

QUINTAVALLE: THE QUANDARY IN BIOETHICS

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I. INTRODUCTION

The case of *R. (Quintavalle) v. Human Fertilisation Embryology Authority (and Secretary of State for Health)* [2005] 2 A.C. 561¹ (“*Quintavalle*”) presents a handful of legal problems. The provisions of the Human Fertilisation and Embryology Act 1990 (as amended, the “1990 Act”)² were interpreted very widely to allow a mother to select embryos for implantation according to her tissue-match preferences. This right is now enshrined into law:

Human Fertilisation and Embryology Act 2008

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.³

The biggest legal query to arise from the case is the inevitable harvest of babies, toddlers and very young children for their bone marrow. This non-therapeutic procedure has never been authorised by the courts and the welfare test under section 1(3) of the Children Act 1989 would no doubt require some form of physical or psychological benefit to the donor child (which is not easy to prove in a baby or a toddler).⁴ There is an additional ethical problem in that embryos can now be created specifically for the purposes of harvest. There is nothing new in conceiving children to meet the desires of their parents (e.g. to take over the family business, to keep the older sibling company, etc.) but the screening technology was not designed to create embryos specifically for participation in non-therapeutic medical procedures after birth. In addition, the 1990 Act was composed strictly in light of its controversial nature but its wide interpretation by the lords surprised many, and what of the embryos that do not provide a tissue match? There is an embryo wastage issue that was not addressed by the lords despite embryos enjoying a good deal of protection in law.⁵

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R (*Quintavalle*) v. Human Fertilisation Embryology Authority (and Secretary of State for Health), [2005] 2 A.C. 561 (H.L.).

2 Human Fertilisation and Embryology Act, 1990, c. 37 (Eng.).

3 Human Fertilisation and Embryology Act, 2008, c. 22, § 11, sch. 2 (Eng.).

4 The Human Tissue Act 2004 allows for the storage and use of materials from children under section 2, but not removal. This is left to the common law. Human Tissue Act, 2004, c. 30 (Eng.).

5 Embryos created during fertility treatment only tend to be frozen for future use when the couple are genuinely struggling to conceive, leading to an increased wastage of healthy embryos. Human Tissue Act, 2004, c. 30 (Eng.).

This article unpacks the judicial story behind *Quintavalle* to reveal how the strict provisions of the Human Fertilisation and Embryology Act 1990 - namely 'suitable condition' under schedule 2 paragraph 1(1)(a) and 'treatment services' and 'assisting' under section 2(1) - were widely misinterpreted to introduce the social selection of embryos into law.⁶ The legal loopholes created by the judgment (embryo wastage, welfare, eugenics and the legality of child harvest in particular) are also identified. It will be concluded that screening for a tissue match is social selection despite arguments to the contrary and that parents are not yet entitled in law to harvest a very young child for bone marrow, making the creation of a saviour sibling under the 1990 Act as a result of *Quintavalle* ultimately futile.

II. THE NEED FOR A SAVIOUR SIBLING

The judgment in *Quintavalle* came about as a result of the swift technological developments in fertility treatment. Preimplantation Genetic Diagnosis (PGD) was developing during the eighties to screen embryos created for genetic diseases.⁷ The early embryo is biopsied (i.e. one or two cells are removed) and examined for the presence of x-linked genetic diseases. The first live birth occurred in 1990.⁸ The breakthrough was heralded as an end to the stressful combination of fertility treatment and abortion due to defective embryos.⁹ PGD has now developed to detect non-gender related genetic diseases and more recently, late-onset adult diseases such as cancer.¹⁰ Screening for a Human Leukocyte Antigen (HLA) tissue match was added to the process to allow parents to find a cure for an existing child (often referred to as Preimplantation Tissue Typing or PTT).¹¹ Adam Nash became the first ever tissue matched sibling to be born in Chicago, USA in 2001 when his umbilical cord blood cured his sister of the autosomal recessive disorder fanconi anaemia.¹² Dr Yury Verlinsky explained the advantages of the treatment in his project report:

These new indications make PGD a genuine alternative to conventional prenatal diagnosis, providing patients with important prospects not only to avoid an inherited risk without facing termination of pregnancy, but also to establish a pregnancy with particular genetic parameters that benefit an affected member of the family.¹³

The introduction of Preimplantation Tissue Typing (PTT)¹⁴ changed everything. Fertility treatment was no longer a means to conceive a healthy baby, it was an opportunity to place an

⁶ See Human Fertilisation and Embryology Act, 1990, c. 37 (Eng.).

⁷ *Preimplantation genetic diagnosis (PGD or PIGD) in the context of international reproductive medicine*, Medica, http://www.medica-tradefair.com/cgi-bin/md_medica/custom/pub/content.cgi?oid=34045&lang=2&ticket=g_u_e_s_t&page_number=1 (last visited Mar. 3, 2016).

⁸ The first successful project was published in: Handyside, A.H., Pattinson, J.K., Penketh, R.J. *et al.*, *Biopsy of Human Preimplantation Embryos and Sexing by DNA Amplification*, 333, *The Lancet*, 347-9 (1989); Handyside, A.H., Lesko, J.G., Tarin, J.J. *et al.*, *Birth of a Normal Girl After In Vitro Fertilisation and Preimplantation Diagnosis Testing for Cystic Fibrosis*, 327(13) *New Eng. J. Med.* 905 (1992).

⁹ Daar, J.F. *ART and the Search for Perfectionism: on Selecting Gender, Genes, and Gametes*, 9 *J. of Gender, Race and Justice* 241, 247 (2005).

¹⁰ Alan R. Thornhill & Karen Snow, *Molecular Diagnostics in Preimplantation Genetic Diagnosis*, *J. MOL. DIAGN.* Feb. 2002, at 12.

¹¹ Ilan Tur-Kaspa & Roohi Jeelani, *Clinical Guidelines for IVF and PGD for HLA Matching*, 30 *REPROD. BIOMEDICINE ONLINE* 115, 115 (2015).

¹² Verlinsky, Y., Rechitsky, S., Schoolcraft, W. *et al.*, *Preimplantation Diagnosis for Fanconi Anemia Combined with HLA Matching*, 285 *Journal of the American Medical Association* 24, 3130 (2001).

¹³ *Id.*

order for a *particular* baby. The academic commentary was littered with concerns about sex selection and eugenics (such as perfect pitch or intelligence)¹⁵ but no such ‘master race’ has emerged despite PGD/PTT being largely unregulated in the United States.¹⁶ The United Kingdom was due to jump on the bandwagon, and the one thing it can do better than any other country is regulate.

III. MR & MRS HASHMI AND THE HIGH COURT¹⁷

Mr. and Mrs. Hashmi in the United Kingdom learnt of the breakthrough in Chicago, USA.¹⁸ Their son Zain, the fourth of five children, was suffering from beta thalassaemia major and required a daily combination of drugs and regular blood transfusions.¹⁹ A stem cell transplant from umbilical cord blood or bone marrow was his only chance of a cure.²⁰ Mrs Hashmi already had three non-compatible children older than Zain, had conceived after Zain for a matching sibling but on finding out it was not a match underwent an abortion, and gave birth to another child who was not a tissue match before she asked the Human Fertilisation and Embryology Authority (HFE Authority) to issue a licence for a course of PTT to create a match for Zain.²¹ The HFE Authority announced its historic decision to licence PTT in a press release as long as any embryo created for the purpose of providing cord blood would itself be *at risk from the same disorder*:

2001 Policy:

- (a) the condition of the affected child should be severe or life-threatening, of a sufficient seriousness to justify the use of PGD;
- (b) the embryos conceived in the course of this treatment should themselves be at risk from the condition by which the existing child is affected;
- (c) all other possibilities of treatment and sources of tissue for the affected child should have been explored;²²

14 HUMAN FERTILISATION AND EMBRYOLOGY AUTHORITY, *Pre-implantation Tissue Typing* (‘Saviour Siblings’), available at <http://www.hfea.gov.uk/preimplantation-tissue-typing.html>.

15 The following articles address the issue of eugenics: Caplan, A.L. *What is Immoral About Eugenics?*, 319 *British Medical Journal* 1284 (1999); Robertson, J.A., *Extending Preimplantation Genetic Diagnosis: Medical and Non-Medical Uses*, 29 *Journal of Medical Ethics* 213 (2003) *Extending Preimplantation Genetic Diagnosis: The Ethical Debate*, 18 *Human Reproduction* 3, 465-471 (2003) and Wilkinson, S. *Eugenics, Embryo Selection, and the Equal Value Principle*, 1 *Clinical Ethics* 46 (2006).

16 The U.S. does not regulate the area because it is considered ‘research’ but the American Society for Reproductive Medicine has published some non-binding recommendations: <http://www.asrm.org/?vs=1>.

17 For a briefer commentary on *Quintavalle* see Cherkassky, L., *The Wrong Harvest: The Law on Saviour Siblings*, 1 *The International Journal of Law, Policy and Family*, 1 (2015).

18 *R (Quintavalle) v. Human Fertilisation Embryology Authority (and Secretary of State for Health)*, [2005] 2 A.C. 561 (H.L.) 5.

19 *Id.* at 2.

20 *Id.*

21 *Id.* at 3, 8.

22 A transplant from an HLA identical sibling is associated with a much higher success rate than a transplant from alternative donors. Humans inherit half of their HLA type from their mother and the other half from their father, so each sibling has a one in four chance of being HLA identical to one of his siblings. See Devolder, K., *Pre-implantation HLA Typing: Having Children to Save Our Loved Ones*, 31 *Journal of Medical Ethics* 582 (2005).

- (d) the technique should not be available where the intended tissue recipient is a parent;
- (e) the intention should be to take only blood for the purposes of the treatment, and not other tissues or organs;
- (f) appropriate implications counselling should be a requirement for couples undergoing this type of treatment;
- (g) families should be encouraged to participate in follow up studies and, as with PGD, clinics should provide detailed information about treatment cycles and their outcomes;
- (h) embryos should not be genetically modified to provide a tissue match.²³

A licence was granted to Park Hospital in Nottingham.²⁴ Mr and Mrs Hashmi created a total of 25 embryos in two cycles.²⁵ The interest group Comment on Reproductive Ethics (CORE) sought permission to apply for a judicial review on the grounds that the HFE Authority had acted *ultra vires* to the Human Fertilisation and Embryology Act 1990, presenting a unique opportunity for the courts to discuss the creation of saviour siblings.²⁶ The relevant provisions from the 1990 Act are as follows:

Section 2(1): In this act, “treatment services” means medical, surgical or obstetric services provided...for the purpose of assisting women to carry children.

Section 11(1)(a): The Authority may grant licences under paragraph 1 of schedule 2 authorising activities in the course of treatment services.

Schedule 2.

Paragraph 1(1): A licence under this paragraph may authorise any of the following in the course of providing treatment services:

- (d) practices designed to secure that embryos are in a suitable condition to be placed in a woman or to determine whether embryos are suitable for that purpose.

Paragraph 1(3): A licence under this paragraph cannot authorise any activity unless it appears to the Authority to be necessary or desirable for the purposes of providing treatment services.²⁷

The question to be answered by the High Court was whether the screening of an embryo for a tissue preference was ‘necessary or desirable’ to ensure that it was ‘in a suitable condition’ to be placed in a woman for it to be ‘in the course of’ treatment services. CORE argued that it was not.²⁸ Mr and Mrs Hashmi temporarily stopped treatment in anticipation of the judgment, handed down in *R (on the application of Josephine Quintavalle) on behalf of CORE v Human Fertilisation and Embryology Authority*²⁹. Mr Justice Maurice Kay began by stating that the case was only about statutory interpretation (at paragraph 7) which seemed strange

23 This is the original 2001 Policy, which can be found in the revised 2004 Policy document: Human Fertilisation and Embryology Authority Report: Preimplantation Tissue Typing. (2004), available at http://www.hfea.gov.uk/docs/PolicyReview_PreimplantationTissueReport.pdf.

24 *R (Quintavalle) v. Human Fertilisation Embryology Authority (and Secretary of State for Health)*, [2005] 2 A.C. 561 (H.L.) 5.

25 *Id.*

26 The United Kingdom would have been the first developed country to legalise the creation of saviour siblings.

27 Human Fertilisation and Embryology Act 1990, c. 37 (Eng.).

28 *R (on the application of Josephine Quintavalle) on behalf of CORE v. Human Fertilisation and Embryology Authority*, [2002] EWHC 2000.

considering the ethical undertones of the action,³⁰ but CORE was successful on the grounds that PTT did not assist women to carry children in the literal sense:

...section 2(1) expressly defines “treatment services” by reference to a single purpose - that of “assisting women to carry children”. The sole purpose of tissue typing is to ensure that any such child would have tissue compatibility with its older sibling. I do not consider that it can be said to be “necessary or desirable” for the purpose of assisting a woman to carry a child. The carrying of such a child after implantation would be wholly unaffected by the tissue typing. It seems to me that the language of the Act does not bear the strain which would be necessary to read “with particular characteristics” into the carrying of a child.³¹

Mr Justice Maurice Kay was of the opinion that a tissue match to a sibling was not necessary or desirable to assist a woman in carrying a child because the phrases ‘assisting’, ‘carrying’ and ‘treatment service’ under the 1990 Act had medical connotations. A tissue match was *not* a treatment service because it was merely a social characteristic that was highly subjective to the parents. Lord Wilberforce in a much earlier case named *Royal College of Nursing of the United Kingdom v Department of Health and Social Security* stated that the role of the courts when interpreting a statute was to focus on the intentions of Parliament:

When a new state of affairs, or a fresh set of facts bearing on policy, comes into existence, the courts have to consider whether they fall within the Parliamentary intention. The courts should be less willing to extend expressed meanings if it is clear that the Act in question was designed to be restrictive or circumscribed in its operation rather than liberal or permissive. [The courts] cannot fill gaps; they cannot by asking the question ‘What would Parliament have done in this current case – not being one in contemplation – if the facts had been before it?’ attempt themselves to supply the answer, if the answer is not to be found in the terms of the Act itself.³²

Lord Bingham in the more recent case of *R (Quintavalle) v Secretary of State for Health* stated clearly that the 1990 Act was intended to be strict in nature:

It is, however, plain that while Parliament outlawed certain grotesque possibilities (such as placing a live animal embryo in a woman or a live human embryo in an animal) it otherwise opted for a strict regime of control. No activity within this field was left unregulated. There was to be no free for all.³³

The words ‘assisting’, ‘carrying’ and ‘treatment services’ under section 2(1) of the 1990 Act are therefore likely to refer to an activity that is *medically essential* to assist a woman in carrying a child.

29 *Id.*

30 The High Court has not hesitated in the past to have lengthy discussions about the social and ethical ramifications of a judgment. See *Airedale NHS Trust v Bland* [1993] AC 789 and *Re A (Children) (Conjoined Twins: Surgical Separation)* [2001] Fam. 147.

31 *R (on the application of Josephine Quintavalle) on behalf of CORE v. Human Fertilisation and Embryology Authority*, [2002] EWHC 2000, Per Justice Maurice Kay, at paragraph 17.

32 [1981] A.C. 800, at page 822.

33 *R (Quintavalle) v Secretary of State for Health* [2003] UKHL 13 (unrelated to the current case but interpreting the same provisions) at paragraph 13.

The HFE Authority was given leave to appeal to the Court of Appeal on the basis that the case raised “substantial matters of public importance in the interest of the community...[and had] an impact on human life”.³⁴ In other words, there were legal, social and ethical issues that needed to be discussed and the Court of Appeal was the best place to do it.

IV. QUINTAVALLE IN THE COURT OF APPEAL

The Court of Appeal overturned the decision of the High Court and held in *R (on the application of Quintavalle) v Secretary of State for Health* that PTT was a treatment service for the ‘purpose of assisting women to carry children’ under section 2(1) of the 1990 Act and what was more, the word ‘suitable’ under schedule 2 paragraph 1(1)(d) was to be read subjectively according to the desires of the mother.³⁵

Lord Phillips MR was the first to overturn the strict interpretation of Mr Justice Maurice Kay:

My initial reaction to the meaning of “for the purpose of assisting women to carry children” was the same as that of Maurice Kay J. The phrase naturally suggests treatment designed to assist the physical processes from fertilisation to the birth of a child...my conclusion is that whether the PGD has the purpose of producing a child free from genetic defects, or of producing a child with stem cells matching a sick or dying sibling, the IVF treatment that includes the PGD constitutes ‘treatment for the purpose of assisting women to bear children.’³⁶

Lord Phillips MR admitted that the relevant provisions appeared to be objective but then stated that *any* service offered to a woman could be considered treatment for the purposes of assisting her to carry a child as long as PGD was included.³⁷ This is a frustrating interpretation because PGD (screening for a defect) is quite different from PTT (screening for a tissue match), and it oversimplifies the technology to place both procedures in the same category. Lord Phillips MR turned his attention to ‘suitable condition’ under schedule 2 paragraph 1(1)(d) and decided to interpret it subjectively:

Just as in the case of PGD screening for genetic defects, the meaning of “suitable” falls to be determined having regard to its context. When the object of the treatment is to enable a woman to bear a child with a tissue type that will enable stem cells to be provided to a sick sibling an embryo will only be suitable for the purpose of being placed within her if it will lead to the birth of a child with the tissue type in question.³⁸

Lord Phillips MR took the phrase ‘suitable condition’ to mean suitable to the preferences of the mother, which is strange because the wording of the provision - “practices designed to secure that embryos are in a suitable condition to be placed in a woman” - suggests medical viability for a successful pregnancy, not social suitability. It is unclear where this subjective interpretation came from in light of such a strict provision, but the “object of the treatment” could now potentially expand to include many subjective characteristics including blue eyes, blond hair, perfect pitch, height, weight, metabolism and that old classic: sex selection. Lord

³⁴ *Id.* Mr Justice Maurice Kay, at paragraphs 7 and 20.

³⁵ [2003] EWCA Civ. 667

³⁶ *Id.* at paragraphs 43 and 48.

³⁷ *Id.*

³⁸ *Id.* at paragraph 49.

Phillips MR *did* address the ethical issues briefly as if realising just how far he had expanded the ambit of the 1990 Act by stating that he preferred to leave ethics to one side:

Whether and for what purposes such a choice should be permitted raises difficult ethical questions. My conclusion is that Parliament has placed that choice in the hands of the HFE Authority.³⁹

It is submitted that Parliament did not intend to leave difficult ethical questions to the HFE Authority. The provisions of the 1990 Act are strict in nature because the idea of embryonic research was highly controversial when it was first introduced to the public, and it would have been unacceptable to provide eager scientists with an opportunity to misinterpret or manipulate the law. Embryos, for example, are not to be kept beyond fourteen days after the development of the primitive streak under section 3(4) of the 1990 Act.⁴⁰ This level of detail does not suggest a statute that can be read subjectively depending on the context of the woman (or scientist) seeking services, it suggests a statute that is objective and restrictive in nature to control unethical practices.

Lord Justice Schiemann handed down a second judgment in the Court of Appeal but it did not make any sense - he effectively deleted the 'treatment services' from his deliberations and worked with what he had left:

A combination of section 2(1) and schedule 2 paragraph 1(3) reads: "A licence under this paragraph cannot authorise any activity unless it appears to the Authority to be necessary or desirable *for the purpose of providing medical, surgical or obstetric services provided to the public or a section of the public* for the purpose of assisting women to carry children." All parties, faced with this inelegant amalgam, have proceeded on the basis that the issues before us can be resolved more easily by simply ignoring the words which I have placed in italics. I agree that this seems the most sensible approach. The primary question can thus be phrased: *Can the process in issue lawfully appear to the Authority as necessary or desirable for the purpose of assisting a woman to carry a child?*⁴¹

In rewording the provisions in a way that was suitable for him, was Schiemann LJ attempting to change the nature of the statute from objective/medical to subjective/social? Schiemann LJ turned his eye to embryonic wastage, denying that it was an issue that some good embryos would be wasted if they were not a tissue match:

It seems to me that the creation of embryos with the knowledge that some perfectly healthy embryos will deliberately be allowed to perish was not regarded by Parliament as always unacceptable. The contrary has not been argued. Allowing embryos which do not suffer from a genetic defect to perish was also not regarded by Parliament as always unacceptable. Again, the contrary has not been argued.⁴²

It is strongly submitted that Parliament, when drafting the 1990 Act, actually kept a close eye on embryonic wastage as a result of the Warnock report (1984) which requested that "the

³⁹ *Id.* at paragraph 50.

⁴⁰ Human Fertilisation and Embryology Act, 1990, (Eng.).

⁴¹ *R (on the application of Quintavalle) v Secretary of State for Health* [2003] EWCA Civ 667 at paragraphs 74, 75 and 76. Emphasis in original.

⁴² *Id.* at paragraphs 81 and 83.

embryo of the human species should be afforded some protection in law”.⁴³ There are three references to embryo destruction under the Human Fertilisation and Embryology Act 1990: section 3(4) demands the destruction of the embryo following the emergence of the primitive streak, and section 4A(4)(b) of schedule 3 states that an embryo must be destroyed if consent to storage is withdrawn, and section 13(5) refers to the welfare of the child “to be born” (more below). The Abortion Act 1967, on a separate note, does not allow the social destruction of a pregnancy beyond twenty-four weeks because the unborn baby is close to viable (a provision inserted by the Human Fertilisation and Embryology Act 1990). It is strongly submitted, therefore, that Parliament wished to *limit* embryonic wastage and the 1990 Act was a means to this end.

Schiemann LJ nevertheless decided that screening for a tissue match came within the ambit of the 1990 Act:

In my judgment it was lawfully open to the Authority to come to the conclusion that the Process in Issue would assist some women...to carry a child.⁴⁴

This was, of course, an easy conclusion to reach when the phrase ‘for the purpose of providing medical services’ was conveniently deleted, giving the provisions a social context rather than a medical one. PTT probably *would* assist a woman to carry a child if she is only seeking to locate a particular social characteristic in her embryos, but PTT does not assist a woman to carry a child if she is seeking *medical assistance in carrying that child* (as required under the 1990 Act).

Schiemann LJ rounded off by inserting tissue compatibility into the suitability provision and made one of the most contradictory comments in the whole *Quintavalle* story:

...the concept of suitability in [schedule 2] paragraph 1(1)(d) is wide enough to embrace ensuring that the embryo does not suffer from a genetic defect and tissue incompatibility... if the decision of the Authority is upheld in the present case it does not mean that parents have a right to *in vitro* fertilisation for social selection purposes.⁴⁵

By reading tissue incompatibility into the ‘suitable condition’ provision, Schiemann LJ declared that an embryo was unsuitable simply because it did not match its sibling. This was a highly controversial conclusion to draw because it inserted social selection into the 1990 Act as a new ground for embryo destruction. It also contradicted his final statement on social selection being inaccessible to parents. Parents now *do* have a right to *in vitro* fertilisation for social purposes because references to medical treatment were removed from his interpretation of the law and he added tissue incompatibility to the meaning of ‘suitability’ under schedule 2 paragraph 1(1)(d). Schiemann LJ was denying the very “right” he had just granted.

Mance LJ handed down the most interesting judgment in the Court of Appeal, but inadvertently caused the most confusion. Firstly he addressed the welfare provision under

43 Warnock Report, Report of the Committee of Enquiry into Human Fertilisation and Embryology, DEP’T OF HEALTH & SOC. SEC, July 1984, Her Majesty’s Stationary Office, at paragraph 11.17, <http://www.hfea.gov.uk/2068.html> (last accessed 8th February 2016).

44 *Id.*, at paragraph 89.

45 *R (on the application of Quintavalle) v Secretary of State for Health* [2003] EWCA Civ 667 at paragraphs 96 and 98.

section 13(5) of the 1990 Act and decided that creating a sibling for the benefit of another sibling was not against the welfare of the child to be born:

Whilst that subsection probably had primarily in mind consideration of any adverse effects on the welfare of the future or any existing child, the language does not exclude positive effects.⁴⁶

The full text of the welfare provision reads as follows:

Section 13(5): A woman shall not be provided with treatment services unless account has been taken of the welfare of any child who may be born as a result of the treatment (including the need of that child for supportive parenting), and of any other child who may be affected by the birth.⁴⁷

It is a concern that the welfare provision can be so easily reversed to *support* the creation of an embryo for its blood and bone marrow. Mance LJ may have read the welfare provision in a way that supported the child to be *cured*.⁴⁸

Mance LJ moved on to address the most glaring ethical issue: eugenics. He admitted that there is a difference between screening out abnormalities and screening in preferences but he denied that the Hashmi family had a choice:

The crucial distinction has been put as being between “screening out abnormalities” and “screening in preferences”. That distinction raises a spectre of eugenics and “designer babies”. But it is a crude over-simplification to view this case as being about “preferences”. The word suggests personal indulgence or predilection and the luxury of a real choice. But there is no element of whim in the circumstances that the HFE Authority had it in mind to licence in December 2001, and Mr and Mrs Hashmi are not seeking to indulge themselves. The case is about a family’s reaction, understandable in the light of current scientific possibilities, to a cruel fate which one of its members is suffering and will continue to suffer, without a successful stem cell transplant.⁴⁹

Mance LJ added that the facts in the Hashmi case were anything but “purely social”:

There are here good medical reasons for screening any embryo, although *they do not relate to any future child’s health*. The concerns to which the HFEA’s decision and the licence for Mr and Mrs Hashmi are directed are anything but “purely social”, relating as they do to the health of a sibling and the wellbeing of the whole family. What matters in any event is that the Warnock committee proposed in Chap. 9.11 of its report to leave even the general question of the acceptability of sex selection to the authority which it recommended should be established...the present circumstances involve a form of selection which is much less obviously problematic than, and very far removed from, selection for social purposes.⁵⁰

⁴⁶ *Id.* at paragraph 133.

⁴⁷ *Id.*

⁴⁸ There is a feeling amongst writers that the welfare provision under section 13(5) is not effective anyway because no one can enforce it: see Jackson, E., *Conception and the Irrelevance of the Welfare Principle*, 65 MOD. L. REV., 176,176 (2002), and Cherkassky, L., *The Wrong Harvest: The Law on Saviour Siblings*, 1 The International Journal of Law, Policy and Family, 1 (2015)..

⁴⁹ *R (on the application of Quintavalle) v Secretary of State for Health* [2003] EWCA Civ 667 at paragraph 134.

⁵⁰ *Id.* at paragraphs 135 and 143. Emphasis added.

There are two quotes above that cause confusion. Firstly, Mance LJ was clearly of the opinion that screening in preferences was acceptable because Mr and Mrs Hashmi were not merely “indulging in luxury” but sought to protect the “wellbeing of the whole family”, but it is submitted that using the technology to locate an embryo for a particular characteristic *is* an indulgence and it *is* a luxury. An expensive one. The “cruel fate” and “suffering” bestowed upon their existing child does not turn the voluntary use of the technology into a necessity. It is not a treatment service to *assist the carriage of a child* in the medical sense under section 2(1) of the 1990 Act. Secondly, Mance LJ admitted that screening in preferences did not relate to the health of the embryo, but he *still* denied that it was a “purely social” use of the technology. In light of the subsequent ban on sex selection for social purposes under schedule 2 paragraph 1ZB of the 1990 Act which states:

...a licence cannot authorise any practice designed to secure that a resulting child will be of one sex rather than the other, unless there is a particular risk that a woman will give birth to a child who will develop a gender-related physical or mental disability or disease...

it is likely that Parliament did not intend for embryos to be selected or destroyed on any ground other than medical reasons.⁵¹

Mance LJ turned his attention to the definition of ‘treatment services’ and decided that screening in a tissue preference could constitute such a service under section 2(1):

...once it is recognised that the concept of “services for the purpose of assisting women to carry children” extends beyond purely physical problems affecting the viability of the embryo during pregnancy and birth...it becomes clear that such services may have regard to prospective parents’ and society’s concern for others and for the future. The concept is in other words to be read in a general, rather than a restrictive sense...I have further concluded that a biopsy for the purpose of tissue typing and of enabling a choice to be made regarding implantation based on the compatibility of the embryo’s tissue with that of a sibling is capable of constituting a service for the purpose of assisting women to carry children.⁵²

This definition of ‘treatment services’ was rather puzzling because section 2(1) clearly states:

In this act, “treatment services” means medical, surgical or obstetric services provided for the purpose of assisting women to carry children.

Mance LJ disposed of the words ‘medical, surgical or obstetric’ and replaced them with social preferences. Parliament did not intend for section 2(1) to be read in a wider social context because it very clearly defines “treatment services” as medical, surgical or obstetric services which do not extend beyond the “purely physical problems affecting the viability of the embryo” (as per Mance LJ). Therefore, as a result of Mance LJ interpreting treatment services as a wider social service, the screening in of a tissue preference is confirmed as social selection.

51 Confusingly, the screening in of preferences was frequently compared to sex selection (a well-known method of social selection) throughout the Court of Appeal judgment *R (on the application of Josephine Quintavalle) on behalf of CORE v Human Fertilisation and Embryology Authority*, [2002] EWHC 2000, at paragraphs 27, 124, 135, 140 and 143.

52 *Id.* at paragraphs 142 and 145.

The Court of Appeal was clearly content to widen the scope of the 1990 Act to allow the HFE Authority to authorise PTT as an activity in the course of treatment services for the purpose of assisting women to carry children under section 2(1). The suitable condition of the embryo under schedule 2 paragraph 1(1)(d) was given a wider social meaning to support the desires of the mother. She was not indulging in luxury, she had no choice (per Mance LJ). The medical connotations were removed from the relevant provisions and replaced by the wellbeing of the family as a whole (per Schiemann LJ and Mance LJ). The lords effectively placed PTT in the social selection category despite strong denials that social selection was taking place, permitting a mother to select or destroy her healthy embryos simply because they did or did not match her existing child.

Notwithstanding a Court of Appeal judgment beset with confusion and contradiction, the common law had changed. Mr and Mrs Hashmi restarted their PTT treatment in May 2003 but a pregnancy did not result.⁵³ Mr and Mrs Whitaker, who had made an identical plea to the HFE Authority at the same time as Mr and Mrs Hashmi but were rejected on the grounds that their son's disease diamond blackfan anaemia was sporadic rather than hereditary according to the original PTT policy published in 2001 (above), travelled to the Chicago Reproductive Institute which first pioneered the procedure and successfully gave birth to Jamie Whitaker in June 2003. He was ironically heralded as "Britain's first saviour sibling"⁵⁴ but concerns were raised that the technology was going too far by a spokesman for LIFE:

To create another child as a transplant source, however, could set a dangerous precedent for uses of this kind of technology. How will baby James feel, for example, when he discovers that he was brought into the world to supply 'spare parts' for his elder brother?⁵⁵

The HFE Authority, in light of the Whitaker development and the newly found freedom in *R (on the application of Quintavalle) v Secretary of State for Health*, decided to take another look at its PTT policy and announced two changes in 2004:

1. PTT can be offered in cases where the embryo is not at risk from the condition affecting the existing child;
2. Depending on the needs of the existing child, it can be acceptable to offer PTT with a view to harvesting bone marrow.⁵⁶

The changes were justified by the HFE Authority on the following grounds:

Faced with potential requests from parents who want to save a sick child, the emotional focus is understandably on the child who is ill. Our job is also to consider the welfare of the tissue matched child which will be born. Our review of the evidence

53 Mr and Mrs Hashmi underwent six trials of IVF with PTT and created 25 embryos, but were ultimately unsuccessful in establishing a pregnancy. BioNews, *Hashmis Fail in 'Saviour Sibling' Attempt*, Issue 266 (13 July 2004), http://www.bionews.org.uk/page_12031.asp.

54 Dobson, R. *Saviour Sibling is Born After Embryo Selection in the United States*, -326 BRIT. MED. J., 1416, 1416 (2003).

55 Patrick Cusworth, LIFE charity spokesman, quoted in the article cited in fn. 33 above.

56 [2003] EWCA Civ 667; Human Fertilisation and Embryology Authority Report: Preimplantation Tissue Typing. (2004). <http://www.hfea.gov.uk/515.html>, last accessed 8th February 2016, at paragraph 37.

does not indicate that the embryo biopsy procedure disadvantages resulting babies compared to other IVF babies.⁵⁷

The 2004 changes expanded the original 2001 policy considerably. Parents no longer needed to screen their embryos for hereditary defects, disabilities or disorders in order to use PTT, turning PGD/HLA into a purely subjective/social procedure. CORE was granted an appeal to the House of Lords in 2005. It was the final opportunity for the judiciary to clear up the following legal, social and ethical loopholes that were created by the Court of Appeal:

- the 1990 Act was designed to be interpreted in a strictly objective/medical sense;
- the true meaning of ‘treatment service’ under section 2(1) did not include the creation of embryos for social purposes;
- the welfare of the saviour child (not the sick child) could be offered some protection under section 13(5) of the 1990 Act;
- the phrase ‘suitable condition’ under schedule 2 paragraph 1(1)(d) was not subjective and did not support the social selection of embryos;
- there was a much higher risk of embryonic wastage;
- the introduction of social selection under the 1990 Act paved the way for eugenics in the future;
- it was not in the best interests of a very young donor child to undergo a non-therapeutic harvesting procedure.

It is worth noting a particularly unpleasant statement in the revised PTT Report (2004) to demonstrate why the House of Lords judgment was so important to the welfare of the saviour sibling:

...should the existing child relapse, there is likely to be insufficient time to go through the process of creating a tissue-matched sibling. If such a sibling existed already, tissue that could be used in treatment *would then be at hand if and when required*.⁵⁸

In light of the ‘commodity’ feel to the newly published guidelines, it would have been damaging for the House of Lords to uphold the decision of the Court of Appeal.

V. QUINTAVALLE IN THE HOUSE OF LORDS

The House of Lords upheld the decision in the Court of Appeal in *R (Quintavalle) v Human Fertilisation and Embryology Authority (and Secretary of State for Health)*, choosing to bypass matters of law, harvest, eugenics, welfare and ethics to focus solely on statutory interpretation.⁵⁹

Lord Hoffman handed down the main judgment, starting with the difficulty presented by ‘suitability’:

The claimant [CORE] says that this gives far too wide a meaning to the notion of being suitable. It would enable the authority to authorise a single cell biopsy to test the embryo for whatever characteristics the mother might wish to know: whether the child would be male or female, dark or blonde, perhaps even, in time to come,

57 Suzi Leather, who was the Chair of the HFE Authority at the time, 21st July 2004. The original press release is on the official website: www.hfea.gov.uk/763.html (last accessed 8th February 2016).

58 *Id.*, at page 9, paragraph 34. Emphasis added.

59 2 A.C. 561 [2005].

intelligent or stupid. Suitable must therefore have a narrower meaning than suitable for that particular mother.⁶⁰

Despite the valid points raised by CORE, Lord Hoffman decided that the phrase ‘suitable condition’ should be interpreted as widely as possible:

‘Suitable’ is one of those adjectives which leaves its content to be determined entirely by context...[The Authority] may consider that allowing the mother to select an embryo on such grounds is undesirable on ethical or other grounds. But the breadth of the concept of suitability is what determines the breadth of the authority’s discretion.⁶¹

Lord Hoffman was of the opinion that the HFE Authority had complete discretion over the meaning of ‘suitable condition’ because of the comments in the Warnock Report (1984) regarding sex selection:

...the Warnock Report...went on to consider the use of gender identification to select the sex of a child “for purely social reasons”...the committee said that...“the whole question of the acceptability of sex selection should be kept under review”. The committee [also] said: “the authority should be specifically charged with the responsibility to regulate and monitor practice in relation to those sensitive areas which raise fundamental ethical questions”. The conclusion which I draw is that the committee contemplated that the authority would decide the circumstances, if any, in which sex selection on social grounds should be authorised. As sex selection on social grounds is the most obvious case of selecting an embryo on grounds *other than its health*, I would infer that the Warnock committee did not intend that selection of IVF embryos on grounds which went beyond genetic abnormality should be altogether banned.⁶²

Lord Hoffman inadvertently stated that PTT was not connected to the health of the embryo providing an explanation for the constant references to sex selection in both appeal courts: they are clearly both methods of *social selection*. To put it in stark terms, if PTT can accurately be said to be an ‘activity in the course of medical/surgical/obstetric treatment services’ to be licenced under section 11(1)(a) then it is neither here nor there that the Warnock Report left sex selection - a widely known social preference - to the discretion of the HFE Authority. Lord Hoffman then felt free to announce that ‘suitable condition’ was to be read subjectively according to the desires of the mother:

...there was no proposal [in the White Paper: Human Fertilisation and Embryology: A Framework for Legislation, November 1987 (Cm 259)] to include in the “clearly prohibited” list the testing of embryos to enable the mother to choose to carry a child with *characteristics of her choice*...Thus, if the concept of suitability is broad enough to include suitability for the purposes of the particular mother, it seems to me clear enough that the activity of determining the genetic characteristics of the embryo by way of PGD or HLA typing would be “in the course of” providing the mother with IVF services and that the authority would be entitled to take the view that it was

⁶⁰ *Id.* at paragraph 13.

⁶¹ *Id.* at paragraph 14.

⁶² *Id.* at paragraphs 16, 17 and 19 (emphasis added).

necessary or desirable for the purpose of providing such services...the word 'suitable' is an empty vessel which is filled with meaning by context and background.⁶³

Lord Hoffman with this paragraph authorised the creation of saviour siblings in the United Kingdom. However, it is submitted that he focused too heavily on section 11 of the 1990 Act, which states:

Section 11(1)(a): The Authority may grant licences under paragraph 1 of schedule 2 authorising activities in the course of treatment services.

It is probably acceptable to say that PTT is an *activity* in the course of PGD and therefore the HFE Authority have discretion to licence it, but under section 2(1) treatment services are defined as 'medical, surgical or obstetric' placing an emphasis on medical viability. Additionally, 'suitable condition' under schedule 2 paragraph 1(1)(d) refers to the medical status of the embryo (i.e. free from defect or disease), not an empty vessel to be filled by the social desires of the mother. Lord Hoffman appears to be setting some of the relevant provisions to one side in his interpretation of the law. It is highly unlikely that during the construction of the 1990 Act Parliament wished to leave the question of whether or not to create a baby for its social characteristics (i.e. eugenics) to the licencing authority. It is simply too controversial.

Lord Hoffman finished his judgment on a rather strange note, concluding that should the best interests of the potential child be in any doubt, "a ruling from the court may be obtained".⁶⁴ This was his only reference to the more pressing issue of the legitimate harvesting of young children for their bone marrow:

I have no doubt that medical practitioners take very seriously the law that any operation upon a child for which there is no clinical reason relating to the child itself must be justified as being for other reasons in the child's best interests...The authority is in my opinion entitled to assume that a child conceived pursuant to its licence will, after birth, receive the full protection of the law.⁶⁵

By stating that issues of welfare will be dealt with after birth, Lord Hoffman moved the ethical responsibility of creating babies for harvest *away* from the HFE Authority and thrust it into welfare law (the Children Act 1989) and transplant law (the Human Tissue Act 2004). These three areas of practice (fertility, welfare and transplant) do not sit separately - they are intricately tied to each other as a result of *Quintavalle*. There is no point in helping parents to select embryos with a tissue preference if the harvesting procedure after birth does not support the welfare of the child. Lord Hoffman did not address this legal loophole, preferring instead to maintain that the HFE Authority was to "grapple with such issues" at its discretion.⁶⁶ The proof of this discretion, in his opinion, was the fact that Parliament excluded sex selection from the original 1990 Act:

The authority was specifically created to make ethical distinctions and, if Parliament should consider it to be failing in that task, it has in reserve its regulatory powers

⁶³ Emphasis added, *Id.* at paragraphs 22, 24 and 33.

⁶⁴ *Id.* at paragraphs 35 and 38.

⁶⁵ *Id.* at paragraph 38.

⁶⁶ *Id.* at paragraph 26. This is nonsense because the HFE Authority have nothing to do with the saviour child after it has been born.

under section 3(3)(c)...Perhaps the most telling indication that parliament did not intend to confine the authority's powers to unsuitability on grounds of genetic defects is the absence of any reference in the Act to selection on grounds of sex...It is hard to imagine that the reason why the Act said nothing on the subject was because Parliament thought it was clearly prohibited by the use of the word 'suitable' or because it wanted to leave the question over for later primary legislation. In my opinion the only reasonable inference is that parliament intended to leave the matter to the authority to decide.⁶⁷

It is submitted that Parliament did not refer to sex selection in the 1990 Act because the provisions were already strict enough to exclude every kind of social selection. Once again, the HFE Authority's perceived discretion over sex selection is used to justify the inclusion of PTT into the 1990 Act, placing both procedures into the 'social selection' category. Lord Brown delivered the smaller judgment in the House of Lords and began by turning an eye to the bigger ethical issues:

The ethical questions raised by such a process are, it need hardly be stated, profound. Should genetic testing be used to enable a choice to be made between a number of healthy embryos, a choice based on the selection of certain preferred genetic characteristics?...Is this straying into the field of "designer babies" or - as the celebrated geneticist Lord Winston, has put it, "treating the offspring to be born as a commodity".⁶⁸

It is clear that *Quintavalle* was not merely a case about statutory interpretation - there were social and ethical problems to discuss too, especially the legality of the subsequent harvest upon the donor child. However, Lord Brown quickly reigned in his enthusiasm for ethical issues by stating that the "sole concern" of the House of Lords was merely to decide whether the 1990 Act allowed the HFE Authority to licence tissue typing,⁶⁹ and instead turned to 'suitability' with a supporting comment for the appellant Josephine Quintavalle:

Initially, I confess to having found some considerable force in the claimant's argument that PGD screening is one thing, and properly licensable under the 1990 Act, tissue typing a completely different concept and impermissible. It is one thing to enable a woman to conceive and bear a child which will itself be free of genetic abnormality; quite another to bear a child specifically selected for the purpose of treating someone else. One can read into the statutory purpose specified by section 2(1), that of "assisting women to carry children", the notion of healthy children - only a genetically healthy embryo being "suitable" for placing in the woman within the meaning of paragraph 1(1)(d).⁷⁰

Despite this admission that the provisions were strictly objective/medical in nature, Lord Brown frustratingly turned back to sex selection and drew strength from the fact that the Warnock Report left sex selection "under review":

The [Warnock] committee, at paragraph 9.11, expressly envisaged the future possibility of sex selection "for purely social reasons" and concluded that "the whole

⁶⁷ *Id.* at paragraphs 28 and 29.

⁶⁸ *Id.* at paragraph 43.

⁶⁹ *Id.* at paragraph 46.

⁷⁰ *Id.* at paragraph 51.

question of the acceptability of sex selection should be kept under review” - review which inferentially was to be undertaken by a proposed new statutory licencing authority established “to regulate and monitor practice in relation to those sensitive areas which raise fundamental ethical questions” at paragraph 13.3.⁷¹

Tissue typing had been denied on many occasions throughout the appeal courts as emulating the social selection of embryos, including this strong statement by Lord Brown himself:

In the unlikely event that the Authority were to propose licencing genetic selection for purely social reasons, Parliament would surely act at once to remove that possibility, doubtless using for the purpose the regulation making power under section 3(3)(c). Failing that, in an extreme case the court’s supervisory jurisdiction could be invoked.⁷²

The frequent comparisons to sex selection in both appeal courts therefore gives a very strong impression that tissue typing is a form of social selection and the lords are having to draw parallels between PTT and sex selection in order to justify its inclusion in the strict provisions of the 1990 Act.

Lord Brown finished his contradictory judgment with an even more baffling reason to authorise tissue typing:

I was at one time attracted to [the] dividing line between selection aimed purely at eliminating serious genetic or chromosome defects (permissible) and other selective criteria (impermissible). As, however, Lord Hoffman points out, what amounts to a serious genetic defect will itself often be contentious.⁷³

Lord Brown, in an attempt to authorise PTT, suggested that the line between ‘serious defects’ and ‘selective criteria’ was ambiguous. It is agreed that some defects, disabilities or diseases are not as harmful as others (i.e. partial deafness vs. diamond blackfan anaemia), but a very clear line can be drawn between genetic conditions and *preferred characteristics*. A tissue match to a sibling is not a genetic defect, nor does it assist a woman to carry a child in the medical sense, so is Lord Brown suggesting that a non-matching embryo is defective, disabled or diseased? This would be highly controversial and could lead to wasteful embryonic destruction. Lord Brown goes further, reducing PGD to a social, as opposed to a medical, procedure:

PGD with a view to producing a healthy child assists a woman to carry a child only in the sense that it helps her decide whether the embryo is “suitable” and whether she will bear the child. Whereas, however, suitability is for the woman, the limits of permissible embryo selection are for the authority.⁷⁴

This statement appears to be judicial confirmation that suitability is subjective and that embryos can be selected for purely social reasons. PGD was, however, developed to screen embryos for genetic diseases as opposed to tissue match to suit the desires of the mother.

71 *Id.* at paragraph 53.

72 *Id.* at paragraph 62. Lord Hoffmann made an almost identical statement at paragraph 28.

73 *Id.* at paragraph 61.

74 *Id.* at paragraph 62.

The House of Lords were content to close their brief judgment at this point, failing to address the legal, social and ethical and consequences of their controversial decision.

Tissue typing is now a 'treatment service' for the 'purpose of assisting women to carry children' under section 2(1) of the 1990 Act and what is more, the suitability of the embryos under schedule 2 paragraph 1(1)(d) is subjective according to the desires of the mother. In social terms, it is now possible to 'design' a saviour sibling by screening in a preferred tissue match and destroy any remaining embryos on the grounds that they do not match this personal preference.

It is highly unlikely that the legitimacy of tissue typing will ever be questioned now that it is enshrined into statute:

Human Fertilisation and Embryology Act 2008

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.

As a result of the judgment in *Quintavalle*, embryos created to save a sibling are now stuck in even more legal loopholes:

- on what ground can the appeal courts justify the change in character of the 1990 Act from objective/medical to subjective/social despite its strict provisions?
- is it acceptable to destroy embryos for their social characteristics when there are legal provisions in place to offer protection to embryos?
- how does the screening in of a social preference constitute an activity in the course of medical, surgical or obstetric treatment services under section 2(1) of the 1990 Act?
- on what grounds can 'suitable condition' to 'assist' a woman to carry a child under schedule 2 paragraph 1(1)(d) be read to support the social selection of embryos?
- does the welfare test under section 13(5) protect an embryo from being destroyed for social purposes, or from being selected for harvesting purposes, or both? Or neither?
- on what grounds can the HFE Authority exercise such sweeping ethical discretion?
- why do the lords deny that screening in preferences constitutes the social selection of embryos when the liberal attitude towards sex selection in the Warnock Report (1984) formed the basis for their decision to incorporate PTT into the 1990 Act?
- has the inclusion of social selection under the 1990 Act paved the way for eugenics in the future?
- can the matching sibling, once born, be legally harvested for its bone marrow under the Human Tissue Act 2004?

The Court of Appeal and the House of Lords had the opportunity to address these legal loopholes but instead reverted responsibility back to the HFE Authority.⁷⁵

⁷⁵ There are examples of the House of Lords refusing to discuss the ethical issues at paragraphs 20, 26, 29, 39, 46, 48, 55, 56 and 58 of the judgment.

The biggest concern is the legitimacy of the bone marrow harvest upon the donor child once born. This unique non-therapeutic procedure has not yet been authorised by the courts and the lords did not further investigate the welfare of the donor child. The saviour sibling could well be ‘unusable’ until she is much older and able to consent for herself, by which time it may be too late.⁷⁶

VI. THE LEGAL LANDSCAPE AFTER *QUINTAVALLE*

Looking at the *Quintavalle* story as a whole, it appears that both appeal courts placed tissue typing in the same category as sex selection to confirm that the Human Fertilisation and Embryology Authority does have discretion to licence PTT as an activity in the course of treatment services under s.11(1)(a) of the 1990 Act. The House of Lords attached to this decision a guarantee that should the HFE Authority ever authorise the selection of embryos for ‘purely social reasons’ the legislature would act immediately to shut the practice down (at paragraphs 28 and 62). This is a remarkable contradiction. PTT is clearly a method of social selection, so why was its social nature denied?

The welfare loophole is just as confusing. The 1990 Act contains a welfare provision under section 13(5) but the prospective child (according to Lord Hoffman) is protected by law *after* birth under the Children Act 1989, leaving the Human Tissue Authority to bear the brunt of the ethical issues of harvesting very young donors.

Embryonic wastage was not addressed in any detail by the lords, despite the mother now being able to destroy healthy embryos simply because they do not match a sibling. Embryos are protected from harm and wasteful destruction under section 3(4), section 4A(4)(b) and section 13(5) of the 1990 Act and section 1(1)(a) of the Abortion Act 1967. *Quintavalle* inadvertently created a new and unregulated ground upon which to socially destroy healthy embryos. The biggest legal loophole of all, however, is the legitimacy of harvesting a baby, toddler or young child for her bone marrow. What is the current legal position should a couple come forward and ask for a saviour sibling?

The only saviour sibling authority in the UK is *Re Y (Mental Patient: Bone Marrow Donation)*⁷⁷ and it uses the interfamilial principle to justify a bone marrow harvest upon an incompetent adult.⁷⁸ This would not be appropriate for children, whose needs are paramount under section 1(3) of the Children Act 1989⁷⁹. *Re Y* was underpinned by the US case of *Curran v Bosze* (1990) which stated that for bone marrow harvests upon children there must be an ‘existing relationship’ between siblings:

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.⁸⁰

⁷⁶ The Human Tissue Authority have jurisdiction over this matter which is outside the ambit of this article, but it is the next issue to be explored by the author.

⁷⁷ [1997] Fam. 110.

⁷⁸ *Id.* Per Connell J, at pages 115-116.

⁷⁹ Children Act 1989 (Eng.), available at <http://www.legislation.gov.uk/ukpga/1989/41/contents>.

⁸⁰ 566 N.E.2d 1319 Per Calvo J, at pages 1343-4.

Calvo J was also of the opinion that it could be as much as twenty years before the psychological benefits of a bone marrow donation are felt by a donor child,⁸¹ and the benefit was not to be “one of personal, individual altruism in an abstract, theoretical sense”.⁸² He also suggested that the benefit should be present *at the time of the harvest* - not in the future to retrospectively justify the harvest - because intention could not be supplied after the fact.⁸³ Additionally, the age of the minor was important to the validity of the procedure in law:

[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.⁸⁴

The notion that a psychological benefit must be tangible *and* proven at the time of the non-therapeutic procedure is supported by Butler-Sloss LJ in *Re A (Male Sterilisation)*:

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.*⁸⁵

In addition to *Curran v Bosze* and *Re A*, there are other medical cases that support the welfare of the donor child. For example, the plight of the saviour sibling cannot be balanced against the plight of the sick sibling unless both siblings are warded at the same time, this was confirmed in *Court of Appeal* [1993] and *Birmingham City Council v H (A Minor)*.⁸⁶ Additionally, the consent of the parents to the non-therapeutic procedure is not decisive.⁸⁷ The parents can also not subsume the rights of the saviour child into their own to control her medical care.⁸⁸

Therefore, without absolute proof that the *saviour* child (not the wider family or the sick child) will experience a tangible psychological benefit *at the time of the harvest*, the procedure is not legitimate in law. It would be a trespass to her person and would not serve her best interests. Balancing acts, substituted judgments, parental consent and retrospective benefits do not validate the procedure. Parents may be free in fertility law to create their own saviour sibling, but it does not mean that the sibling can be harvested after birth.⁸⁹ The lords in *Quintavalle* should have addressed this matter.

VII. CONCLUSION

81 *Id.* at page 1335.

82 *Id.* at page 1343

83 *Id.* at page 1336.

84 *Id.* Per Calvo J at pages 1343, 1344, 1319, 1326 and 1336. Bosze (the father) argued in response that if the sick sibling was kept alive, the donor children (twins) would have the opportunity to get to know him. This speculative future benefit did not hold any weight in court. The sick sibling eventually died of leukaemia.

85 [2000] 1 F.L.R. 549, at page 555. Emphasis added.

86 [*Court of Appeal* [1993] 1 FLR 883 and *Birmingham City Council v H (A Minor)* [1994] 2 AC 212]

87 as seen in *Re B (A Minor) (Wardship: Medical Treatment)* [1981] 1 W.L.R. 1421, *Re K.D. (A Minor) (Ward: Termination of Access)* [1988] A.C. 806, *Re J (A Minor) (Wardship: Medical Treatment)* [1991] Fam. 33, *Re E (A Minor) (Wardship: Medical Treatment)* [1992] 2 FCR 219, *Re Z (Identification: Restrictions on Publication)* [1997] Fam. 1 and *Wyatt v Portsmouth Hospital NHS Trust* [2005] EWCA Civ 1811.

88 *Re C (A Child) (HIV Test)* [2000] Fam. 48.

89 For a rigorous examination of welfare law in the context of donor children, see Cherkassky L., *Children and the Doctrine of Substituted Judgment*, Medical Law International, (2015), vol. 1, 1-23.

R (Quintavalle) introduced the social selection of embryos into law on contradictory grounds.⁹⁰ Mr Justice Maurice Kay in the High Court interpreted the 1990 Act in a literal sense and concluded that tissue match to a sibling was not necessary or desirable to assist a woman in carrying a child. It is submitted that this was the correct approach in light of the earlier discussions in *Royal College of Nursing of the United Kingdom v Department of Health and Social Security* and *Quintavalle* that the 1990 Act was intended to be strict in nature.⁹¹

The Court of Appeal ended up raising more questions than it did answers, owing to the unexpected wide interpretation of the 1990 Act and its silence on welfare, eugenics, embryo wastage and the lawfulness of the subsequent harvest. Phrases that caused particular concern were those of Lord Phillips MR, who stated that ‘suitable condition’ under section 2(1) was to refer to the *purpose* of the treatment, including the search for a tissue match. This idea would have introduced widespread eugenics if the House of Lords had adopted it. Schiemann LJ removed the phrase ‘medical treatment’ from the provisions for convenience, changing the tone of the 1990 Act from objective/medical to subjective/social. He also (rather confusingly) denied that parents have a right to social selection in the same breath as he read tissue compatibility into ‘suitable condition’. Mance LJ removed ‘medical, surgical or obstetric’ from his interpretation of ‘treatment services’ under section 2(1) to support the plight of Mr & Mrs Hashmi, and inadvertently accepted PGD/PTT as a social procedure when he stated that it cared for the “wellbeing of the whole family”. He merely confused matters when he then denied that selecting a tissue match was a “purely social” use of the technology.

In the House of Lords, Lord Hoffman focussed heavily on section 11 (the power to licence activities), largely shelving the provisions of ‘suitability’, ‘treatment services’ and ‘assisting’ under sections 2(1) and schedule 2 paragraph 1(1)(d) of the 1990 Act. Suitability was assigned to the mother without proper explanation, and he separated fertility law from welfare and transplant law by stating that the saviour child is protected after birth. The ambiguous handling of sex selection by the Warnock Report was also evidence, according to Lord Hoffman, of the discretion afforded to the HFE Authority to licence PTT, but sex selection for social reasons is now explicitly banned by the reforming 2008 Act (now schedule 2 paragraph 1ZB of the 1990 Act) leaving this perceived openness to social selection highly unlikely. Lord Brown focussed on sex selection and the Warnock Report too. In the end, the House of Lords merely raised even more questions with its baffling interpretation of the law and its refusal to address any of the queries created by the Court of Appeal.

The common law in the UK (and the US in *Curran v Bosze*⁹²) makes it clear that the welfare of the saviour sibling is paramount, and a tangible psychiatric benefit must be proven at the time of the bone marrow harvest for the donor child to benefit from it. In babies, toddlers and very young children, this is probably not possible.

It is concluded that only the beginning of the saviour sibling process (i.e. the selection of the matching embryo using PTT) is lawful under schedule 2 paragraph 1ZA(1)(d) of the Human Fertilisation and Embryology Act 1990 (as amended) and even then, the roots of this provision are based on a confusing misinterpretation of the relevant provisions in *Quintavalle*, particularly ‘suitable condition’ under schedule 2 paragraph 1(1)(a) and

90 [*R (Quintavalle) v Human Fertilisation Embryology Authority (and Secretary of State for Health)*] [2005] 2 A.C. 561]

91 *Royal College of Nursing of the United Kingdom v Department of Health and Social Security* [1981] A.C. 800 and *Quintavalle R (Quintavalle) v Secretary of State for Health* [2003] UKHL 13].

92 *Curran v Bosze* (1990) 566 N.E.2d 1319.

‘treatment services’ and ‘assisting’ under section 2(1).⁹³ The Human Tissue Authority have published guidelines on bone marrow donations from minors but the decision to harvest is taken in-house without court approval as long as both parents consent.⁹⁴ This is staggering considering the lack of judicial precedent. Parents are therefore free in law to create their own saviour sibling, cannot yet *harvest* that child in law, but proceed under the ambit of the Human Tissue Authority anyway (figure 1):

Statistics from the Human Tissue Authority (as of January 2015)⁹⁵		
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

(Figure 1)

The guidelines published by the Human Tissue Authority now require an urgent rigorous analysis. In the meantime, should the courts approve a bone marrow harvest upon a child in the near future, their interpretation of the law of welfare should be very interesting.

⁹³ *Quintavalle v Human Fertilisation and Embryology Authority (and Secretary of State for Health)* [2005] 2 A.C. 561].

⁹⁴ Code of Practice 6: Donation of Allogeneic Bone Marrow and Peripheral Blood Stem Cells for Transplantation. (2014). Human Tissue Authority. www.hta.gov.uk, at paragraphs 107 and 108.

⁹⁵ These statistics were requested from the Human Tissue Authority by the writer under the Data Protection Act in January 2015 and delivered via email.