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The Human Tissue Authority and Saviour Siblings

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Abstract

It is widely accepted that a child under the age of eighteen can donate his or her bone marrow to a sick sibling in the hope of saving their life. The Human Tissue Authority in the United Kingdom has published guidelines (currently under review) relating specifically to the harvest of blood and tissues from children, but the law has not yet confirmed the validity of such procedures. Younger donors require parental consent which can be highly subjective given the circumstances, and a Gillick consent from an older child is not confirmed in law as applicable to non-therapeutic medical procedures. This article suggests that the current child donation procedures under the Human Tissue Authority are not legally tenable and do not support the welfare of the child.

Keywords: Human tissue authority; Minors; Donation; Saviour siblings; Welfare

Introduction

The creation of saviour siblings using fertility treatment is now possible in the United Kingdom as a result of the decision in Quintavalle v Human Fertilisation and Embryology Authority (and Secretary of State for Health) (2005) 2 A.C. 561. Lord Hoffman stated that the word 'suitable' under schedule 2 paragraph 1 (1) (d) of the Human Fertilisation and Embryology Act 1990 was to be read subjectively according to the desires of the mother. The Human Fertilisation and Embryology Act 2008 inserted the following passage into the 1990 Act as a result of the judgment:

Schedule 2: Activities that may be licenced under the 1990 Act.

Paragraph 1ZA (1): A licence…cannot authorise the testing of an embryo, except for one or more of the following purposes:

(d) in a case where a person ('the sibling') who is the child of the persons whose gametes are used to bring about the creation of the embryo (or of either of those persons) suffers from a serious medical condition which could be treated by umbilical cord blood stem cells, bone marrow or other tissue of any resulting child, establishing whether the tissue of any resulting child would be compatible with that of the sibling.

The Lords in Quintavalle did not wish to address the wider ethical issues of creating babies for the purposes of harvesting bone marrow or whether the procedure would even be legal considering the young age of the donors. Lord Hoffman preferred to let the Human Fertilisation and Embryology Authority "grapple with such issues" at its discretion (per Lord Hoffman at paragraph 26). There is now a significant loophole in the law as a result of Quintavalle and the following questions require further investigation: what are the Human Tissue Authority guidelines on bone marrow donation from child donors and do they support the welfare of the child? How much importance is placed on parental consent in light of its unusual subjectivity? Is a psychological benefit required for a child donor and if so, how much awareness must the child have for it to manifest? Are measures in place to identify coercion? In the case of older donors could a Gillick consent qualify for a non-therapeutic medical procedure, and does the law in similar jurisdictions (e.g. the US) provide any guidance?

The Human Tissue Authority (HT Authority) forwarded statistics as part of this research and its history of child bone marrow donations states the following: (Table 1).

The constant "zero" in the cases rejected column suggests that the HT Authority is satisfied that its guidelines have been met in every single child donation case since 2007. The High Court has not yet confirmed the validity of bone marrow harvests on children in law, making these statistics curious. It is time to examine the HT Authority guidelines (which are due to be updated in 2016) to reveal whether the welfare of the child donor is supported throughout the donation process.

The human tissue authority guidelines

The Human Tissue Authority in the United Kingdom has published guidelines - Code of Practice 6: Donation of Allogeneic Bone Marrow and Peripheral Blood Stem Cells for Transplantation (2014) - on the harvest of bone marrow from children and incompetent adults [1]. An adult donor is always preferable provided there is a suitable match.

The law is fractured when it comes to donations from children. In regards to the storage and use of materials, the Human Tissue Act 2004 allows a child to consent to the storage and use of his bone marrow under section 2(2) and a parent can consent on his behalf if he fails to consent or is unable to consent under section 2(3). These provisions are incorporated into the HT Authority guidelines. There is separate legislation in Scotland entitled the Human Tissue (Scotland) Act 2006 where the different rules are detailed under section 17, but Scotland is outside the ambit of this article.

Year	Child bone marrow/blood stem cell cases approved	Cases rejected
2007 - 2008	71	0
2008 - 2009	57	0
2009 - 2010	78	0
2010 - 2011	67	0
2011 - 2012	68	0
2012 - 2013	69	0
2013 - 2014	78	0

Table 1: Statistics from the Human Tissue Authority (as of January 2015).

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The removal of bone marrow requires a trespass to the child and is covered by common law. A parental consent is usually sufficient for regular medical treatment because of the inherent therapeutic benefit (e.g. immunisations), but consent is not enough to validate an invasive trespass (e.g. a bone marrow harvest) if there is no therapeutic benefit whatsoever (R v Brown [1994] 1 AC 212 per Lord Jauncey and Lord Mustill). Therefore, the role of the HT Authority is to approve the bone marrow harvest as being in the best interests of the child by the powers invested in it under the Human Tissue Act 2004 and the Human Tissue (Quality and Safety for Human Application) Regulations.

In cases requiring approval (i.e. all non-competent children), the clinician responsible for the donor must make a written referral to the HT Authority via an Accredited Assessor (AA). The AA conducts interviews with the donor, the person giving consent on behalf of the donor and the recipient, and then submits a report of the assessment to the HT Authority. The AA must state whether the relevant requirements of the Human Tissue Act 2004 have been met. The HT Authority then makes a final decision. In an examination of how these approval procedures align with the welfare of the child, this article will split child donors into three groups:

i. very young donors;

ii. young donors with enough awareness to refuse; and

iii. Gillick-competent donors.

Very young donor

A child who is too young to consent to medical treatment that is in his best interests can refer a parent or guardian to consent on his behalf. A bone marrow harvest presents a new legal quandary: it has no physical benefit in donors of any age and it has no psychological benefit in very young donors. The approval process is described in plain terms in the HT Authority guidelines:

A. Paragraph 28: Before the HT Authority can approve such cases, the HT Authority must be satisfied that:

1. no reward has been, or is to be, given;

2. consent to removal for the purpose of transplantation has been given;

3. an AA has conducted separate interviews with the donor, the person giving consent, and the recipient and submitted a report of their assessment to the HT Authority.

B. Paragraph 30: Matters to be covered for every interview:

1. evidence of duress or coercion;

2. evidence of an offer of a reward;

3. difficulties in communicating.

C. Paragraph 31: In addition for interviews with the donor and parent:

1. information given as to the nature of the medical procedure and the risks involved;

2. the name of the person who gave that information to the (parent) and their qualification to give it;

3. the capacity of the person interviewed to understand the nature of the medical procedure and the risk involved and that consent may be withdrawn at any time before the removal.

D. Paragraph 82: A person with parental responsibility can consent to storage and use of bone marrow for transplantation on behalf of the child, if the donation is assessed as being in the child's overall best interests, taking into account not only the medical but also emotional, psychological and social aspects of the donation, as well as the risks [1].

The key phrases used in paragraphs 28, 30, 31 and 82 include: 'reward', 'consent', 'interviews', 'communicating', 'overall best interests' and 'emotional, psychological and social aspects'. These paint a picture of wider familial interests where the benefit to the younger donor is spread thinly across the family unit. It is not clear whether this social approach is enough to validate a non-therapeutic medical procedure upon a child in law.

Does the very young donor need awareness?

The HT Authority guidelines state that there must be interviews with the child donor as part of the approval process. This is to determine a benefit to the child as well as to reveal any evidence of coercion. However, the guidelines advise that the consenting parent is present during the interview.

A. Paragraph 60: The HT Authority advises that AA's should interview younger child donors along with the person providing the consent on their behalf.

B. Paragraph 83: It is good practice that the practitioners involved assess the donor child's best interests by talking to the child and the person who has parental responsibility for them.

C. Paragraph 89: In some circumstances children may experience feelings of guilt or a fear that love may be withdrawn if they do not proceed with donation and these feelings could influence the child's decision to donate. In trying to determine whether a child has been coerced into donating, it is important for the AA to discuss any feelings of pressure or duty the child holds and explore their origins.

Paragraph 60 may not be entirely fair. The guidelines list duress, coercion and rewards as concerns regarding young donors, but if the parent is present during the interview the child is far less likely to answer questions honestly (i.e. that mommy promised a trip to Disneyland, for example) for fear of reprisal. The guidelines do, however, acknowledge feelings of guilt or fear.

It is unlikely, if the parent is present, that any meaningful discussions with the child would occur. Adults find it difficult to be honest to colleagues and friends on a daily basis; it would be extra challenging for very young children with their parents present. This is frustrating because they are far more likely to be taken advantage of as a result of their inability to voice their discontent. The Children Act 1989 clearly states under section 1.

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.

(2) 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.

It is not in any child's interests to be coerced, manipulated, prodded or manoeuvred into a non-therapeutic medical procedure. The High Court in the United Kingdom has not ruled on the issue of child donation yet but it is highly unlikely that the welfare test will be used as a mechanism to enforce a bone marrow harvest upon a child who is showing signs of duress. Crouch and Elliott agree that altruism is not a characteristic associated with young children:

"…if the donor is not mentally developed to a sufficient degree, he will not only fail to understand why he is in the hospital and why he has been physically harmed, he will also fail to understand the important role that he has played in the care of his sibling. Thus he may well not receive any psychological benefits as a result of his donation" [2].

A definitive passage by Wilson J in Re C (A Child) (HIV Test) (2000) Fam. 48 made it very clear that parents have no legal right to manipulate, coerce or subsume the rights of their child into their own:

"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."

It would clearly not be appropriate for a parent to use his child to meet his own interests when the child has separate national and international rights, but the HT Authority guidelines do not appear to support the autonomy of the child. If anything, by requesting the parent to stay with the donor child during the interview the HT Authority is encouraging the subjugation of the child's voice (if he is old enough to have one) into the voice of the parent, who is no doubt very supportive of the harvest.

AAs are encouraged to raise concerns about coercion in their report to the HT Authority and a donor, a recipient, a person acting on behalf of either or a medical practitioner can ask for a review, but judging by the statistics (further above) there must have been very few concerns raised because no cases of child donation have yet been rejected since records began in 2007.

A related issue in this section is communication. The ability of the young donor to communicate his thoughts on donation is a significant barrier to proving a psychological benefit and the younger he is, the less likely he is to be aware of the plight of the older sibling. The HT Authority guidelines have advised on this issue:

A. Paragraph 70: The level of communication required for child donors depends on the child's ability to understand the donation procedure.

B. Paragraph 71: Where children are able to understand the donation procedure and give consent, the information should be explained in terms that they find easy to understand - with help from appropriately qualified staff, as required.

C. Paragraph 72: Even small children can be helped to understand some aspects of the procedure and its associated risks. This understanding can be assisted by involving a play therapist, psychologist or specialist nurse in the communication process so that the child can gain a better understanding of what the donation would involve.

Paragraph 72 is a cause for concern. A child who requires a play therapist, a psychologist or a specialist nurse to understand the basics of a bone marrow harvest is probably too young to glean a psychological benefit from the procedure. The suggestion that he would simply benefit from "having a sibling for company" or "having a complete family around her" is not enough, as per Calvo J in the leading U.S. saviour sibling case of Curran v Bosze (1990) 566 N.E.2d 1319:

The psychological benefit is grounded firmly in the fact that the donor and recipient are known to each other as family. Only where there is an existing relationship between a healthy child and his or her ill sister or brother may a psychological benefit to the child from donating bone marrow to a sibling realistically be found to exist…it is not in the best interest of either Allison or James (the twins) to undergo the proposed bone marrow harvesting procedure…it is not possible to discover the child's likely treatment/non-treatment preferences by examining the child's philosophical, religious and moral views, life goals, values about the purpose of life and the way it should be lived, and attitudes toward sickness, medical procedures, suffering and death…at the age of three and a half, it is very difficult if not impossible to predict what a specific individual will do in a specific circumstance at a specific point of time in the future.

The judgment in Curran underpinned our very own saviour sibling case of Re Y (1997) Fam. 110 (examined below), making it a highly influential authority. Other cases on welfare and medical procedures have also pointed to a fundamental connection between awareness and best interests:

1. U.S. common law:

i. Strunk v Strunk (1969) 445 S. W. 2d 145 Ky.: "Jerry (is) greatly dependant on Tommy, emotionally and psychologically, and his well-being would be jeopardised more severely by the loss of his brother than by the removal of a kidney" and "he identifies with his brother".

ii. Hart v Brown (1972) 289 A. 2d 386, Conn. Super Ct.: "(Margaret Hart) desired to donate her kidney so that her sister may return to her", "strong identification with her twin sister" and "it would be a very great loss to the donor if the donee were to die from her illness".

iii. Little v Little (1979) 576 S. W. 2d 493 Tex.: "existence of a close relationship between Anne and Stephen, a genuine concern by each for the welfare of the other" and "awareness by Anne of the nature of Stephen's plight and an awareness of the fact that she is in a position to ameliorate Stephen's burden".

2. U.K. common law:

i. Re B (A Minor) (Wardship: Sterilisation) (1988) A.C. 199: the primary question is one of "welfare and benefit".

ii. Re F (Mental Patient: Sterilisation) (1990) 2 A.C. 1: treatment must "save lives, ensure improvement or prevent deterioration" inferring an actual benefit.

iii. Airedale NHS Trust v Bland (1993) A.C. 789: "the treatment is of no benefit to him because he is totally unconscious".

iv. Re Y (Mental Patient: Bone Marrow Donation) (1997) Fam. 110: adult donor had an "emotional, psychological and social benefit".

v. An NHS Trust v MB (2006) EWHC 507: a balance sheet of actual benefits and burdens helps the judge to objectively deliberate welfare.

In particular is the case of Re A (Male Sterilisation) (2000) 1 F.L.R. 549 where Butler-Sloss L.J. stated that a benefit must be proved:

"In my judgment best interests encompasses medical, emotional and all other welfare issues…An operation to sterilise has to be demonstrated to be in the best interests of the person unable to consent."

The case has to be proved.

The HT Authority guidelines do not place a very strong emphasis on awareness (they do not, for example, limit donation to older children or provide a list of suitable psychiatric benefits). This is a concern because the law clearly states that the benefit has to be proved, and a psychiatric benefit in a child donor can only be proved if he had awareness of that benefit. In conclusion, a very young donor cannot glean a psychological benefit from the harvest. This view is supported in [3-7].

How authoritive is parental consent?

The HT Authority places a great deal of weight behind parental consent in its donation guidelines. This stems in part from section 2 of the Human Tissue Act 2004 which allows a parent to consent to the storage and use of a child's bone marrow if the child cannot consent or fails to reach a decision on consent. The guidelines translate the law as follows:

A. Paragraph 64: The giving of consent is a positive act. For consent to be valid, it must be given voluntarily, by an appropriately informed person who has the capacity to agree to the activity in question.

B. Paragraph 65: In cases where donors are unable to give consent themselves, i.e. children who are not competent to consent, the decision about consent will be made by a person acting on their behalf. In these cases HTA approval will be required.

C. Paragraph 68: Donation is an entirely voluntary act and the donor (and where applicable the person consenting on their behalf) must be free of any kind of coercion or pressure.

D. Paragraph 81: A person who has parental responsibility can consent to the storage and use of bone marrow for transplantation on the child's behalf if there is no decision by the child either to, or not to, consent, and:

1. the child is not competent to deal with the issue of consent to donation for transplantation.

Paragraph 82: The consent of only one person with parental responsibility is necessary.

Paragraph 83: It is good practice that the practitioners involved assess the donor child's best interests by talking to the child and the person who has parental responsibility for them.

These guidelines are disappointing. Consent is described as a 'positive' and 'voluntary' act by an 'appropriately informed person' with 'the capacity to agree' under paragraph 64. This should be the case for every bone marrow donor in light of the non-therapeutic nature of the procedure, but it only serves to highlight that a newly born or toddling donor cannot meet any of these criteria and his parent effectively substitutes his lack of capacity in order to push the harvest forward. Paragraph 68 requires the consenting parent to be 'free from coercion or pressure', but this must turn a blind eye to the situation at home where the other sibling is morbidly ill and in need of a life-saving bone marrow donation. Paragraph 82 requires only one parent to consent, but it is unlikely that the second parent would disagree if their child is facing death in the near future. Finally, paragraph 83 is particularly unsatisfactory in that it incorporates the opinions of third parties (the parents) into the assessment process. The autonomy of the very young donor is not supported here if the parent is in a desperate predicament.

It appears, as far as the HT Authority guidelines are concerned, that parents can substitute the silence of the donor child with a positive, voluntary and informed consent on his behalf (subject to approval). This consent would be highly subjective because of the situation at home.

Fortunately, the common law has grappled with parental consent in controversial cases and readily disposed of it when the best interests of the child are not supported. The law is quite settled on this point, even in medical cases where the facts are grave.

S v M (1970) 1 W.L.R. 672 was the first modern case to move away from the old notion that parents always know best for their child, per Sachs L.J.:

"…the parens patriae jurisdiction is one for the benefit and protection - I emphasis the words 'and protection' - of the infant; and that it…can be something very different from the self-centred interests that adults may have in sorting out their own affairs…upon the authorities that I have seen to date, one should look at what are the paramount interests of the child: other interests are subordinate unless they either coincide with them or unless there is some exceptional reason for giving effect to them."

The phrase 'self-centred interests' is intriguing - could the parents of saviour siblings be securing their own interests when presenting their child for harvest? To put it another way, would they consent to the harvest and its inherent risks if they had never met the sick child (i.e. he was adopted at birth)?

The first modern medical case to expressly reject the views of the parents was Re B (A Minor) (Wardship: Medical Treatment) (1981) 1 W.L.R. 1421:

"While great weight ought to be given to the views of the parents they are not views which necessarily must prevail…Fortunately or unfortunately, in this particular case the decision no longer lies with the parents or with the doctors, but lies with the court…The judge was much affected by the reasons given by the parents and came to the conclusion that their wishes ought to be respected. In my judgment he erred in that the duty of the court is to decide whether it is in the interests of the child that an operation should take place… (the court) cannot hide behind the decision of the parents or the decision of the doctors; and in making the decision this court's first and paramount consideration is the welfare of this unhappy little baby."

The common law continued to travel in this direction with the following high profile cases:

a) Re K.D. (A Minor) (Ward: Termination of Access) (1988) A.C. 806: "When the jurisdiction of the court is invoked for the protection of the child the parental privileges…become immediately subservient to the paramount consideration which the court always has in mind, that is to say, the welfare of the child."

b) Re F (Mental Patient: Sterilisation) (1990) 2 AC 1: "(court) guidance should be sought in order to obtain an independent, objective and authoritive view on the lawfulness of the procedure."

c) Re J (A Minor) (Wardship: Medical Treatment) (1991) Fam. 33: "the court adopts the standpoint of the reasonable and responsible parent who had his or her child's best interests at heart."

d) Re E (A Minor) (Wardship: Medical Treatment) (1992) 2 FCR 219: "I regret that I find it essential for his well-being to protect him from himself and his parents, and so I override his and his parents' decision."

e) Re Z (Identification: Restrictions on Publication) (1997) Fam. 1: "the role of the court is to exercise an independent and objective judgment. If that judgment is in accord with that of the devoted and responsible parent, well and good. If it is not, then it is the duty of the court to give effect to its own judgment."

f) Re T (A Minor) (Wardship: Medical Treatment) (1997) 1 W.L.R. 242: "paramountancy will compel the court to substitute the judge's own views over those of natural parents - even in a case where the views of the latter are supported by qualities of devotion, commitment, love and reason."

The most recent notable case on the best interests of children is Wyatt v Portsmouth Hospital NHS Trust (2005) EWCA Civ 1811 in which the wishes of the parents were described as "wholly irrelevant":

(i) …it is the role and duty of the court to…exercise its own independent and objective judgment;

(iv) The matter must be decided by the application of an objective approach or test;

(v) That test is the best interests of the patient. Best interests are used in the widest sense and include every kind of consideration capable of impacting on the decision. These include, non-exhaustively, medical, emotional, sensory (pleasure, pain and suffering) and instinctive (the human instinct to survive) considerations;

(x) The views and opinions of both the doctors and the parents must be carefully considered. Where the parents spend a great deal of time with their child, their views may have particular value because they know the patient…although the court needs to be mindful that the views of any parents may, very understandably, be coloured by their own emotion or sentiment…Their own wishes, however understandable in human terms, are wholly irrelevant to consideration of the objective best interests of the child.

The case law above draws a very strong picture of objectivity. The High Court plays the role of the reasonable parent in difficult medical cases and the consent of the parents is not decisive no matter how grave the circumstances are (as stated in: Re J (A Minor) (Wardship: Medical Treatment) (1991) Fam. 33 per Balcombe L.J.; Re E (A Minor) (Wardship: Medical Treatment) (1992) 2 FCR 219 per Ward J and Re Z (Identification: Restrictions on Publication) (1997) Fam. 1 per Sir Thomas Bingham MR). The wishes of the parents to either be included in deliberations of welfare, to subsume the rights of their child into their own or to instil their own altruistic ideals into their child are rejected in favour of the welfare of the child under Section 1(3) of the Children Act 1989. It is often disappointing for parents to learn that their views have no influence but if, in a child bone marrow donation case, the judge found it to be in his best interests to donate bone marrow to her older sibling, the decision would have had nothing to do with his parents. Judges can choose to listen to and consider their views, but nothing more. This occurred in the US in Curran v Bosze (1990) 566 N.E.2d 1319, but the idea of an "open future" for children dates back to 1891 in Union Pac. R.R. Co. v Botsford (1891) 141 U.S. 250:

"…no right is held more sacred, or is more carefully guarded by the common law, than the right of every individual to the possession and control of his own person, free from all restraint or interference of others, unless by clear and unquestionable authority of law."

The US courts have since recognised that children have a "legal right to begin life with a sound mind and body" as in Stallman v Youngquist (1988) 531 N.E.2d 355 (Illinois Supreme Court) at page 360, supporting the idea that they are independent legal entities with their own rights. Turning back to the HT Authority guidelines, it now seems inappropriate that a parent should give a positive, voluntary and informed consent on the child's behalf to a non-therapeutic medical procedure. It is substituted altruism. The donor cannot be interviewed separately because not only is he too young but the guidelines encourage parents to be present (paragraphs 60 and 83). This does not support the welfare of the child because he is unable to be considered as an autonomous person in his own right. In conclusion, his paramountancy is lost.

What are social interests?

The approval process of the HT Authority is summed up in one paragraph and it is of particular interest:

A. Paragraph 82: A person with parental responsibility can consent to storage and use of bone marrow for transplantation on behalf of the child, if the donation is assessed as being in the child's overall best interests, taking into account not only the medical but also emotional, psychological and social aspects of the donation, as well as the risks (emphasis added) [1].

Parents have the power to consent to the storage and use of bone marrow under the Human Tissue Act 2004 (section 2), but the removal of bone marrow has to be approved by the HT Authority using the conditions set out in paragraph 82. These should align with the statute and common law of welfare because a non-therapeutic removal of bone marrow must be shown to support the welfare of the child before it can be carried out. A reminder of the welfare test reveals a strong alignment to paragraph 82:

Children Act 1989

Section 1: Welfare of the child.

(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.

It is notable, however, that the term 'social' does not feature in the welfare test under the 1989 Act. 'Social' alludes to wider familial benefits

and this was rejected by the common law in Re A (Male Sterilisation) (2000) 1 F.L.R. 549 by Butler-Sloss L.J. who wanted to focus on the other needs of the patient:

"…in my judgment best interests encompasses medical, emotional and all other welfare issues…social reasons for carrying out of non-therapeutic invasive surgery is not part of the present state of the law…An operation to sterilise has to be demonstrated to be in the best interests of the person unable to consent."

A bone marrow harvest could be described as a social procedure in that it is carried out for the emotional benefit of the wider family, but it is clear according to Butler-Sloss L.J. that it is not appropriate to ponder social reasons when deliberating the welfare of an incompetent patient. So where did the 'social' element come from in the HT Authority donation guidelines? The leading (and only) case on saviour siblings in the United Kingdom is Re Y (Mental Patient: Bone Marrow Donation) (1997) Fam. 110. The donor (aged 25) was severely handicapped and lived in a community care home. Her older sister (aged 36) suffered from myelodispastic syndrome and the donor was a good match. The legal quandary was described by Connell J:

"the taking of blood tests and the harvesting of bone marrow from the (donor), who is incapable of giving informed consent, would amount to assaults upon the (donor) and would therefore be illegal unless shown to be in the best interests of the (donor) and therefore lawful."

Connell J decided, despite the lack of awareness on the donor's part, to authorise the bone marrow harvest on the grounds that the connection between the mother and sick sister was strong enough to emotionally and socially benefit the donor:

"In this situation, the (donor) would clearly be harmed by the reduction in or loss of contact with her mother. Accordingly, it is to the benefit of the (donor) that she should act as donor to her sister because in this way her positive relationship with her mother is most likely to be prolonged. Further, if the transplant occurs, this is likely to improve the (donor's) relationship with her mother who in her heart clearly wishes it to take place and also to improve her relationship with the plaintiff who will be eternally grateful to her…it is relevant to ask the question, why subject the (donor) to this process? To this the answer, in my judgment…is because it is to her emotional, psychological and social benefit."

The judgment in Re Y (1997) is difficult to reconcile with the common principles of welfare law. While it is accepted that there is not a paramountancy test for incompetent adults (the best interests test under the Mental Capacity Act 2005 section 4(6) didn't exist at the time), there is still a need to ensure that the welfare of the donor is placed above third parties. Connell J made it clear that the plight of the mother (who was very unwell) and the sick sibling played a large role in his decision to authorise the harvest. This is the interfamilial principle, which places the needs of the wider family into the same melting pot as those of the patient/donor/ward. It clashes with the notion of paramountancy. Children are protected by a much stricter welfare test under the Children Act 1989, but the HT Authority seems to be unaware of this according to its 2014 guidelines:

Paragraph 82: …taking into account not only the medical but also emotional, psychological and social aspects of the donation, as well as the risks.

If social aspects were rejected in an incompetent adult case (Re A), they are highly unlikely to feature in a stricter welfare test for children. Paragraph 82 may need to be urgently addressed - social aspects should not authorise a non-therapeutic medical procedure upon a child. In conclusion, wider familial interests should play no part in the deliberation of the best interests of the very young donor.

As a side line, distressed parents who attempt to justify a bone marrow harvest upon their newly born or toddling child by instigating a balancing act between the siblings may be told by the High Court that it is not appropriate. This is another social approach in determining the welfare of the child and it was rejected in Re X (A Minor) (Wardship: Jurisdiction) (1975) Fam. 47:

"It would be quite impossible to protect award against everything which might do her harm. In particular, the jurisdiction must be exercised with due regard to the rights of outside parties whether such rights arise at common law or by contract or otherwise. By "outside parties" I mean those not in a family or personal relation to the ward."

In fact, only if the siblings are warded together is it appropriate to balance the burden to one against the plight of another (it has been confirmed in common law that the welfare of siblings can only be offset if they are both warded in the same case at the same time: Court of Appeal (1993) 1 FLR 883 per Balcombe LJ, and Birmingham City Council v H (A Minor) (1994) 2 AC 212 per Lord Slynn.

In summary of very young donors, the HT Authority donation guidelines place a heavy emphasis on parental consent, do not require full awareness from the donor, are not clear on psychological benefits, do not support the paramountancy of the child, and include social aspects in deliberations of welfare despite the common law advising not to. This is disappointing. It may have too much discretion and not enough legal precedent to help construct a more rigorous approval process.

Older child donors

Older children who have not acquired Gillick competence but can communicate effectively and can glean a psychological benefit (i.e. perhaps between the ages of 4 - 12) have an even more interesting position in law. If they understand the procedure and consent to the procedure there is simply the question of a psychological benefit to resolve (the approval process detailed above will be applied). If they understand the procedure and refuse the procedure, there is no avenue left for the HT Authority to pursue. The statute law for storage and use of materials only allows parents to consent on the child's behalf if the child fails to reach a decision:

Human Tissue Act 2004

Section 2: Appropriate Consent: Children

(3) Where:

a) the child concerned is alive;

b) neither a decision of his to consent to the activity, nor a decision of his not to consent to it, is in force, and

c) either he is not competent to deal with the issue of consent in relation to the activity or, though he is competent to deal with that issue, he fails to do so,

'appropriate consent' means the consent of a person who has parental responsibility for him.

This is transferred into the HT Authority guidelines:

A. Paragraph 81: A person who has parental responsibility can

consent to the storage and use of bone marrow for transplantation on the child's behalf if there is no decision by the child either to, or not to, consent, and:

1. the child is not competent to deal with the issue of consent to donation for transplantation (i.e. non-Gillick competent).

The common law on removal of materials arrives at the same point: a refusal to harvest bone marrow would mean there is no psychological benefit to the child. In fact, there would be clear psychological burdens such as fear of operations, fear of losing a body part, spite, resentment, force, manipulation, exploitation, guilt, rejection and fear of being treated as an insurance policy, not to mention the physical risks such as bone fracture, bone infection, rupture of an artery, skin scarring, hypertension, anaemia, broken needles, blood transfusion and pain [4, 8-12]. Life threatening risks that have been reported in real cases include non-fatal cardiac arrest, pulmonary embolus, aspiration pneumonitis, ventricular tachycardia and cerebral infarction (connected to the general anaesthetic) [13]. The result, it would seem, is the end of the road for the HT Authority, which is unable to authorise a non-therapeutic medical procedure on a child unless it is found to be in his psychological interests. The HT Authority has taken account of this scenario and has suggested the jurisdiction of the High Court:

B. Paragraph 107: Where a child is a potential bone marrow donor and not competent to consent, a person with parental responsibility can consent to donation on behalf of the child if the donation is assessed as being in the child's overall best interests. However, where there is a dispute between persons with parental responsibility, or between them and the clinicians looking after the child, or there is a doubt as to best interests, the court should be asked to rule in advance.

C. Paragraph 108: In such cases, a court declaration on best interests should be in place before the case is referred to the HT Authority for a decision on approval for the donation to proceed.

Paragraph 107 provides the triggers for court intervention:

i. a dispute between parents;

ii. a dispute between parents and clinicians;

iii. a general doubt as to best interests.

An older child who has not yet reached Gillick competence but refuses the harvest would probably fall under category (iii). The High Court in the UK, using its inherent jurisdiction, would finally get to apply the welfare test under section 1 of the Children Act 1989. The law of welfare in a medical context has already been examined (above) and it is clear that the welfare of the donor child would be paramount. It is also clear that he must have awareness of a psychological benefit, parental consent is not decisive, substituted altruism is not acceptable, social aspects are not to be included in deliberations of welfare, and the discomfort to the donor child is not to be placed in a balancing exercise against the sick sibling. The primary concern of the High Court should a saviour sibling case arrive on its doorstep is the welfare of the donor.

The HT Authority guidelines confirm that should the donor child become a ward of court the Family Proceedings Rules 1991 SI 1247 ensure that a family lawyer at the Children and Family Court Advisory and Support Service (CAFCASS) is involved. A guardian ad litem (litigation friend) will also be appointed by the court for the child to ensure independent representation and to safeguard the interests of the donor child. In these circumstances the guardian will almost certainly be a member of staff at CAFCASS. It is worth noting a concern, however, that the independent guardian may have a family of her own and be highly sympathetic towards the plight of the parents. The AA is also based in the bone marrow transplant unit within the relevant hospital, incorporating a further element of subjectivity into the approval process.

In summary of older child donors, the lack of case law so far suggests a few possibilities:

a) babies and toddlers have been accepted for harvest despite it being very difficult to prove a psychological benefit and despite their inability to effectively communicate how they feel about the procedure;

b) children who are not old enough to be deemed Gillick competent are found to be free of duress or coercion despite their parents being present in interviews with the Accredited Assessor;

c) any children who have refused the procedure have been overridden with parental consent despite no legal provision allowing the parents or the HT Authority to do so; or

d) the social aspects of donation are still considered by the HT Authority even though 'social reasons' to carry out non-therapeutic medical procedures are specifically excluded from the deliberation of welfare under common law (Re A).

What is most disappointing, above everything else, is that only in the event of a disagreement is High Court guidance sought and the welfare test under the Children Act 1989 applied. The welfare test and its associated case law should, it is submitted, be applied to every single case of non-competent child donation to ensure the welfare of the child.

Gillick-Competent donors

A Gillick-competent child can consent as an adult donor without a rigorous approval process. Lord Scarman in Gillick v West Norfolk and Wisbech Area Health Authority (1986) AC 112 stated:

"…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…it is not enough that she should understand the nature of the advice which is being given: she must also have a sufficient maturity to understand what is involved."

An older child donor can therefore consent to the removal of her bone marrow (and its storage and use) if he has sufficient intelligence and maturity to understand the harvest, storage and use of his materials.

The Human Tissue Act 2004 includes a provision on consent:

Section 2: Appropriate consent: children

(2) Where the child concerned is alive, 'appropriate consent' means his consent.

The HT Authority has incorporated the law into its donation guidelines as follows:

A. Paragraph 26: Under the HT Act 2004 and the HT Act (Persons who Lack Capacity to Consent and Transplants) Regulations 2006 donation of bone marrow both by adults with capacity and children competent to give consent may be approved locally.

B. 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'.

C. Paragraph 78: Even if the child is competent to consent, it is

good practice to consult the person who has parental responsibility and to involve them in the child's decision-making about whether to donate bone marrow for transplantation. However, it should be emphasised that if the child is competent the decision to consent must be theirs.

D. Paragraph 79: It is also essential to make sure that a child has consented voluntarily and has not been unduly influenced by anyone else: where older children are the donors, matters should be discussed with them first, where possible in the absence of the person with parental responsibility.

E. Paragraph 81: A person who has parental responsibility can consent to the storage and use of bone marrow for transplantation on the child's behalf if there is no decision by the child either to, or not to, consent, and:

2. even though the child is competent to do so (i.e. Gillick competent), they have not made a decision about consent to donation for transplantation.

These guidelines are difficult to understand. Firstly, paragraph 26 confirms that Gillick-competent children can be approved locally without the need for a rigorous approval process. This is a cause for concern. It is open to debate whether a child donor is Gillick competent or not, and it is unsettling that older children can be harvested without the same rigorous approval process as younger children (an interview to identify coercion, for example). Simply because the older child consents to the harvest and the transplant unit deem him to be competent it does not mean that he is not vulnerable to coercion or emotional blackmail. If anything, older children may be better able to hide the pressure they feel from family members, agreeing to the harvest for fear of reprisal. It is worth noting that incompetent adult donors, in comparison, always require court approval before the HT Authority can even consider the donation (this is confirmed in paragraph 36 of the donation guidelines and by Connell J in Re Y (Mental Patient: Bone Marrow Donation) (1997) Fam. 110. The reason for this discrepancy is not explained.

Secondly, paragraph 75 states that Gillick competence is determined by the bone marrow transplant unit but it is not clear what experience it has of determining the competence of children. It is also a subjective assessor in that it harvests the bone marrow. An older child would know this and may find it impossible to be open about her feelings. Thirdly, paragraphs 78 and 79 are slightly contradictory: it is recommended that the person with parental responsibility should be involved in the child's decision to harvest, yet it is stated that the child should be interviewed on his own to avoid being unduly influenced by anyone else. A parent who is facing the death of his sick child could exert a huge influence on a teenage donor, so if the Gillick-competent child is to be treated as an adult in law then perhaps the parent(s) should not be involved? Paragraphs 78 and 79 also make the point that the decision to harvest must be voluntary and must come from the child, but these elements do not necessarily prove Gillick competence. Finally, paragraph 81 confirms that parents have the right to consent on behalf of their Gillick-competent child if he has not made a decision about donation. Therefore, should the competent child issue a refusal, the parents do not have the legal authority to override it.

It is worth noting that Gillick refusals have been rejected in common law for therapeutic medical procedures. Teenagers have refused life-saving medical treatment in the past and the High Court has overruled them for their own good. This occurred in:

a) Re R (A Minor) (Wardship: Consent to Treatment) (1992) Fam. 11 (CA);

b) Re E (A Minor) (Wardship: Medical Treatment) (1993) 1 FLR 386 [14];

c) Re S (A Minor) (Wardship: Medical Treatment) (1994) 2 FLR 1065;

d) Re L (Medical Treatment: Gillick Competence) (1998) 2 FLR 810 [15];

e) Re P (A Child) (2003) EWHC 2327.

However, a bone marrow harvest can be distinguished from these cases on four grounds:

(i) there is no therapeutic benefit to a bone marrow donation;

(ii) its validity in law is not yet confirmed;

(iii) the Human Tissue Act 2004 does not give a parent the authority to consent over a refusal, and

(iv) a psychological benefit would not be present in the child if he refused the procedure. There is no altruistic joy, only resentment and anger.

Therefore, should a competent child refuse the harvest the case should go to High Court under paragraph 107 of the HT Authority guidelines. This has not occurred yet. In summary of Gillick-competent donors, they can be just as vulnerable as other child donors and the legitimacy of their consent to such a procedure is not yet confirmed in UK law.

Conclusion

The donation guidelines published by the HT Authority are not convincing in their efforts to protect the interests of the donor child. Very young donors have numerous legal requirements including awareness for a psychological benefit to manifest, paramountancy in a national and international context and the obligation that social aspects be removed from the deliberation of welfare. These are not provided for in the current donation guidelines. Ideally, older donors (both non-competent and Gillick-competent) should be taken to the High Court in the event that they strongly oppose the donation, but no cases have been rejected since records began in 2007. It is also worth noting that there is no record of Gillick-competence ever being applied to a non-therapeutic medical procedure. It is effectively a child consenting to serious harm for no good reason and this idea was outlawed in R v Brown (1994) 1 AC 212.

It is also a particular concern that bone marrow harvests on very young children can be approved despite: parents being present in interviews for coercion; very young donors requiring play therapists just to communicate properly; Gillick-competence being taken at face value with no approval process; the Accredited Assessor working in the relevant bone marrow transplant unit, and the High Court being referred to by the HT Authority only when there is a disagreement as to the best interests of the child. Paramountancy is lost, and the evidence is stronger than ever that the donor child is being used as a commodity. The old argument that the discomfort of the saviour child should be balanced against the plight of the sick child is proven as unacceptable in law.

In light of the fact that a bone marrow harvest on a child (of any age) has never been approved by the High Court in the UK it is surely wise to refer to the welfare test (and its accompanying common law) under s.1 of the Children Act 1989 for every case of child donation. This would ensure that the paramountancy of the child is restored. The

donation guidelines are due to be updated by 2016, and it is hoped that the focus will be shifted back onto the welfare of the donor.

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