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Re-Examining the Best Interests Test for the Treatment and Care of Critically Ill Children: A Case for Legal Reform

Introduction

In most aspects of daily life, parents enjoy wide discretion in decision-making in relation to the care and upbringing of their children. Although they may occasionally make suboptimal decisions, the State does not usually interfere with parental decision-making unless the welfare of a child is at risk.[1] This approach is consistent with the right to respect for private and family life[2] and generally extends to decision-making in clinical settings. Since parents and healthcare staff are often motivated by the common goal of doing what is best for critically ill children, in most cases, they can reach an agreement as to the care and treatment that should be provided.[3] In certain cases, however, both parties may differ in their assessments of what is best for the child and the court may be required to determine whether treatment should be administered using the best interests test.[4]

However, in this paper, I shall argue that the best interests test for the care of critically ill children is not fit for purpose because it fails to give sufficient weight to the wishes and feelings of parents in matters which often relate to the quality of life or the manner of death of their child. I shall contend that since such decisions necessarily entail value judgments, the law should be changed to protect the right of parents to make these decisions according to their values provided there is no risk of significant harm to the child. In addition to making a case for a shift from the best interests test to a significant harm threshold, I shall also argue that the financial and emotional costs associated with litigation makes it necessary for parents and clinicians to be legally required to explore alternative dispute resolution methods before instituting legal proceedings.

Hence, this paper shall be divided into three parts. In the first part, I shall demonstrate that the best interests test is idealistic, highly subjective and unjustifiably interferes with parental rights. In the second part, I shall consider the merits of adopting the

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[1] Children Act 1989, s 1(1).

[2] Human Rights Act 1998, sch 1 art 8.

[3] Dominic Wilkinson, Sarah Barclay and Julian Savulescu, 'Disagreement, Mediation, Arbitration: Resolving Disputes about Medical Treatment' (2018) 391 The Lancet 2302.

[4] *Re J (A Minor) (Wardship: Medical Treatment)* [1991] Fam 33; *Portsmouth Hospitals NHS Trust v Wyatt* [2005] EWCA Civ 1181; *Yates & Anor v Great Ormond Street Hospital for Children NHS Foundation Trust & Anor* [2017] EWCA Civ 410; *Evans & Anor v Alder Hey Children's NHS Foundation Trust & Anor* [2018] EWCA Civ 984.

significant harm threshold and show that it is a better alternative to the best interests test. Then I shall conclude by examining various methods of alternative dispute resolution and illustrating how consultation with clinical ethics committees and mediation can be used to reduce litigation in these matters.

Applying the Bests Interests Test in the Care of Critically Ill Children: Idealistic, Inconsistent and Meddlesome

Healthcare staff are legally and professionally required to act in the best interests of their patients.[5] Where such patients are children, clinicians are required to engage with[6] and obtain consent from their parents or others who have parental responsibility for them before proceeding with treatment[7] to avoid civil or criminal liability.[8] Although children who have sufficient understanding and intelligence necessary to grasp the nature of the treatment – that is *Gillick* competent or mature minors – may give consent to treatment which cannot be overridden by their parents[9], this paper shall focus on infants and younger children. This is because, as with adults, clinicians will generally provide treatment to which a mature minor has consented unless it is contrary to their professional judgment.[10] Where the only treatment available is experimental, it is also reasonable to presume that the courts would accede to a mature minor's wishes to undertake such treatment or parental views on the matter if he is no longer able to consent.[11] On the other hand, case law clearly shows that refusal of life-saving treatment by mature minors will be overridden by the courts, irrespective of parental wishes.[12] Since the position of mature minors in these

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[5] *Re R (A Minor) (Wardship: Consent to Treatment)* [1992] Fam 11; General Medical Council, '0 – 18 Years: Guidance for All Doctors' (2018) para 8; General Medical Council, 'Treatment and Care Towards the End of Life: Good Practice in Decision Making' (2010) para 92; Vic Larcher and others, 'Making Decisions to Limit Treatment in Life-Limiting and Life-Threatening Conditions in Children: A Framework for Practice' (2015) 100 Archives of Diseases in Childhood 1, 21.

[6] General Medical Council, '0 – 18 Years: Guidance for All Doctors' (2018) paras 4 and 14(b).

[7] *Re J (A Minor) (Wardship: Medical Treatment)* [1991] Fam 33; *Re R (A Minor) (Wardship: Consent to Treatment)* [1992] Fam 11; General Medical Council, '0 – 18 Years: Guidance for All Doctors' (2018) paras 27 – 29.

[8] *Re R (A Minor) (Wardship: Consent to Treatment)* [1992] Fam 11; Emily Jackson, *Medical Law: Text, Cases and Materials* (4th edn, Oxford University Press 2016) 197.

[9] *Gillick v West Norfolk and Wisbech AHA* [1986] AC 112.

[10] *Re R (A Minor) (Wardship: Consent to Treatment)* [1992] Fam 11; *Re J (A Minor) (Medical Treatment)* [1993] Fam 15; *R (Burke) v General Medical Council & Ors* [2005] EWCA Civ 1003.

[11] *Simms v Simms and An NHS Trust* [2002] EWHC 2734; Dominic Wilkinson and Julian Savulescu, *Ethics, Conflict and Medical Treatment for Children: From Disagreement to Dissensus* (Elsevier 2018) 85.

[12] *Re R (A Minor) (Wardship: Consent to Treatment)* [1991] 4 All ER 177; *Re W (A Minor) (Medical Treatment: Courts Jurisdiction)* [1992] 4 All ER 627; *A NHS Trust v X (In the matter of X (A Child) (No 2))* [2021] EWHC 65 (Fam); Emma Cave, 'Confirmation of the High Court's Power to Override a Child's

circumstances is somewhat clear, it is therefore preferrable to focus greater attention on cases pertaining to infants and younger children.

While parents generally do not hesitate to consent to procedures that are medically indicated[13], there are cases in which they may disagree with the clinicians as to what is best for the child. In such cases, failure to resolve the dispute amicably often necessitates recourse to the court for a determination of what is in the child's best interests. In making such a determination, the court must ensure that the welfare of the child is its paramount consideration[14] and upon the application of the best interests test, it may make a specific issue order pursuant to Section 8 of the Children Act 1989 or may rely on its inherent jurisdiction to make an order authorising or prohibiting treatment.[15]

Although the courts have repeatedly held that best interests are construed in the widest sense possible – encompassing medical, social and emotional considerations[16] – this description is largely idealistic and difficult to attain in practice, as medical interests are often given disproportionate weight in its assessment.[17] Save for a few cases in which the courts have upheld parental views as to what is in a child's best interests[18], majority of judicial decisions in this area merely reflect medical opinion.[19]

Treatment Decision: A NHS Trust v X (In the Matter of X (A Child) (No 2)) [2021] EWHC 65 (Fam)' (2021) 29(3) Medical Law Review 537.

[13] Dominic Wilkinson, Sarah Barclay and Julian Savulescu, 'Disagreement, Mediation, Arbitration: Resolving Disputes about Medical Treatment' (2018) 391 The Lancet 2302.

[14] Children Act 1989, s 1(1); The United Nations Convention on the Rights of a Child 1990, art 3.

[15] Children Act 1989, s 100; *Re W (A Minor) (Medical Treatment: Courts Jurisdiction)* [1992] 4 All ER 627; *Re S (A Minor) (Medical Treatment)* [1993] 1 FLR 376; *Re* O *(A Minor) (Medical Treatment)* [1993] 2 FLR 149; Jo Bridgeman, 'The Provision of Healthcare to Young and Dependent Children: The Principles, Concepts, and Utility of the Children Act 1989' (2017) 25(3) Medical Law Review 363.

[16] *Portsmouth NHS Trust v Wyatt* [2004] EWHC 2247 (Fam); *Aintree University Hospital NHS Trust v James* [2014] AC 591; *Re MB (Medical Treatment)* [1997] 2 FLR 426; *Re A (Male Sterilisation)* [2000] 1 FLR 549; *Re S (Adult Patient: Sterilisation)* [2001] Fam 15.

[17] Rob Heywood, 'Parents and Medical Professionals: Conflict, Cooperation, and Best Interests' (2012) 20 Medical Law Review 29, 34; Douglas Diekema, 'Parental Refusals of Medical Treatment: The Harm Principle as Threshold for State Intervention' (2004) 25(4) Theoretical Medicine and Bioethics 243, 247.

[18] *An NHS Trust v MB* [2006] 2 FLR 319; *Re T (A Minor) (Wardship: Medical Treatment)* [1997] 1 All ER 906; *Re King* [2014] EWHC 2964 (Fam); *Barts Health NHS Trust v Raqeeb* [2019] EWHC 2530 (Fam).

[19] *Re S (A Minor) (Medical Treatment)* [1993] 1 FLR 376; *Re* O *(A Minor) (Medical Treatment)* [1993] 2 FLR 149; *Re C (A Minor)* [1998] 1 FLR 384; *Portsmouth NHS Trust v Wyatt* [2004] EWHC 2247 (Fam); *Central Manchester University Hospitals NHS Foundation Trust v A & Ors* [2015] EWHC 2828 (Fam); *Re JM (A Child)* [2015] EWHC 2832 (Fam); *Re Gard (A Child)* [2017] EWHC 1909 (Fam); *HK (Serious Medical Treatment) (No.3)* [2017] EWHC 2991; *Kings College Hospital NHS Foundation Trust v Haastrup (Withdrawal of Medical Treatment)* [2018] EWHC 127 (Fam); *Evans & Anor v Alder Hey Children's NHS Foundation Trust & Anor* [2018] EWCA Civ 984; *Fixsler & Anor v Manchester University NHS Foundation Trust & Anor* [2021] EWCA Civ 1018.

While it is possible to argue that medical expertise in determining the appropriate treatment for patients justifies this trend, such an argument fails because an individual's welfare does not comprise solely of his physical wellbeing on which medical opinion can be insightful but also includes social and moral aspects on which medical opinion should not be decisive.[20]

Additionally, the best interests test is misleading because it suggests that there is a best course of action which can be ascertained by an objective assessment.[21] However, the best interests test is extremely subjective by its very nature and although the Children Act 1989 provides a set of factors to be considered in making such assessments[22], the judge is at liberty to determine what weight to give to each of these factors in reaching his decision.[23] It is thus unsurprising that the courts may arrive at conflicting conclusions on a similar set of facts using this test. For instance, although both children in *An NHS Trust v MB*[24] and *Re C (A Minor)*[25] who suffered from spinal muscular atrophy were conscious and responded positively to their family, the court held in the former case that the limited pleasures which the child derived from life outweighed the burdens of treatment and that it was not in his best interest to discontinue ventilation while the opposite conclusion was reached in the latter case.

Hence, far from being an objective determination, judicial assessments of best interests involve value-judgments on sensitive matters such as quality of life and questions as to whether a life can become so burdensome that it is no longer considered worth living.[26] These are deeply personal matters on which diverse views can validly be held and it is undesirable that the opinion of another on such matters should outweigh the views of parents, especially as such decisions have far-reaching

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[20] Cressida Auckland and Imogen Goold, 'Parental Rights, Best Interests and Significant Harms: Who Should have the Final Say Over a Child's Medical Care?' (2019) 78(2) Cambridge Law Journal 287, 301.

[21] Douglas Diekema, 'Parental Refusals of Medical Treatment: The Harm Principle as Threshold for State Intervention' (2004) 25(4) Theoretical Medicine and Bioethics 243, 247; Janine Penfield Winters, 'When Parents Refuse: Resolving Entrenched Disagreements Between Parents and Clinicians in Situations of Uncertainty and Complexity' (2018) 18(8) The American Journal of Bioethics 20, 21.

[22] Children Act 1989, s 1(3) (a) – (g).

[23] Douglas Diekema, 'Parental Refusals of Medical Treatment: The Harm Principle as Threshold for State Intervention' (2004) 25(4) Theoretical Medicine and Bioethics 243, 247; Erica Salter, 'Deciding for a Child: A Comprehensive Analysis of the Best Interest Standard' (2012) 33 Theoretical Medicine and Bioethics 179, 189.

[24] [2006] 2 FLR 319.

[25] [1998] 1 FLR 384.

consequences not only for the child but for the parents and other members of the family.[27]

For these reasons, it has been argued that the best interests test sets an extremely low threshold for interfering with parental autonomy and risks encroaching on the right to respect for private and family life and the freedom of thought, conscience and religion.[28] More so, it is contended that it is inconsistent with the general approach of the State to parental decision-making in other aspects of a child's life where parents are allowed to make suboptimal decisions provided the child is not at risk of significant harm.[29] Although Giles Birchley has argued that this approach is justifiable in medical cases because health is of special moral importance and a higher threshold should be set to protect it,[30] this position is difficult to justify in the light of recent judicial decisions which have shown that an application of a best interests test may result in the court preventing parents from seeking treatment for their child from clinicians who are willing to provide it in other jurisdictions.[31] If indeed the best interests test is directed at ensuring that parental autonomy does not jeopardise a child's health, then it also follows that the application of the test should not preclude a child from accessing treatment outside this jurisdiction merely because treating clinicians disapprove of such treatment. Even where the treatment is experimental, the view that health is of special moral importance should allow parents to explore such treatment as these are often life-or-death situations in which there is little to lose but everything to gain.[32]

Hence, it is evident that the best interests test is not fit for purpose because it is highly subjective, results in inconsistent conclusions and accords disproportionate weight to medical opinion, with little consideration of other relevant factors. For these reasons,

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[28] Cressida Auckland and Imogen Goold, 'Parental Rights, Best Interests and Significant Harms: Who Should have the Final Say Over a Child's Medical Care?' (2019) 78(2) Cambridge Law Journal 287, 293; Erica Salter, 'Deciding for a Child: A Comprehensive Analysis of the Best Interest Standard' (2012) 33 Theoretical Medicine and Bioethics 179, 195.

[29] Dominic Wilkinson and Tara Nair, 'Harm Isn't All You Need: Parental Discretion and Medical Decisions for a Child' (2016) 42(2) Journal of Medical Ethics 116, 117; Cressida Auckland and Imogen Goold, 'Parental Rights, Best Interests and Significant Harms: Who Should have the Final Say Over a Child's Medical Care?' (2019) 78(2) Cambridge Law Journal 287, 313.

[30] Giles Birchley, 'The Harm Threshold and Parents' Obligation to Benefit their Children' (2016) 42(2) Journal of Medical Ethics 123, 124.

[31] *Re Gard (A Child)* [2017] EWHC 1909 (Fam); *Fixsler & Anor v Manchester University NHS Foundation Trust & Anor* [2021] EWCA Civ 1018.

[32] Dominic Wilkinson and Julian Savulescu, 'After Charlie Gard: Ethically Ensuring Access to Innovative Treatment' (2017) 390 The Lancet 540.

there is a clear case for a change in the law to replace the best interests test. To this end, I shall now consider the significant harm threshold as a viable alternative to the best interests test for the care and treatment of critically ill children.

The Significant Harm Threshold: A Better Alternative?

The significant harm threshold is widely accepted in the literature as the preferred test for determining when State interference with parental decision-making in the treatment of children is justifiable.[33] However, the case of *Re Gard (A Child)*[34] which involved Charlie – a child with a mitochondrial disease that resulted in significant irreversible brain damage – sparked renewed interest in its relevance to resolving legal disputes between parents and clinicians. In *Gard*[35], the Trust sought and obtained a declaration that it was in Charlie's best interests for ventilation to be withdrawn and to be prevented from being taken to the United States by his parents to undergo nucleoside therapy. At the Court of Appeal, counsel for Charlie's parents argued that *Re King*[36] had established that the State should only interfere with parental decisions to pursue viable treatment alternatives where treatment was likely to cause significant harm.

Although the court was unequivocal in its rejection of the significant harm threshold and has continued to apply the best interests test in similar cases related to the treatment of critically ill children[37], there appears to be growing support for this approach in recent proposed legislative reforms. Specifically, the Access to Palliative Care and Treatment of Children Bill proposes the adoption of this approach as it provides that treatment proposed by a person with parental responsibility for a child

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[33] Rosalind McDougall and Lauren Notini, 'Overriding Parents' Medical Decisions for their Children: A Systematic Review of Normative Literature' (2014) 40 Journal of Medical Ethics 448, 452; Douglas Diekema, 'Parental Refusals of Medical Treatment: The Harm Principle as Threshold for State Intervention' (2004) 25(4) Theoretical Medicine and Bioethics 243; Dominic Wilkinson and Tara Nair, 'Harm Isn't All You Need: Parental Discretion and Medical Decisions for a Child' (2016) 42(2) Journal of Medical Ethics 116; Rosalind McDougall, 'Indeterminacy and the Normative Basis of the Harm Threshold for Overriding Parental Decisions: A Response to Birchley' (2016) 42(2) Journal of Medical Ethics 119; Charles Foster, 'Harm: As Indeterminate as 'Best Interests', But Useful for Triage' (2016) 42(2) Journal of Medical Ethics 121; Cressida Auckland and Imogen Goold, 'Parental Rights, Best Interests and Significant Harms: Who Should have the Final Say Over a Child's Medical Care?' (2019) 78(2) Cambridge Law Journal 287.

[34] [2017] EWHC 1909 (Fam).

[35] [2017] EWHC 1909 (Fam).

[36] [2014] EWHC 2964 (Fam).

[37] *HK (Serious Medical Treatment) (No.3)* [2017] EWHC 2991; *Kings College Hospital NHS Foundation Trust v Haastrup (Withdrawal of Medical Treatment)* [2018] EWHC 127 (Fam); *Evans & Anor v Alder Hey Children's NHS Foundation Trust & Anor* [2018] EWCA Civ 984; *Fixsler & Anor v Manchester University NHS Foundation Trust & Anor* [2021] EWCA Civ 1018.

shall be considered by the court unless it is established that it ‘poses a disproportionate risk of significant harm’.[38] It is thus apposite to consider the merits of the significant harm threshold in view of the increasing support for the approach in recent times.

One of the arguments in favour of this approach is that it accords significant weight to the wishes of parents and is therefore more consistent with the right to respect for private and family life.[39] However, David Benbow has argued that such an approach would allow parents make guinea pigs of their children by allowing them to explore any treatment which they consider to be of benefit, notwithstanding medical evidence to the contrary.[40] This position is seemingly reinforced by examples from other jurisdictions where unfettered parental autonomy in such circumstances has led to the child’s death.[41]

It must however be noted that although the significant harm threshold raises the standard for judicial interference with parental decision-making higher than the best interests test, it does not confer absolute powers on parents to make medical decisions for their children and where a course of action is likely to expose a child to significant harm, it allows the court to intervene to protect the welfare of the child. More so, clinicians would still be required to ensure that the treatment provided to a child even at the request of parents accords with the practice of a responsible body of medical opinion and can withstand logical analysis.[42] Hence, although the significant harm test will enhance parental autonomy in making medical decisions for their children, there are appropriate safeguards under the existing legal framework to ensure that the welfare of children is not jeopardised.

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[38] Access to Palliative Care and Treatment of Children HL Bill (2020 – 01) 13, cl 2(4); HL Deb 7 February 2020, vol 801, col 2034.

[39] Dominic Wilkinson and Tara Nair, ‘Harm Isn’t All You Need: Parental Discretion and Medical Decisions for a Child’ (2016) 42(2) Journal of Medical Ethics 116, 117; Rosalind McDougall, ‘Indeterminacy and the Normative Basis of the Harm Threshold for Overriding Parental Decisions: A Response to Birchley’ (2016) 42(2) Journal of Medical Ethics 119; Lynn Gillam, ‘The Zone of Parental Discretion: An Ethical Tool for Dealing with Disagreement Between Parents and Doctors about Medical Treatment for a Child’ (2016) 11(1) Clinical Ethics 1, 2.

[40] David Benbow, ‘An Analysis of Charlie’s Law and Alfie’s Law’ (2019) 28(2) Medical Review 223, 237.

[41] Edwin Hui, ‘Parental Refusal of Life-Saving Treatments for Adolescents: Chinese Familism in Medical Decision-Making Re-Visited’ (2008) 22(5) Bioethics 286, 289.

[42] Cressida Auckland and Imogen Goold, ‘Parental Rights, Best Interests and Significant Harms: Who Should have the Final Say Over a Child’s Medical Care?’ (2019) 78(2) Cambridge Law Journal 287, 316.

Similarly, the significant harm threshold is better suited for a multicultural society where diverse views can validly be held on issues related to quality or length of life.[43] To this end, it is considered to be more consistent with the right to freedom of thought, conscience and religion.[44] While the application of the test is likely to maintain the current approach to overriding parental refusal of life-saving interventions such as blood transfusions, its most significant effect would probably be in circumstances in which parents request for treatment against the advice of treating clinicians. It has been argued that such an approach will bolster confidence in the medical system among religious and cultural communities where the current application of the best interests test may deter parents from seeking treatment earlier for their children for fear that their beliefs as to how their children ought to be cared for would not be respected.[45] Although it may be argued that giving priority to parental rights to enjoy freedom of thought, conscience and religion would compel clinicians to provide treatment which they do not consider to be clinically indicated, it is trite law that clinicians cannot be compelled to treat a patient against their professional judgment[46] and this position will remain unchanged where the significant harm threshold is applied.

Furthermore, since it has been contended that concerns as to efficient use of limited resources often underlie such disputes[47], a significant harm threshold would ensure that such considerations do not prevent parents from funding their preferred treatment through private means. Benbow has however argued that such an approach is undesirable in a public funded healthcare system and may exacerbate existing health inequalities.[48] He also suggests that it would cause people to donate to treatment which may be futile instead of other worthwhile causes.[49] Although people are clearly at liberty to make donations to whatever lawful causes they believe in, his argument

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[43] Dominic Wilkinson and Tara Nair, 'Harm Isn't All You Need: Parental Discretion and Medical Decisions for a Child' (2016) 42(2) Journal of Medical Ethics 116, 117.

[44] Human Rights Act 1998, sch 1 art 9.

[45] Janine Penfield Winters, 'When Parents Refuse: Resolving Entrenched Disagreements Between Parents and Clinicians in Situations of Uncertainty and Complexity' (2018) 18(8) The American Journal of Bioethics 20, 22.

[46] *Re R (A Minor) (Wardship: Consent to Treatment)* [1992] Fam 11; *Re J (A Minor) (Medical Treatment)* [1993] Fam 15; *R (Burke) v General Medical Council & Ors* [2005] EWCA Civ 1003.

[47] Margot Brazier, 'An Intractable Dispute: When Parents and Professionals Disagree' (2005) 13 Medical Law Review 412, 418; Richard David William Hain, 'Voices of Moral Authority: Parents, Doctors and What Will Actually Help' (2018) 44 Journal of Medical Ethics 458, 459.

[48] David Benbow, 'An Analysis of Charlie's Law and Alfie's Law' (2019) 28(2) Medical Review 223, 239.

[49] David Benbow, 'An Analysis of Charlie's Law and Alfie's Law' (2019) 28(2) Medical Review 223, 239.

is flawed for two further reasons. First, he seems to place concerns as to distributive justice over the need to ensure that parents are not precluded from exploring treatment options that may preserve their child's life. However, such a position is difficult to justify in a society that recognises the principle of sanctity of life.[50] Second, he assumes that medical evidence is always incontrovertible but as Wilkinson and Nair have observed, medical science is not a precise science and as such, medical experts can and often disagree on the efficacy of treatment.[51] Therefore, it is preferable to adopt a test which allows parents to pursue treatment options which they consider to be viable, provided that the child is not put at risk of significant harm.

Notwithstanding these merits of the significant harm threshold, it has been criticised on several grounds. For instance, Birchley has argued that it is as subjective as the best interests test because what amounts to significant harm may vary from one person to another.[52] However, even if every assessment of benefits or harm may invariably reflect the values and preferences of individuals, it is preferable to give determinative weight to the views of parents, provided the child is not exposed to significant harm, because this is not only consistent with the rights to respect for private and family life[53] and freedom of thought, conscience and religion[54] but also with the general approach of the State to parental decision-making in other aspects of life.

Birchley also contends that the language of 'harm' may be more offensive to parents than 'best interests'.[55] However, as Wilkinson and Nair observe, semantics are unlikely to matter if whatever test adopted ultimately results in overriding the clear wishes of parents.[56] Furthermore, Benbow argues that the significant harm threshold is contrary to international law[57] which clearly requires that decisions are to be made in the best

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[50] Julian Savulescu, 'Is it in Charlie Gard's Best Interest to Die?' (2017) 389 The Lancet 1868.

[51] Dominic Wilkinson and Tara Nair, 'Harm Isn't All You Need: Parental Discretion and Medical Decisions for a Child' (2016) 42(2) Journal of Medical Ethics 116, 117; Dominic Wilkinson and Julian Savulescu, 'After Charlie Gard: Ethically Ensuring Access to Innovative Treatment' (2017) 390 The Lancet 540.

[52] Giles Birchley, 'Harm is All You Need? Best Interests and Disputes About Parental Decision-Making' (2016) 42 Journal of Medical Ethics 111, 113; Giles Birchley, 'The Harm Threshold and Parents' Obligation to Benefit their Children' (2016) 42(2) Journal of Medical Ethics 123, 125.

[53] Human Rights Act 1998, sch 1 art 8.

[54] Human Rights Act 1998, sch 1 art 9.

[55] Giles Birchley, 'Harm is All You Need? Best Interests and Disputes About Parental Decision-Making' (2016) 42 Journal of Medical Ethics 111, 113; Giles Birchley, 'The Harm Threshold and Parents' Obligation to Benefit their Children' (2016) 42(2) Journal of Medical Ethics 123.

[56] Dominic Wilkinson and Tara Nair, 'Harm Isn't All You Need: Parental Discretion and Medical Decisions for a Child' (2016) 42(2) Journal of Medical Ethics 116, 118.

[57] The United Nations Convention on the Rights of a Child 1990, art 3.

interests of a child.[58] However, as we have discussed above, the best interests test is idealistic and in its assessment, the courts often give determinative weight to medical interests at the expense of other relevant considerations. Such an approach fails to provide a wholistic assessment of the welfare of the child. In contrast, a significant harm threshold allows for such a wholistic assessment as it gives the views of parents who are more likely to be acquainted with the emotional and social needs of the child greater weight whilst ensuring that the child is not placed at risk of significant harm by so doing. Hence, there is a clear basis for the shift from the best interests test to a significant harm threshold in the law related to the care of critically ill children.

Litigation as a Matter of Last Resort

Although the adoption of the significant harm threshold is a desirable change in the law relating to the care and treatment of critically ill children, the financial and emotional costs associated with litigation render it necessary to explore other dispute resolution mechanisms which are cheaper, faster and preserve the relationship between the parties.[59] One approach to resolving such disputes is through discussions between families and clinicians and research suggests that this may be the most successful method of dispute resolution in these circumstances.[60] In certain cases, however, such discussions may be ineffective in resolving conflict for a variety of reasons including differences in understanding of the available information and the pejorative labelling of parents who disagree with treating clinicians in healthcare settings.[61]

Where parties are unable to resolve their conflict because of such differences in understanding of information, further clinical opinion may be sought to clarify matters.

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[58] David Benbow, ‘An Analysis of Charlie’s Law and Alfie’s Law’ (2019) 28(2) Medical Review 223, 235.

[59] Rob Heywood, 'Parents and Medical Professionals: Conflict, Cooperation, and Best Interests' (2012) 20 Medical Law Review 29, 43.

[60] Louise Austin and Richard Huxtable, ‘Resolving Disagreements about the Care of Critically Ill Children: Evaluating Existing Processes and Setting the Research Agenda’ in Imogen Goold, Jonathan Herring and Cressida Auckland (eds), *Parental Rights, Best Interests and Significant Harms: Great Ormond Street Hospital v Gard* (Bloomsbury Publishing 2019) 214; Joe Brierley, Jim Linthicum and Andy Petros, ‘Should Religious Beliefs be Allowed to Stonewall a Secular Approach to Withdrawing and Withholding Treatment in Children?’ (2013) 39 Journal of Medical Ethics 573.

[61] Louise Austin and Richard Huxtable, ‘Resolving Disagreements about the Care of Critically Ill Children: Evaluating Existing Processes and Setting the Research Agenda’ in Imogen Goold, Jonathan Herring and Cressida Auckland (eds), *Parental Rights, Best Interests and Significant Harms: Great Ormond Street Hospital v Gard* (Bloomsbury Publishing 2019) 215; Emily Parsons and Anne-Sophie Darlington, ‘Parents’ Perspectives on Conflict in Paediatric Healthcare: A Scoping Review’ (2021) 106 Archives of Diseases in Childhood 981, 983.

However, parents may question the independence of experts invited by the clinicians, especially where they agree with the position advanced by the treating team.[62] Although this challenge may be addressed by allowing parents choose the expert, concerns have been raised that this may lead to 'doctor-shopping' for an expert who endorses the views of the parents and may still fail to prevent escalation of conflict where such experts agree with clinicians.[63] Nonetheless, where the disagreement is not merely as to facts but relates to a difference in values, discussions between the parties or a second opinion is unlikely to resolve the conflict. In such cases, two approaches have been proposed for preventing the need for court intervention.

One approach to resolving conflicts in such circumstances is consultation with clinical ethics committees which is widely utilized in Texas, Israel, Chile and Argentina.[64] Since such committees are usually multidisciplinary – often comprising healthcare professionals, ethicists, lawyers and religious leaders – they may be better equipped to conduct a more robust assessment of the conflicting values and may be more successful in identifying areas in which parties may effectively reach a compromise.[65] However, concerns have been raised as to the lack of specific qualifications for membership of such committees and the absence of metrics for evaluating their performance.[66] It has also been argued that since the committees exist to provide practical advice to clinicians, it may be difficult for them to operate independently.[67]

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[62] Simon Meller and Sarah Barclay, 'Mediation: An Approach to Intractable Disputes Between Parents and Paediatricians' (2011) 96(7) Archives of Disease in Childhood 619; Louise Austin and Richard Huxtable, 'Resolving Disagreements about the Care of Critically Ill Children: Evaluating Existing Processes and Setting the Research Agenda' in Imogen Goold, Jonathan Herring and Cressida Auckland (eds), *Parental Rights, Best Interests and Significant Harms: Great Ormond Street Hospital v Gard* (Bloomsbury Publishing 2019) 218.

[63] Simon Meller and Sarah Barclay, 'Mediation: An Approach to Intractable Disputes Between Parents and Paediatricians' (2011) 96(7) Archives of Disease in Childhood 619.

[64] Cressida Auckland and Imogen Goold, 'Resolving Disagreement: A Multi-Jurisdictional Comparative Analysis of Disputes about Children's Medical Care' (2020) 28(4) Medical Law Review 643, 667.

[65] Louise Austin and Richard Huxtable, 'Resolving Disagreements about the Care of Critically Ill Children: Evaluating Existing Processes and Setting the Research Agenda' in Imogen Goold, Jonathan Herring and Cressida Auckland (eds), *Parental Rights, Best Interests and Significant Harms: Great Ormond Street Hospital v Gard* (Bloomsbury Publishing 2019) 219.

[66] Susan Wolf, 'Due Process in Ethics Committee Case Review' (1992) 4 HEC Forum 83, 94; Louise Austin and Richard Huxtable, 'Resolving Disagreements about the Care of Critically Ill Children: Evaluating Existing Processes and Setting the Research Agenda' in Imogen Goold, Jonathan Herring and Cressida Auckland (eds), *Parental Rights, Best Interests and Significant Harms: Great Ormond Street Hospital v Gard* (Bloomsbury Publishing 2019) 221.

[67] Morten Magelssen, Reidar Pedersen and Reidun Førde, 'Sources of Bias in Clinical Ethics Case Deliberation' (2014) 40 Journal of Medical Ethics 678; Louise Austin and Richard Huxtable, 'Resolving Disagreements about the Care of Critically Ill Children: Evaluating Existing Processes and Setting the Research Agenda' in Imogen Goold, Jonathan Herring and Cressida Auckland (eds), *Parental Rights,*

Additionally, it has been contended that their lack of robust and transparent procedures renders such committees ill-suited for making binding decisions in life-or-death situations.[68] Nonetheless, these deficiencies are not irredeemable and as Austin and Huxtable have suggested, members of the committees can be required to undertake training, mechanisms can be established for auditing their decisions and a process for appeals can be created.[69] These can be clearly set out in national guidelines or regulations. Hence, consultations with clinical ethics committees remain a viable alternative for resolving disputes between parents and clinicians in these circumstances.[70]

Mediation has also been proposed as a viable alternative for conflict resolution in these cases as it is flexible and encourages open discussion between the parties which can help rebuild trust.[71] As such, the Access to Palliative Care and Treatment of Children Bill proposes to make it mandatory for parents and clinicians to have attempted to resolve their dispute through mediation before making an application to the High Court under the Children Act 1989.[72] This accords with the recommendations of the trial judge in *Gard*[73] and the Royal College of Paediatric and Child Health[74] which are to

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Best Interests and Significant Harms: Great Ormond Street Hospital v Gard (Bloomsbury Publishing 2019) 221.

[68] Autumn Fiester, 'The Failure of the Consult Model: Why "Mediation" Should Replace "Consultation"' (2007) 7(2) American Journal of Bioethics 31; Louise Austin and Richard Huxtable, 'Resolving Disagreements about the Care of Critically Ill Children: Evaluating Existing Processes and Setting the Research Agenda' in Imogen Goold, Jonathan Herring and Cressida Auckland (eds), *Parental Rights, Best Interests and Significant Harms: Great Ormond Street Hospital v Gard* (Bloomsbury Publishing 2019) 221.

[69] Louise Austin and Richard Huxtable, 'Resolving Disagreements about the Care of Critically Ill Children: Evaluating Existing Processes and Setting the Research Agenda' in Imogen Goold, Jonathan Herring and Cressida Auckland (eds), *Parental Rights, Best Interests and Significant Harms: Great Ormond Street Hospital v Gard* (Bloomsbury Publishing 2019) 222.

[70] Anne Marie Slowther, Leah McClimans and Charlotte Price, 'Development of Clinical Ethics Services in the UK: A National Survey' (2012) 38 Journal of Medical Ethics 210, 214; Dominic Wilkinson and Julian Savulescu, 'Alfie Evans and Charlie Gard – Should the Law Change?' (2018) 361 BMJ Online <https://www-bmj-com.ezproxy.is.ed.ac.uk/content/361/bmj.k1891> accessed 27 December 2021.

[71] Louise Austin and Richard Huxtable, 'Resolving Disagreements about the Care of Critically Ill Children: Evaluating Existing Processes and Setting the Research Agenda' in Imogen Goold, Jonathan Herring and Cressida Auckland (eds), *Parental Rights, Best Interests and Significant Harms: Great Ormond Street Hospital v Gard* (Bloomsbury Publishing 2019) 223; Nuffield Council on Bioethics, *Critical Care Decisions in Fetal and Neonatal Medicine: Ethical Issues* (Nuffield Council on Bioethics 2006) 146; Ben Gray and Fern Brunger, '(Mis)Understandings and Uses of 'Culture' in Bioethics Deliberations over Parental Refusal of Treatment: Children with Cancer' (2018) 13(2) Clinical Ethics 55, 60; Dominic Wilkinson and Julian Savulescu, 'Alfie Evans and Charlie Gard – Should the Law Change?' (2018) 361 BMJ Online <https://www-bmj-com.ezproxy.is.ed.ac.uk/content/361/bmj.k1891> accessed 27 December 2021.

[72] Access to Palliative Care and Treatment of Children HL Bill (2020 – 01) 13, cl 2(2) (a) – (b).

[73] [2017] EWHC 1909 (Fam) [20].

[74] Vic Larcher and others, 'Making Decisions to Limit Treatment in Life-Limiting and Life-Threatening Conditions in Children: A Framework for Practice' (2015) 100 Archives of Diseases in Childhood 1, 9.

the effect that mediation should be employed to deescalate conflict between parents and clinicians before resorting to litigation. However, Austin and Huxtable contend that since mediation requires parties to be willing to make compromises, it may be unsuccessful in these circumstances because each party usually has deeply entrenched positions.[75] For this reason, it has been argued that mediation may do little more than delay recourse to litigation in these cases.[76]

However, certain changes can be made to enhance the efficacy of mediation in these cases. First, the current provisions of the Bill will be further strengthened by an amendment which will make it mandatory for all parties – and not only health service bodies – to attempt mediation before instituting legal proceedings. [77] This will ensure that other parties are unable to bypass this provision and will emphasise that it is as important for them to engage in mediation as it is for health service bodies. Second, engaging with mediators who are skilled in medical law and ethics, understand paediatric issues and have access to independent specialist advice would facilitate the identification and resolution of conflicting values which are often at the heart of such disputes.[78] Hence, mediation remains a promising approach to resolving disputes between parents and as proposed in the Bill, there should be a legal requirement to resort to mediation before instituting legal proceedings.

Conclusion

In this paper, I have argued that despite the alluring descriptions of the best interests test by the judiciary and its proponents in the literature, it is not fit for purpose for the care and treatment of critically ill children because it is idealistic, highly subjective and unduly interferes with parental rights. I have also illustrated how the significant harm threshold, which appears to have growing support in proposed legislative reforms, addresses these deficiencies of the best interests test and is better suited for

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[75] Louise Austin and Richard Huxtable, 'Resolving Disagreements about the Care of Critically Ill Children: Evaluating Existing Processes and Setting the Research Agenda' in Imogen Goold, Jonathan Herring and Cressida Auckland (eds), *Parental Rights, Best Interests and Significant Harms: Great Ormond Street Hospital v Gard* (Bloomsbury Publishing 2019) 223.

[76] Cressida Auckland and Imogen Goold, 'Resolving Disagreement: A Multi-Jurisdictional Comparative Analysis of Disputes about Children's Medical Care' (2020) 28(4) Medical Law Review 643, 665; Anne Sorbie, 'Children's Best Interests and Parents' Views: Challenges from Medical Law' (2021) 43(1) Journal of Social Welfare and Family Law 23, 37.

[77] Anne Sorbie, 'Children's Best Interests and Parents' Views: Challenges from Medical Law' (2021) 43(1) Journal of Social Welfare and Family Law 23, 35.

[78] Simon Meller and Sarah Barclay, 'Mediation: An Approach to Intractable Disputes Between Parents and Paediatricians' (2011) 96(7) Archives of Disease in Childhood 619.

determining cases in which parents and healthcare staff disagree on the treatment of a child. However, I have suggested that since litigation often comes at great financial and emotional costs, it is preferable to explore other forms of dispute resolution before instituting legal action. Specifically, I have demonstrated support for a legal requirement for parties to engage in mediation before instituting legal proceedings and encouraged increased use of consultations with clinical ethics committees. A combination of these approaches will not only foster amicable resolution of conflict between parents and healthcare staff but will ensure that both parties do not lose sight of the most important person in such disputes: the critically ill child.

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