorpe LJ in *Re A (Male Sterilisation)* [2000] 1 FLR 549.

The common law has already rejected two views in support of bone marrow harvests on children: (i) that it is acceptable to balance the plight of the sick against the health of the saviour, and (ii) that it is acceptable to merge the interests of the saviour with other family members. Firstly, the court in *McKay v Essex Area Health Authority* [1982] QB 1166 refused to measure the consequence of death, rendering the morbidity of the sick sibling irrelevant (see Lord Ackner at page 1189 and Lord Griffiths at page 1192). The U.S. courts came to the same conclusion in *Gleitman v Cosgrove* 227 A.2d 689 (N.J. 1967). Lord Morris also warned of prejudice in *S v M* [1972] AC 24:

> “D is a separate party in the issue which is to be tried. Her position and her future are at stake. The interests of the other parties must not be advanced by those other parties so as to prejudice or to dominate over the interests of D” (at page 53).

Sir John Pennyruick in *Re X (A Minor) (Wardship: Jurisdiction)* [1975] Fam 47 later added that any third parties included in welfare deliberations were *not* to be family members (at page 61). The minor was also placed at the heart of proceedings in *Re B (A Minor) (Wardship: Sterilisation)* [1988] AC 199, *Re A (Medical Treatment: Male Sterilisation)* [2000] 1 FLR 549, and *Re A (Children) (Conjoined Twins: Surgical Separation)* [2001] Fam 147.

“Secondly, the courts have openly rejected a merging of interests, i.e. the interfamilial principle,” unless both siblings are warded at the same time. This occurred in *Court of Appeal* [1993] 1 FLR 883 and Balcombe LJ stated at pages 890–892: “paramount means above all others in rank, order or jurisdiction…” (see also Evans LJ at page 899). This was confirmed in *Birmingham City Council v H (A Minor)* [1994] 2 AC 212 per Lord Slynn:

> “That child is the subject matter of the application. The question to be determined relates to that child’s upbringing and it is that child’s welfare which must be the court’s paramount consideration. The fact that the [other party] is also a child does not mean that both [parties’] welfare is paramount and that each has to be balanced against the other” (at page 222).

It is clear that there are to be no balancing exercises and no merging of interests under the welfare test. The donor is entitled to stand alone in her paramountcy. We are left with nothing but a speculative desire for the family unit to be complete. The law has not confirmed that this is enough to validate a non-therapeutic medical procedure on a child. In *Re Y (Mental Patient: Bone Marrow Donation)* [1997] Fam 110 Connell J validated the harvest on an incompetent adult donor on the grounds that the relationship between Y and her mother would be improved if the sick sister survived (at pages 115–116).

**Conclusion**

The HT Authority relies on *Gillick* competence to validate bone marrow harvests on older child donors. *Gillick* has never been confirmed in law as applicable to non-therapeutic medical procedures, which are distinguishable from regular diagnostic and therapeutic treatments because there are no physical benefits, and any psychological benefits are purely speculative. The High Court has previously disposed of parental consent if it is too subjective – the objective best interests of the donor are paramount in accordance with s.1 of the Children Act 1989. The courts will not balance the plight of the sick child against the minimal detriment to the saviour child, nor will they merge the interests of several parties via the interfamilial principle unless both children are warded at the same time.

We are left with a competent child pressured to undergo an invasive non-therapeutic medical procedure to save a sibling. Consent may be real, but it is not confirmed as authoritative in light of the purely speculative social benefit to be achieved. Parental consent is too fraught to be objective. It is concluded that without court approval bone marrow harvests on children are on shaky legal ground.
References

5. For an Australian-based perspective on the welfare of the saviour sibling, including feminist and communist ethics, see Taylor-Sands, M. *Saviour siblings: a relational approach to the welfare of the child in selective reproduction*. Oxford: Routledge, 2013.