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The harm threshold: A view from the clinic

Introduction

It is a well-known legal trope that difficult cases make a bad basis for policy.¹ One such difficult case is that of Charlie Gard,² a high-profile disagreement between the parents and doctors of a critically ill infant with mitochondrial disease whose parents asserted it was in his best interests to receive an innovative treatment. In this chapter I shall argue that *Gard* proves no exception to this observation. “Charlie’s law”, drafted with the support of Charlie’s parents, “proposes to clarify the law around ‘best interests’ and ensure families going through ... difficult times are properly supported”.³ *Inter alia* “Charlie’s law” seeks to strengthen parental rights by preventing legal interference with parental decisions about their child’s best interests unless the decision causes significant harm to the child – a so-called ‘harm threshold’. The move would bring medical decisions into line with social decisions about children for example those about education, religion or diet.⁴ “Charlie’s law” has support within parliament and, while yet to influence the law, retains significant momentum.

The harm threshold has significant support in bioethics.⁵ Its proponents claim numerous motivations, several of which are outlined in detail in this volume by Dominic Wilkinson.⁶ These arguments assert: (1) we allow suboptimality in other areas of parental decision-making. Therefore the absence of a harm threshold in medical law amounts to an unjustifiable inconsistency both with the way the law considers other types of parental decisions and with the usual catholic approach to parental decisions in medical practice; (2) the best interests test is too vague to deal with complex, value laden decisions where benefits and harms are marginal and uncertain, and; (3) parents have fundamental rights to autonomy. These are underpinned by the fact that parents have an epistemically privileged view of the welfare of their child and are most affected by any decisions that are made about their child. While parental autonomy rights are not unrestricted, they should be constrained by the harm threshold rather than a test of best interests.

These arguments can be characterised as a rights claim on behalf of parents: that ‘parental autonomy’ is infringed by lack of a harm threshold in medical law. The arguments contain a mixture of normative and empirical claims, so this chapter is divided into two parts. Part one investigates the

¹ Brazier M, 'Hard cases make bad law?' (1997) 23 *Journal of Medical Ethics* 341

² The case went through multiple stages of appeal and reached the European court of human rights: *GOSH v Yates* [2017] EWHC 972; *GOSH v Yates No.2* [2017] EWHC 1909; *Yates and Gard v GOSH* [2017] EWCA Civ 410; *Gard and Others v UK* [2017] ECHR 39793-17

³ The Charlie Gard Foundation, 'Charlie’s Law' (*The Charlie Gard Foundation*, 2018) <<https://www.thecharliegardfoundation.org/charlies-law/>> accessed 31st January 2019

⁴ Add reference for Rachel Taylor’s chapter in this volume

⁵ F Schoeman, 'Parental Discretion and Children's Rights: Background and Implications for Medical Decision Making' (1985) *Journal of Medicine and Philosophy* 45R. Dresser, 'Standards for family decisions: replacing best interests with harm prevention' (2003) 3 *The American journal of bioethics* : AJOB 54Douglas S. Diekema, 'Parental Refusals of Medical Treatment: The Harm Principle As Threshold for State Intervention' (2004) 25 *Theoretical Medicine and Bioethics* 243R. J. McDougall, 'Indeterminacy and the normative basis of the harm threshold for overriding parental decisions: a response to Birchley' (2016) 42 *J Med Ethics* 119S. K. Shah, A. R. Rosenberg and D. S. Diekema, 'Charlie Gard and the Limits of Best Interests' (2017) 171 *JAMA Pediatr* 937J. P. Winters, 'When Parents Refuse: Resolving Entrenched Disagreements Between Parents and Clinicians in Situations of Uncertainty and Complexity' (2018) 18 *The American journal of bioethics* : AJOB 20D. Wilkinson and J. Savulescu, *Ethics, Conflict and Medical Treatment for Children: From Disagreement to Dissensus* (Elsevier 2019)

⁶ Add reference to Wilkinson chapter in this volume

empirical basis of the claim about parental decision-making in medical practice. It uses an analysis of interviews that reveal some thresholds of decision-making that are volunteered by parents and healthcare professionals in discussions about non-treatment decisions in paediatric intensive care. A number of thresholds occur. While these suggest that a complex range of factors are considered, the dominant threshold adopted by parents is that a decision is best for the child, whereas the dominant threshold for clinicians is that a decision is best for the family. This indicates that healthcare professionals' approaches are indeed sensitive to the rights of parents. To some extent this bears out the analysis of clinical decision-making offered by proponents of the harm threshold. In the second part of the chapter, I take issue with the normative conclusion that this clinical picture means we ought to support the introduction of a harm threshold into medical law. I argue that a harm threshold is largely unmotivated because the current system of decision-making patently does consider the rights of parents as well as children. While this may not be a good fit for some interpretations of the best interests standard, I suggest that this discord may arise from fundamental differences between clinical and legal decision-making. Proponents of the harm threshold may nevertheless be motivated simply by the desire to make medical law consistent with public law. I argue that there are differences in the level of certainty in clinical and social outcomes, that imply we need significantly more caution when making social welfare decisions. I also note that there may be unintended consequences from the adoption of the harm threshold that may impinge on the rights of parents and increase conflict in the healthcare arena. Finally I argue that the very characterisation of arguments for parental as being about liberty is incorrect. While I accept that the best interests test may need of reform, I deny that the harm threshold is the answer.

The harm threshold as a current issue

The case of Charlie Gard has excited interest in the potential impact of introducing a harm threshold into medical law. Charlie Gard was a critically ill infant with a mitochondrial illness whose parents wished him to receive an experimental treatment, nucleoside therapy, offered by a Professor Michael Hirano, a U.S. neurologist. Professor Hirano had published a case series of eighteen children with a related, but distinct, genetic illness. The research suggested that the treatment had a positive effect on that condition. The treatment was a dietary supplement, and thus involved minimal risks. Charlie's hospital initially agreed to a trial of the treatment having established (because the therapy could not reverse brain damage) that Charlie's brain was undamaged. However, before treatment was begun, Charlie did sustain severe brain damage, after suffered almost three weeks of persistent sub-clinical seizures (meaning that he was having continuous epileptic fits with no outward clinical signs). The damage was evidenced by severely abnormal scans of his brain's electrical activity (known as EEG scans). His doctors and a second opinion from a specialist team from Barcelona agreed that further treatment would prolong Charlie's life without offering any hope of recovery, and thus further treatment would not in his best interests. While accepting that he was extremely ill, Charlie's parents did not accept that his condition was beyond help, and, importantly, did not accept that the EEG scans were accurate (because Charlie was receiving a sedative). Encouraged by Professor Hirano, who had not seen the scans, they continued to demand access to nucleoside therapy, for which they now proposed to take Charlie to the U.S.A. The treating hospital sought, and obtained, a legal declaration that treatment was not in Charlie's best interests. The parents appealed, seeking to identify a precedent that, in respect of treatment offered by "expert physicians in a reputable hospital ...the court may not interfere with a decision by parents in the exercise of their parental rights and responsibilities with regard to their child's medical treatment, save where there is a risk the parents' proposed course of action may cause significant harm."⁷ While the courts

⁷ *In the Matter of Charles Gard* [2017] EWCA Civ 410 at [54]

rejected this argument, these proposals suggested a fundamental revision of the workings of private law under the Children Act 1989.

The overarching international framework is that decisions about children should be made in their 'best interests'. This principle is found in Article 3.1 of the 1989 United Nations Convention on the Rights of the Child, and in England and Wales is reflected in the language of section 1(1) of the Children Act 1989⁸ as well as a large volume of case law. Pertaining to public law, section 31(2) of the Act provides that any proposal to intervene with the living arrangements of children by Local Authorities (the lowest tier of English government who are tasked *inter alia* with child protection) should first pass a 'harm threshold'. The upshot of this public law threshold is that only if a child is at risk of significant harm can a care or supervision order be made, an order which will be based on the best interests of that child.⁹ This is broadly founded on a principle that the courts should avoid removing children from parents whose parenting is merely mediocre (or simply unusual), since to act otherwise would amount to social engineering.¹⁰ In this context, the harm threshold is designed to ensure that only parenting that is seriously substandard merits state intervention.¹¹ Since the local authority is not usually a party in medical decisions (although there are exceptions),¹² the harm threshold does not generally apply to medical decision-making.¹³ Instead, interventions by healthcare professionals fall under the Children Act's private law provisions for interventions by private parties with an interest in the child's welfare. Private applications do not require a harm threshold to be satisfied, in part because they fall under s.3(5) of the Act, which permits anyone caring for a child to 'do what is reasonable in all the circumstances of the case for the purpose of safeguarding or promoting the child's welfare.'¹⁴ However, given both the powerful legal apparatus that a hospital can bring to bear in a dispute between doctors and parents about the best interests of medical treatment, and the connection of healthcare provision in England to the state due to the function and governance of the NHS, it is unsurprising that some consider hospitals as the apparatus of the state.¹⁵ This was nowhere more true than in the eyes of the family of Charlie Gard and their supporters.¹⁶

These supporters have kept up the momentum for legal change. Although, Charlie died after his treatment was eventually withdrawn, Charlie's parents have proposed a raft of legal changes they

⁸ More detailed descriptions of the workings of the Children Act can be found in this volume in the Chapters by Rachel Taylor, Above, n.6 and by Rob George

⁹ Of course, the Local Authority can make decisions about what educational support, social work intervention and so on may be needed without crossing the threshold, and with parental consent all kinds of intervention are possible.

¹⁰ E.g. *B (A Child)* [2013] UKSC 33 at [180]; The Children Act 1989 was widely viewed to mark a break from the the legal approach lasting from the Poor law amendment act 1889, where powers to remove children for their welfare were first introduced, until Children Act 1975, which sanctioned permanent Local Authority care automatically for any child who had been for more than 3 years. These approaches disproportionately affected the poor and are now usually held to either be inspired by or result in social engineering.

¹¹ Chapters by Imogen Goold and Dominic Wilkinson n.8 in this volume present reasons for not intervening too readily in parental decisions.

¹² E.g. *Re R (A Child)* [2018] EWFC 28; I will discuss these in part 2

¹³ Although NHS bodies must still seek leave see Chapter by Rachel Taylor Above n.6

¹⁴ J. Bridgeman, 'The Provision of Healthcare to Young and Dependent Children: The Principles, Concepts, and Utility of the Children Act 1989' (2017) 25 Med Law Rev 363

¹⁵ E.g. *Great Ormond Street Hospital for Children NHS Foundation Trust v Yates and others (No 2)* [2017] EWHC 1909 (Fam) at [17] per Francis J.; J. Bridgeman, 'A threshold of significant harm (f) or a viable alternative therapeutic option?' (2018) 44 J Med Ethics 466

¹⁶ L. Johnson, 'Charlie Gard 'is being held prisoner by the NHS' – family spokesman blasts authorities' *Daily Express* (16th July)

call “Charlie’s Law”. They argue these will reduce conflict between hospitals and families. These changes have three central features: (1) to provide parties access to mediation and clinical ethics committees; (2) to provide parents access to independent second opinions and legal aid and (3) to strengthen parental rights by introducing a “Harm Threshold” for court involvement.¹⁷ The proposals have some parliamentary support: having introduced amendments to the Mental Capacity (amendment) Bill based on the first proposal,¹⁸ Lord MacKay is reported as saying: “I hope will be the first small step toward realising Charlie’s Law.”¹⁹ Although these amendments were withdrawn at committee stage, the Parliamentary Under-Secretary of State for the Department of Health and Social Security undertook to work on these issues with interested parties.²⁰ This suggests there is still significant impetus for statutory changes that may introduce a harm threshold into medical law.

The harm threshold in bioethics

Bioethical arguments for the harm threshold claim to have historical and philosophical roots in J.S. Mill’s harm principle: “The only purpose for which power can be rightfully exercised over any member of a civilized community, against his will, is to prevent harm to others.”²¹ Mill claimed that such a principle would protect individuality²² which he characterized as the source of both happiness,²³ personal growth and human genius.²⁴ His doctrine remains a central tenet of liberal philosophy. We should note that, in variance to contemporary supporters of the harm threshold, Mill argued that parenting decisions were separate from the exercise of liberty. In Mill’s view, parental autonomy was an exercise of power rather than of liberty,²⁵ and he did not believe that the harm principle should protect parental choices from the interference of the community. Yet such a view depends on a recognition that children’s best interests can be legitimately determined by persons other than their parents. A significant constituency of contemporary bioethicists are sceptical of this view – citing, as Wilkinson does in this volume, the uncertainty about what is good is a pluralist society and the deep familiarity between parent and child.²⁶ A number have voiced support for the harm threshold.²⁷ Of these, Douglas Diekema offers the most developed theoretical

¹⁷ The Charlie Gard Foundation, ‘Charlie’s Law’

¹⁸ [https://publications.parliament.uk/pa/bills/lbill/2017-2019/0117/18117-l\(a\).pdf](https://publications.parliament.uk/pa/bills/lbill/2017-2019/0117/18117-l(a).pdf)

¹⁹ Sam Greenhill, ‘No other family should be put through our heartbreak: Charlie Gard’s parents fight for ‘Charlie’s Law’ that would allow parents of sick children to move them to a different hospital if they disagree with doctors’ *Daily Mail* (5th September 2018) <<https://www.dailymail.co.uk/news/article-6136369/Charlie-Gards-parents-vowed-boys-death-make-difference.html>> accessed 27th September 2018

²⁰ HL Deb 15 October 2018 vol 793 col 387

²¹ J. S. Mill, *On Liberty* (Dover Publications 2002, [1859]) 8

²² *Ibid.* 46

²³ *Ibid.* 47

²⁴ *Ibid.* 53

²⁵ Mill argued that “it is in the case of children, that misapplied notions of liberty are a real obstacle to the fulfilment by the State of its duties. One would think that a man’s children were supposed to be literally, rather than metaphorically, a part of himself, so jealous is opinion of the smallest interference of law with his absolute and exclusive control over them; more jealous than of almost any interference with his own freedom of action: so much less do the generality of mankind value liberty than power.” *Ibid.* 88-89. Mill’s resistance to parental rights has not been shared by more libertarian wing of contemporary liberalism. Such a view, as popularised by thinkers such as Robert Nozick (See e.g.: Nozick R, *Anarchy, State and Utopia* (Basic Books 1977): 167) can be placed within the context of a wider project to minimise the state to a bare ‘night-watchman’, that implicitly sees family affairs as voluntary, and therefore private and inviolable. It is within such a political philosophy that we might cast the case for the Harm threshold as it appears in bioethics.

²⁶ Wilkinson Chapter n.6

²⁷ *Ibid.* n.7

explanation, which is both widely cited²⁸ and largely unrevised²⁹ since. Therein Diekema argues that judgements of best interests should be mediated by the harm standard. Only if a parental refusal of treatment poses a serious risk of significant harm to their child should doctors invoke the power of the state to override that refusal or preference.³⁰ Advocates of the harm threshold have stated they intend these arguments is to form a basis for reshaping the law so that the approach found in law pertaining to custody and residence of children is mirrored in medical law.³¹

Justifications for this theory make a number of common assertions. Typical is the recent iteration proposed by Wilkinson and Savelescu,³² who argue that: parents are commonly allowed to make imperfect choices, so this should follow for medical treatment;³³ it is often not clear what is best when making decisions for children, and this follows for deciding between medical treatments;³⁴ parents know the child best and will express family values that are valid proxies of the child's current or future values;³⁵ parents will bear a significant burden of any decision that is made;³⁶ medical and judicial practice generally approximates the level of discretion offered by the harm threshold;³⁷ there is something potentially dangerous about the operation of the current legal standard, since it raises the possibility of untoward damage to the interests of parents.³⁸ Of the latter, Wilkinson and Savalescu suggest legal precedent may be to blame, while Diekema asserts that the lack of clarity about the best interests test³⁹ may lead decision-makers to challenge decisions that are legitimately within the bounds of parental discretion.⁴⁰ Numerous advocates of the harm threshold have also argued that the harm threshold is clearer and more actionable than best interests.⁴¹ A further

²⁸ Diekema is cited almost everywhere the harm threshold is advocated, and I am unaware of any attempt to finesse or reappraise his theory. The theoretical characterisation of the harm threshold is usually light. For example, the sustained analysis in the context of the Gard case by Wilkinson and Savelescu is typical in this respect. These authors define the harm threshold as a prohibition on parents making a decision if their child is likely to suffer significant harm as a result, cite Diekema and claim they follow JS Mill. see: Wilkinson and Savulescu, *Ethics, Conflict and Medical Treatment for Children: From Disagreement to Dissensus*

²⁹ In his 2004 article Diekema identifies harm with the concept of basic interest without further definition. In his 2011 article, he expands on this definition somewhat, quoting several other authors to offer a list including "interference with interests necessary for more ultimate goals such as physical health and vigor, integrity and normal functioning of one's body, absence of absorbing pain and suffering, or grotesque disfigurement, minimal intellectual acuity, and emotional stability. ... loss of health or some other major interest, deprivation of basic needs, and deprivation of future opportunities or freedoms ... death". Diekema's later work has also clarified ambiguities relating to the status of the best interests standard: He asserts that best interests should govern the types of advice that doctors give parents, the decisions of judges when parents cannot agree between themselves and, ideally, should guide parental decisions. The latter notwithstanding, parental decisions should only be subject to state intervention if they pose a serious risk of significant harm. See: Douglas S. Diekema, 'Revisiting the Best Interest Standard: Uses and Misuses' (2011) 22 *Journal of Clinical Ethics* 128

³⁰ Shah, Rosenberg and Diekema, 'Charlie Gard and the Limits of Best Interests'.

³¹ Diekema, 'Revisiting the Best Interest Standard: Uses and Misuses'

³² Wilkinson and Savulescu, *Ethics, Conflict and Medical Treatment for Children: From Disagreement to Dissensus*, but also see other advocates in note n.5

³³ Above, n.32: 14

³⁴ *Ibid.*

³⁵ *Ibid.* 89

³⁶ *Ibid.* 91

³⁷ *Ibid.* 93

³⁸ *Ibid.* 93

³⁹ See **Dominic Wilkinson's chapter within this volume Above, n.???** for a similar argument

⁴⁰ Diekema, 'Parental Refusals of Medical Treatment: The Harm Principle As Threshold for State Intervention'

⁴¹ L. Gillam, 'The zone of parental discretion: An ethical tool for dealing with disagreement between parents and doctors about medical treatment for a child' (2015) 11 *Clinical Ethics* 1 Winters, 'When Parents Refuse:

common assertion is that the harm threshold correctly ensures that discussion is focused on whether intervention in a parental decision is justified, rather which option is best for the child.⁴²

Together with the focus on the concept of 'parental autonomy', the latter apparently identifies the harm threshold with a claim that parental rights should be strengthened. This seems compatible with the assertions made on behalf of the Gard family during that case. It is nevertheless true that advocates of the harm threshold often use the term 'parental autonomy' rather than 'parental rights'.⁴³ This indicates a preference that the harm threshold is seen as an extension of liberal democratic principles of liberty that confer a limited privacy right for parents. While use of 'autonomy' in this context is perhaps a questionable characterisation of parental *authority*,⁴⁴ I shall nevertheless use this preferred terminology to avoid misunderstanding.

Taken together, I suggest these arguments for the harm threshold seem to make the following claims:

- 1) Parental autonomy is ethically justified and commonly allowed
- 2) In practice, the harm threshold governs decision-making in medicine
- 3) The lack of formal legal basis for (2) risks both parental autonomy being infringed, and the law being inconsistent
- 4) (3) is caused by the current operation of the best interests standard
- 5) The optimal remedy to (3) is to adopt the harm threshold

For now, I shall not dwell on parental autonomy to any great extent, other than to observe two things: first, the harm threshold argues that parents are the best people to identify the child's welfare, but does not dispute the basic assumption that parental rights should be based on children's welfare. Without further argument, I suggest children's welfare should be the motivation for any policy in this area.⁴⁵ Second, even if we accept the harm threshold is a justifiable approach to children's welfare in some examples, it may not be similarly justified in other examples such as parental medical decision-making.⁴⁶ I will offer argument for this latter claim in due course, as well

Resolving Entrenched Disagreements Between Parents and Clinicians in Situations of Uncertainty and Complexity'

⁴² Gillam, 'The zone of parental discretion: An ethical tool for dealing with disagreement between parents and doctors about medical treatment for a child' McDougall, 'Indeterminacy and the normative basis of the harm threshold for overriding parental decisions: a response to Birchley', but also see others in note n.5

⁴³ Wilkinson and Savulescu, *Ethics, Conflict and Medical Treatment for Children: From Disagreement to Dissensus*

⁴⁴ The term 'parental autonomy' has a long history of underwriting parental rights claims in Bioethics. For example Schoeman argues that parents should have autonomy because the question of what is good parenting is not amenable to expertise, while Ross asserts constrained parental autonomy on the basis that children are not full Kantian persons. Nevertheless it is not an altogether coherent concept as commitment to parental autonomy raises conflicts with children's autonomy: the more we extend autonomy to parents by lowering the bar of parental competence, the more we allow parents to disvalue their children's autonomy even where their decision-making ability exceeds the same bar of competence. However such problems do not immediately apply in the case of very young children. See: Schoeman, 'Parental Discretion and Children's Rights: Background and Implications for Medical Decision Making' L.F. Ross, *Children, Families, and Health Care Decision Making* (Oxford University Press 1998).

⁴⁵ I have examined the difficulties in making a non-welfare based argument based on property elsewhere, observing that it seems to collapse ultimately into an argument against harm. see: G. Birchley, 'Charlie Gard and the weight of parental rights to seek experimental treatment' (2018) 44 J Med Ethics 448. For the sorts of reasons commonly given for why parents might be thought to have prima facie have authority see Imogen Gould's chapter -PROVIDE REFERENCE- and Dominic Wilkinson's chapter n.8

⁴⁶ Further discussion of the latter point is contained in Rachel Taylor's chapter n.6

as making a more general normative critique of the harm threshold. First, however, I wish to engage with the argument that something akin to the harm threshold is used in clinical practice. In doing so I will use empirical data to illustrate the complexity of clinical decision-making practice.

Part 1: Investigating empirical claims with a view from the clinic

In an attempt to gauge the situation in clinical practice, an analysis of interviews with parents and clinicians (doctors, nurses and clinical ethics committee members) who had experience of making decisions in the ‘best interests’ of sick children in intensive care was undertaken.⁴⁷ Somewhat unsurprisingly, the interviews contained few instances the word “harm”. Nevertheless, the interviews did contain numerous, usually spontaneous, discussions of thresholds of (non)treatment. Because some of these thresholds alighted on the role of parents, they nevertheless seemed useful in adding more detail to the picture of practice that is presented in discussions of the harm threshold. From these we can broadly appraise how closely decision-making in the clinic resembles the harm threshold.

Themes

Interviews and information about the study were focused on what the ‘best interests’ of children might imply. Perhaps due to this framing, despite participants being given space to talk freely, the word ‘harm’ was mentioned only seven times in over fifty hours of interviews. Where the word ‘harm’ occurred, there was little pattern to the way it was used. For example: a clinical ethicist remarked that patients could be caused harm by overtreatment; a parent remarked that sometimes it was necessary to risk doing harm to treat a child; another parent remarked that an incorrect diagnosis had not caused any harm. The word harm was applied to both physical harms and, potentially, to more holistic understandings of harm. This absence of the word harm from discussions perhaps signals; that the way decision-making was framed by the term ‘best interests’ meant that concepts of harm did not spring into participants minds; that harm was very rarely a justificatory focus for a decision (presumably we intend our actions to benefit rather than be harmful or merely be harmless) or; that other terms are more often used as proxies for the word harm, for example ‘pain and suffering’ (which I discuss later). The topic may be worthy of investigation in future studies that focus more specifically on harm.

Minor thresholds of (non)treatment

More informatively, a number of thresholds of (non)treatment were also discussed. While not always have a direct bearing on my later argument, I include them here to remind us that clinical

⁴⁷ The data is drawn from the ‘Best Interests in Paediatric Intensive Care’ (BIPIC) project, a doctoral fellowship funded by the Wellcome Trust (grant WT097725R). The data was collected in 2014 in thirty-nine semi-structured interviews with 45 clinicians and parents who had experience of making decisions about critically ill children in one of three English Paediatric Intensive Care Units (PICUs). Participants had a variety of different experiences, for example, some parents had been bereaved, while others had a child who recovered. The characteristics of parents and clinicians are described in the appendix. Interviews discussed the participants experiences of making decisions in the “best interests” of critically ill children. Interviews had three broad stages; they began by asking participants to give an account of a situation where they had to make potentially life or death decisions. For parents this often involved a detailed narrative of how their child became sick, how decisions were made about treatment and how the parent felt about the outcome. A second stage asked the participant to reflect on some of the dilemmas encountered in treating children (for example, who should make a final decision if there were differences between parental and medical views). A final stage considered understandings of common terminology such as ‘best interests’ and ‘quality of life’. While the focus of the study was on ‘best interests’, the first and second stages in particular offered accounts of decision-making that had not sharply focused on any theoretical account. A re-analysis of this portion of the data was undertaken in the final quarter of 2017, with a particular focus on what the results could tell us about the harm threshold.

decision-making is complex, and poses challenges to theoretical approaches like best interests and the harm threshold. Decision-makers bring a plurality of views, some of which may aid, and some pose difficulties, to agreeing decisions in practice.

The first four thresholds were mentioned by only a few participants, while a further four occurred more widely.⁴⁸ Importantly, these thresholds occurred in an early portion of the interview where participants were asked to give narratives of own experiences of decision-making for children, so were usually offered spontaneously. It was not always clear if participants advocated a threshold, rather these were thoughts expressed aloud. Sometimes participants made later, contradictory statements, or mentioned more than one threshold. What the data most clearly illustrates is that these ideas entered the decision-making approaches of some participants. To paraphrase Anspach,⁴⁹ they were part of the decision-making 'ecology'.

The four less frequently mentioned thresholds were 'child's body deciding'; 'life at any cost'; 'cost of treatment' and; 'happiness'. 'Child's body deciding' was mentioned by two participants. This threshold viewed the child's survival or death, with or despite full intensive care, as an expression of the child's will that was worthy of respect. It was exemplified by a father in interview P40 saying:

"...my philosophy started to change and it was actually more about, you know, we've got to start listening to his body. And that's what began to drive our decisions towards the end, wasn't it? that we would support him as long as his body kept fighting."

Bearing in mind the children being discussed were below four years old (and hence unlikely to have expressed complex antecedent wishes) and fully anaesthetised (so did not talk or express feelings clearly), this threshold had little to do with taking the views of a child into account. Nor is the death of the child on full intensive care in any way a 'natural' death. Children in this situation die despite being connected to ventilators and being given powerful medicines that help the heart to function. Instead, this threshold seemed to be a way of shifting the vast burden of making a decision about a child's treatment away from any of those who had real agency in the situation. This response does not seem uncommon in other types of medical decision-making, for example in legal decisions to withdraw medical feeding from adults in minimally conscious state.⁵⁰

Several participants discussed 'life at any cost' as a potential threshold, although only one (a parent, P55) sustained vehemently pro-life views (others merely recognised that 'life at any cost' was a possibility), and later expressed some doubts in the case of terminal illness. Before this point, she expressed the view was that there should be no threshold of non-treatment, besides death:

"a person's life, you know, it's priceless."

Such views are relatively rare, but the diversity of beliefs encountered in medical treatment decisions, and the fact that they may be tied to particular, strongly held religious beliefs, mean that they feature relatively frequently as reported bases of parental objections to non-treatment.⁵¹

⁴⁸ Given this was a non-randomised study, numbers need not be significant

⁴⁹ R. Anspach, 'Prognostic Conflict in Life-and-Death Decisions: The Organization as an Ecology of Knowledge' (1987) 28 *Journal of Health and Social Behavior* 215

⁵⁰ G. Birchley, "'...What God and the Angels Know of us?' Character, Autonomy, and best Interests in Minimally Conscious State' (2018) 26 *Med Law Rev* 392

⁵¹ J. Brierley, J. Linthicum and A. 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

Three participants (a member of a clinical ethics committee, a doctor and a parent) cited economic reasons as a potential threshold. Significantly, while advancing economic considerations, none considered the ‘cost of treatment’ to be sufficient in its own right to be a threshold of non-treatment. The threshold is exemplified by this quote from parent P64:

“You could be fighting so much to get that child to survive, which is another two to three weeks But in those two weeks of fighting and trying, there could have been another four or five children that could have used that medication, used that time, and they could have all been fine.”

The small numbers of participants suggesting this threshold may reflect a reluctance to discuss resource constraints as a basis for non-treatment. This may be more acute in a state funded health system like the NHS, where costs are communalised.

Finally, in ‘happiness’, five participants (two nurses, two members of clinical ethics committees and one parent) considered that the child’s potential to be happy presents a threshold of non-treatment. A quote from clinical ethics committee member E33:

“[If I were in their shoes] actually I want some pleasure in life in some way, shape or form, whatever it is I do that gives me pleasure...”

In some ways it is curious that happiness did not feature more as a spontaneous threshold – the briefest sweep of the media suggests that the desire to raise happy children is keenly felt in society at large.⁵² However, happiness is both fleeting and difficult to measure. As Rawls notes, there is no happiness metric.⁵³ Moreover, given the discomforts associated with intensive care, happiness would be a high bar for decisions to continue the treatment of critically ill children.

More broadly, while the themes ‘child’s body deciding’; ‘life at any cost’; ‘cost of treatment’ and; ‘happiness’ suggest the wide range of potential thresholds that any putative standard, be it best interests or the harm threshold, may need to navigate in contested decisions. As I have observed, some present severe difficulties to any standard: attention to costs of treatment suggests challenges to any child-facing (rather than public-facing) standard like the best interest test; whether being (un)happy, or pursuing life at any cost is a significant harm or a benefit does not seem readily apparent, perhaps indicating that a harm threshold is unlikely to reduce conflicts in the clinic in the way the Gard Foundation hopes. The significance of ‘child’s body deciding’ may be less relevant to either the harm threshold or best interests, while being more relevant to actual cases. Certainly it is redolent of the difficulties even deeply committed parents may experience when taking responsibility for fatal decisions about their child.

While these four thresholds were spontaneously voiced relatively rarely across the interviews, four further thresholds were more widely distributed. These were ‘minimising pain and suffering’; ‘quasi-quality of life’; ‘best for the child’ and; ‘best for the family’. These seem to have a more direct bearing on the use of something approaching the harm threshold in medical practice.

⁵² Lamb, M. ‘7 Secrets to Raising a Happy Child’ Parents <<https://www.parents.com/toddlers-preschoolers/development/fear/raising-happy-children/>> Accessed 19th September 2018.

⁵³ J. Rawls, *A Theory of Justice (Revised Edition)* (Harvard University Press 1999, [1971]): 486-491

Major thresholds of (non)treatment

The larger number of participants discussing major thresholds allows for an interesting breakdown of which groups of participants found particular thresholds significant enough to spontaneously mention them. A full breakdown of this information is given on table 3, below.

Table 1: Spontaneous thresholds of (non)treatment

Threshold	Clinical ethics	Doctor	Nurse	Parent	Total
<i>Child's body deciding</i>	0	1	0	1	2
<i>Life at any cost</i>	1	0	0	2	3
<i>Cost of treatment</i>	1	1	0	1	3
<i>Happiness</i>	2	0	2	1	5
<i>Pain and suffering</i>	3	4	1	5	13
<i>Quasi-quality of life</i>	3	2	5	4	14
<i>Best for the child</i>	6	2	1	11	21
<i>Best for the family</i>	2	6	7	5	20

In total thirteen participants spontaneously mentioned a ‘minimising pain and suffering’ threshold of (non)treatment. Those volunteering this threshold saw the avoidance or minimisation of discomfort as an imperative. As one doctor (D50) said:

“I suppose where I come from is that there’s worse things in life than death. So living a life that is full of pain and discomfort isn’t – isn’t appropriate, so there is worse than dying.”

Another participant, this time a mother (P42) recollected of her dying child:

“I wanted him to be out of pain, and I wanted him to be as comfortable as he could, no matter what was going on.”

Scholars asserting the harm threshold often give pain (or its absence) as one example of harm (or its absence).⁵⁴ To this extent, the frequency of the threshold of pain and suffering seems to confirm that the rare instances of the actual word ‘harm’ belie fairly common use of such a threshold by both clinicians and parents. However, as the quote from the doctor (D50) shows, pain may not be the only potentially harmful consideration, and there is inherent questionability of what is taken to be a harm or a benefit. Moreover, given the invasive nature of intensive care it is potentially surprising that

⁵⁴ For example: Dresser, 'Standards for family decisions: replacing best interests with harm prevention' Diekema, 'Parental Refusals of Medical Treatment: The Harm Principle As Threshold for State Intervention' Gillam, 'The zone of parental discretion: An ethical tool for dealing with disagreement between parents and doctors about medical treatment for a child' T. Nair and others, 'Settling for second best: when should doctors agree to parental demands for suboptimal medical treatment?' (2017) J Med Ethics R. Gillon, 'Why Charlie Gard's parents should have been the decision-makers about their son's best interests' (2018) 44 J Med Ethics 462

that pain and suffering is not more universally cited (other thresholds were cited more), because pain and suffering are so commonplace in intensive care. It may be that pain and suffering are not always seen as indicative of harm. Most intensive care interventions are uncomfortable and many are painful, especially as there are difficulties with maintaining anaesthesia over periods extending to days and weeks. The overall effect is that there is a clinical difficulty in preventing suffering in intensive care. Therapies are frequently a trade-off between short-term pain and long-term recovery. Thus, pain has limitations as an indicator of (non)treatment. Given pain is easily equated to harm, this might indicate potential complications for the harm threshold, at least in critical care environments and other settings where trade-offs between suffering and recovery are common (like oncology).

A similar number of participants (fourteen) used quasi-quality of life thresholds. These posited that certain abilities and/or experiences characterised a life that was worth living. For example, one experienced Nurse (N29) suggested:

“You can keep somebody alive on machines, but if they can’t communicate, if they can’t feel, touch, if they can’t be cuddled, if they can’t smile or if they can’t feed, if they can’t do any of those things, then they might be alive but actually do they have any niceness in their life, do they have any quality?”

While one parent (P58) said:

“... if my child had got to the stage where they were going to be fully dependent in terms of they couldn’t feed themselves, um they could not begin to even lead any kind of independent sort of life, you know, they’re gonna need 24 hour every day help, constant help ... and they’re pretty much not able to do anything, that’s not the kind of life that I could imagine would be a good one.”

As these examples indicate, there was not necessarily agreement between the quasi-quality of life measures used by participants. A wide variety of different thresholds and language were used, for example “flourishing” (an ethics committee member in E28), “brain damaged and not able to use their limbs” (a parent in P40) and “indicat[ing] wants ... enjoy[ing] food” (a doctor in D52). The huge difficulties in successfully determining quality of life measures that are both objectively and subjectively agreeable are well documented.⁵⁵ It is important to note that, while the thresholds reported here were spontaneously reported, the later stages of these interviews elicited participants views on quality of life as a concept. This indicated that many participants perceived these difficulties in ‘quality of life’ as a quantitative concept, even if they accepted that it could house useful qualitative considerations. As one parent (P62) said: “[Quality of Life is] questionable, isn’t it? It’s questionable. But I would still use it.”

The most frequently mentioned threshold was what is ‘best for the child’. It was mentioned by twenty-one participants, a majority made up of parents and members of clinical ethics committee members. This threshold emphasised that the welfare of the child was the goal of any decision, without necessarily defining the goal further. For example one ethics committee member (E32) described a case involving a dying child that had been referred to the committee where an intervention had been proposed due to the distress of the child’s parents:

⁵⁵ Bognar, Greg. 2005. "The Concept of Quality of Life." *Social Theory and Practice* 31 (4):561-580.

“we were very clear that that was not acceptable to treat for the parents; you had to be doing it in the best interests of the baby that you’re talking about at the time.”

While sometimes clearly motivated by a legalistic understanding of ‘best interests’, such cases were frequently nuanced. In the example above, E32 discussed at length how the parent and the child’s interests are difficult to extricate. A poignant example of this came from one mother’s (P59) contemplation of the looming death of their (severely chronically ill) daughter:

“We’re gonna get to the point one day where we’re gonna [say] enough is enough, [child’s name] – it’s gonna come, you know how much can you actually put a child through? You can’t – you know, we’re not the one that – we’re not the ones that are laid there on that – on that bed, on a ventilator ... there is only so much you can put a kid through. And I think it is, a lot of it’s selfishness ... you are just thinking of you at the time, aren’t you really? ‘Cos you’re like, “I don’t wanna lose her. I don’t want her to – to go and I don’t want her to die.”

The nuanced nature of the discussion is a powerful refutation of the possibility that, motivated by both a knowledge of the law and the topic of research, participants suggesting a threshold based what is best for the child were offered an answer that they felt the interviewer wanted to hear (what is technically known as a ‘satisficing’ response). Indeed, the discussion by the mother above seems to lay bare the struggle many parents are likely to feel between powerful emotional drives to avoid the pain of losing their child, and the perception that doing so would not be what is best for their child. Overall, participants who offered this response felt that a threshold of what was best for the child was both practically and emotionally demanding (for which parents often expressed the need for guidance and support) but normatively the correct approach.

It is interesting to note that very few doctors or nurses spontaneously volunteered a threshold based on what was best for the child. This may simply mean that doctors and nurses used more nuanced accounts – a sizable cluster (5/7) nurses used quasi-quality of life thresholds. Yet there were no similar correlations except among the twenty participants who volunteered a threshold of (non)treatment based on what was ‘best for the family’. The relative popularity of the latter among doctors (half the doctor participants) and nurses (all nurse participants) potentially bears out the assertion by advocates of the harm threshold that clinicians use a family-facing approach that ill matches the best interests test.⁵⁶ This is because the threshold allowed limited trades against a child’s wellbeing to secure a parental benefit. For example one doctor (D47) described a situation where treatment continued to be given to allow parents come to terms with their child’s death:

“we were carrying on infusions and we didn’t stop then, I suppose that is primarily to protect, to help the parents with the situation. We never thought that – well I never thought that he was going to recover enough to have the [definitive treatment] at that point, so yes you could argue that we continued because the parents wanted it. ... we had kept him um fairly sedated and on the same treatment as he was before, I don’t think we were extending his burden much more ... But you could argue, yes, 12 hours of intensive care wasn’t in his best interests.”

⁵⁶ Above, n.7

Another clinician, a nurse (N37), recalling a case where treatment was given that the healthcare team though was ‘futile’, said:

“I’d say it wasn’t wrong [to give the treatment], because we had to do what was – the family wanted to carry on. And there was quite intense discussions at the time, and we agreed in the end that it was, well we’d go for what the family wanted, and then after [an agreed time] stop, or review”

Thus an uneasy balance was struck between a primary duty toward (as participants saw it) satisfying the wishes of the family, and attempting to minimise deleterious effect on the child.⁵⁷ This viewpoint is apparent in similar studies,⁵⁸ which suggests it is a frequent feature in the ecology of paediatric medical decision-making. Indeed, an increasing appreciation of children’s rights⁵⁹ in the legal steer has gone hand in hand with the growth of a shared decision-making approach, where the judiciary accepts that medical decisions are usually a private matter between parents and doctors.⁶⁰

To summarise, when discussing their experiences of making decisions for children, participants spontaneously volunteered a range of decision-making thresholds – indeed, only three of 39 interviews did not include a spontaneously mentioned threshold at this stage in the interview. These data should give some sense of the types of argument that inform the thinking of decision-makers in the clinic. These indicate that decision-making is extremely nuanced – indeed, factors may challenge any standard that claims to focus on the experience of the child, which both best interests and harm aim, in their own ways, to do. The data also indicate the plurality of different views around for example, quality of life, which suggests that any standard or threshold would struggle to clarify its objectives. Pain and suffering were a relatively frequent threshold of non-treatment that is perhaps totemic of “harm”. However, the commonplaceness of this type of harm in intensive care perhaps belies the usefulness of harm simpliciter, at least in the most arduous clinical environments. More comfort for the harm threshold may be derived from the most predominant thresholds. These were focused the welfare of the child (‘best for the child’ and those that focused on the welfare of the child’s parents (‘best for the family’). Arguably, the introduction of a harm threshold are about advancing parental autonomy. While these data indicate considerable nuance, potentially the fact that support for the ‘best for the family’ threshold of (non)treatment is concentrated among clinicians could be read to offer empirical support to the claim that a harm threshold is commonly used by clinicians in practice.⁶¹ A threshold consistent with one view of the best interests standard (as a maximisation of what is best) was also popular, but it was concentrated particularly among parents rather than clinicians. Once again, this is not necessarily inconsistent with harm threshold: the harm threshold’s advocates argue that parental decisions generally aim at what is best for their child.⁶²

⁵⁷ See Jo Bridgman’s chapter in this volume for more discussion about the motivations of doctors and potential thresholds beyond which they will not go.

⁵⁸ M. A. de Vos and others, 'Talking with parents about end-of-life decisions for their children' (2015) 135 *Pediatrics* e465

⁵⁹ Janet Read and Luke Clements, 'Demonstrably Awful: The Right to Life and the Selective Non-Treatment of Disabled Babies and Young Children' (2004) 31 *Journal of Law and Society* 482

⁶⁰ G. Birchley, 'Deciding together? Best interests and shared decision-making in paediatric intensive care' (2014) 22 *Health care analysis : HCA : journal of health philosophy and policy* 203

⁶¹ Diekema, 'Parental Refusals of Medical Treatment: The Harm Principle As Threshold for State Intervention' Wilkinson and Savulescu, *Ethics, Conflict and Medical Treatment for Children: From Disagreement to Dissensus*

⁶² E.g. See note n.29 for Diekema’s position on this.

Yet the arguable empirical reasonableness of claims made on behalf of a harm threshold are only one part of the story. In the second part of this chapter I shall dispute some of the normative arguments made on behalf of a harm threshold. I suggest that parental autonomy is generally respected, indicating that the harm threshold may not be needed; that there may be valid differences in legal and clinical decision-making; that there are also differences in assessing welfare in clinical and social situations that speak against legal consistency; and that there may be unintended effects arising from the harm threshold. Ultimately, I suggest that, while the best interests standard is clearly problematic, these problems are not best solved by adopting the harm threshold.

Part 2: Disputing normative arguments for the harm threshold

The status of parents as partners in shared decision-making is decided law and embedded in medical practice. Even in patient-doctor encounters, shared decision-making has always been an ambiguous concept, potentially supporting a variety of types of relationship and approaches.⁶³ These problems are more acute in situations where decision-making is shared with proxies of the patient.⁶⁴ Where that patient is a child, bioethicists have gravitated toward a threshold approach to clarify these ambiguities, with thresholds based on harm,⁶⁵ reasonableness⁶⁶ and basic interests⁶⁷ (many of which overlap on detail). Some assert that such thresholds cannot satisfactorily work under the best interests test. They claim the best interests test does not consider important factors in decision-making, holding parents up to impossible standards and denying the essential interconnectedness of the interests of parents and children.⁶⁸ Others dispute this characterisation, and argue the best interests test allows a broad and flexible assessment of the interests at stake.⁶⁹ A final argument, that to an extent runs besides these debates, is that a harm threshold is more consistent with practice⁷⁰ or other parts of the law.⁷¹ This debate raises a number of questions; does the current operation of the best interests indicate inflexibility, such that stronger protections of parental

⁶³ L. Sandman and C. Munthe, 'Shared decision making, paternalism and patient choice' (2010) 18 *Health Care Analysis* 60C. Charles, A. Gafni and T. Whelan, 'Shared decision-making in the medical encounter: What does it mean? (or it takes at least two to tango)' (1997) 44 *Social Science & Medicine* 681

⁶⁴ Birchley, 'Deciding together? Best interests and shared decision-making in paediatric intensive care'

⁶⁵ Winters, 'When Parents Refuse: Resolving Entrenched Disagreements Between Parents and Clinicians in Situations of Uncertainty and Complexity' Shah, Rosenberg and Diekema, 'Charlie Gard and the Limits of Best Interests'

⁶⁶ J. C. Bester, 'The Harm Principle Cannot Replace the Best Interest Standard: Problems With Using the Harm Principle for Medical Decision Making for Children' (2018) 18 *American Journal of Bioethics* 9Loretta M. Kopelman, 'Disputes Over Moral Standards Guiding Treatments for Imperiled Infants' (2009) 33 *Seminars in Perinatology* 372Diekema, 'Parental Refusals of Medical Treatment: The Harm Principle As Threshold for State Intervention'

⁶⁷ A Buchanan and D Brock, *Deciding for others* (Cambridge University Press 1990)Diekema, 'Parental Refusals of Medical Treatment: The Harm Principle As Threshold for State Intervention'

⁶⁸ Gillam, 'The zone of parental discretion: An ethical tool for dealing with disagreement between parents and doctors about medical treatment for a child'D. Wilkinson and T. Nair, 'Harm isn't all you need: parental discretion and medical decisions for a child' (2016) 42 *J Med Ethics* 116Winters, 'When Parents Refuse: Resolving Entrenched Disagreements Between Parents and Clinicians in Situations of Uncertainty and Complexity'

⁶⁹ J. C. Bester, 'The best interest standard and children: clarifying a concept and responding to its critics' (2018) *J Med Ethics* Loretta M. Kopelman, 'The Best-Interests Standard as Threshold, Ideal, and Standard of Reasonableness' (1997) 22 *Journal of Medicine and Philosophy* 271

⁷⁰ Diekema, 'Revisiting the Best Interest Standard: Uses and Misuses'

⁷¹ Wilkinson and Savulescu, *Ethics, Conflict and Medical Treatment for Children: From Disagreement to Dissensus*

autonomy are needed in medical decisions?; should the law adopt a harm threshold because it is more consistent with practice? If so, what would be the impact of a harm threshold on practice?

Decisions are made in practice has been subject to some, although I believe insufficient, study, which has tended to concentrate on non-treatment rather than routine issues. There are historical instances of doctors acceding to parental requests of this nature.⁷² Yet Anspach's⁷³ study of end-of-life decisions in U.S. neonatal intensive care in the late 1980s, and McHaffie's lengthy interview study with UK parents of neonates in the late 1990's, suggested parents more often experienced insensitivity and disempowerment.⁷⁴ On the other hand, perhaps indicating an evolution of practice, contemporary studies suggest that clinicians allow a latitude of parental discretion.⁷⁵ In some cases this is clearly intended to benefit a parent rather than a child, for example, delaying withdrawal of treatment to allow parents to come to their own appreciation of physiological realities. Such a view of practice is, unsurprisingly, not shared by parents who have failed to convince a court that their view is in the child's best interests. Charlie Gard's mother suggests that the ameliorative measures proposed in 'Charlie's law' would bring "a much-needed balance that we passionately feel has been absent to date."⁷⁶ Yet, without belittling these sincere feelings, I must observe that Charlie Gard's case did not contain the features of a system that systemically fails to seek a balance between parental autonomy and claims about children's welfare:⁷⁷ Charlie's clinicians consulted an ethics committee about plans for long term ventilation. They spent several months seeking expert opinions to check there was wider clinical agreement about withdrawal of treatment once they had reached that view. While the case became associated with value conflict about seeking miraculous cures, this assessment sits uncomfortably with the facts of the case. These suggest it was an inability of Charlie's parents to accept the expert interpretation of the EEG scan as empirical evidence of brain damage that lay at the heart of the dispute. Once evidentially accepted, the brain damage indicated the impossibility of the sort of the benefit Charlie's parents sought. Continuing treatment in these circumstances needed to be balanced against the very real deprivations of intensive care: modern anaesthetics have are limited in the duration that they can prevent pain and anxiety.⁷⁸ The severe

⁷² Indeed, the most notorious of these instances, *R v Arthur [1981] 12 BMLR 1* shows neither parent or doctor is a cast-iron guarantor of the welfare of children in such private decisions.

⁷³ R. Anspach, *Deciding Who Lives: Fateful choices in the Intensive-Care Nursery* (University of California Press 1993)

⁷⁴ H. E. McHaffie, *Crucial Decisions at the Beginning of Life: Parents' Experiences of Treatment Withdrawal from Infants* (Radcliffe Medical Press 2001)

⁷⁵ de Vos and others, 'Talking with parents about end-of-life decisions for their children' G. Birchley and others, 'Best interests' in paediatric intensive care: an empirical ethics study' (2017) 102 Arch Dis Child 930

⁷⁶ Greenhill, 'No other family should be put through our heartbreak: Charlie Gard's parents fight for 'Charlie's Law' that would allow parents of sick children to move them to a different hospital if they disagree with doctors'

⁷⁷ Per *GOSH v Yates [2017] EWHC 972* as concerns about Charlie's quality of life grew, advice was sought from an ethics committee who advised not to offer a tracheostomy (that would facilitate long term ventilation). Once a clinical consensus had been reached that Charlie would not benefit from further treatment, 3 months passed, during which numerous second opinions were sought to ensure that the clinical facts were correct and the implications agreed, before an application to the court was made to resolve the disagreement. It could still be argued that these interventions were insufficient compromise as they aimed primarily to persuade Charlie's parents, rather than accommodate their view. Yet given the extremely polarised positions of the parties, a delay while the medical evidence was scrutinised seems the only possible compromise.

⁷⁸ Megan E. Cunningham and Adam M. Vogel, 'Analgesia, Sedation, and Delirium in Pediatric Surgical Critical Care' (2019) Seminars in Pediatric Surgery E.M. Boyle and K.J.S. Anand, 'Sedation, Analgesia and Neuromuscular Blockade in the Neonatal ICU' in P. Rimensberger (ed), *Pediatric and Neonatal Mechanical Ventilation* (Pediatric and Neonatal Mechanical Ventilation, Springer 2015)

psychological scars experienced by adult patients⁷⁹ and children⁸⁰ after experiencing intensive care of the sort Charlie Gard received, lead paediatricians commonly to liken the experience of intensive care to torture.⁸¹ It is unclear if Charlie's doctors could have more satisfactorily balanced the rights of his parents to seek months of further intensive care with scant chance of the cure they sought, with a duty to ensure that the view of Charlie's welfare most closely underwritten by robust physiological findings and research evidence, was protected. In this case, and more generally, the empirical picture suggests that parents are frequently given discretion. Widespread disregard of parental autonomy is not obviously apparent.

If the operation of the best interests test does not result in practice that disregards parental autonomy, it may still be unhelpful since it fails to indicate that such practice is legitimate. Scholars may therefore make the argument that the harm threshold better concurs with the way decisions are made in practice. They may suggest we should close this gap to avoid misunderstandings⁸² or legal fictions,⁸³ or simply in the name of consistency.⁸⁴ As I note above, the claim about practice appears *prima facie* plausible: clinicians arguably see a fair balance between the interests of the parents and the interests of their child as an implicit part of a good decision. Yet it is simplistic to simply see this as a manifestation of clinical acceptance of parental autonomy. I have argued elsewhere⁸⁵ that clinicians' attempts to balance the needs of children and parents is apparently motivated by a desire to fairly balance the immediate needs of a child with the potentially devastating long-term impacts of a mishandled bereavement.⁸⁶ This is hardly a *laissez faire* approach to parental autonomy, and fits neither the best interests standard or the harm threshold very perfectly. How the law should respond to this inconsistency raises serious questions about the purpose of law in this area. To translate clinical behaviour into a legal prescription ignores potential differences between the legal and clinical decision-making.⁸⁷ As Cave and Nottingham⁸⁸ have argued, a clinical assessment of best interests takes place against constantly changing dynamics where failures to compromise have penalties including increased burdens to the patient, heightened scrutiny of the decision-makers and expended resources, whereas court decision can only judge whether the declaration sought is supported by the evidence submitted.⁸⁹ If this is the case, unless

⁷⁹ K. Chahraoui and others, 'Psychological experience of patients 3 months after a stay in the intensive care unit: A descriptive and qualitative study' (2015) 30 *J Crit Care* 599

⁸⁰ L. P. Nelson and J. I. Gold, 'Posttraumatic stress disorder in children and their parents following admission to the pediatric intensive care unit: a review' (2012) 13 *Pediatric critical care medicine : a journal of the Society of Critical Care Medicine and the World Federation of Pediatric Intensive and Critical Care Societies* 338

⁸¹ Brierley, Linthicum and Petros, 'Should religious beliefs be allowed to stonewall a secular approach to withdrawing and withholding treatment in children?' G. A. Pearson, 'Intensive care: because we can or because we should?' (2018) *Arch Dis Child*

⁸² Diekema, 'Revisiting the Best Interest Standard: Uses and Misuses'

⁸³ Seema K. Shah, 'Does Research with Children Violate the Best Interests Standard? An Empirical and Conceptual Analysis' (2013) 8 *Northwestern Journal of Law and Social Policy* 121

⁸⁴ Wilkinson and Savulescu, *Ethics, Conflict and Medical Treatment for Children: From Disagreement to Dissensus*

⁸⁵ Birchley and others, 'Best interests' in paediatric intensive care: an empirical ethics study' G. Birchley, 'The Harm Principle and the Best Interests Standard: Are Aspirational or Minimal Standards the Key?' (2018) 18 *The American journal of bioethics : AJOB* 32

⁸⁶ To simply view this behaviour as misguided paternalism seems to ignore a quite fundamental expectation that a doctor should be motivated by a conscientious care for their patients.

⁸⁷ See Rachel Taylor's chapter in this volume

⁸⁸ E. Cave and E. Nottingham, 'Who Knows Best (Interests)? The Case of Charlie Gard' (2017) *Med Law Rev*

⁸⁹ *ibid*: 11

harm is a less discretionary judgement than is best interests (and the limited evidence suggests that this is unlikely to be the case)⁹⁰ it is likely that a gap between legal and clinical decision-making will remain. It is also unclear how the harm threshold would operate when determining medical welfare. Some have expressed concerns that, far from bulwarking parental autonomy, the very ambiguity of harm will reduce, rather than reinforce, the ability of parents to offer their view of the good of the child.⁹¹ The harm threshold is already used in child protection cases where a question about where a child lives is raised. Some cases, such as *Re AB* [2018] EWFC 3 and *Re R (A Child)* [2018] EWFC 28, involve a combination of residency and medical issues. These are able to give direct examples of how the harm threshold is employed if it becomes the key boundary demarcating the limits of parental discretion. These cases show that the orders granted under the harm threshold can curtail parental views whenever they disagree with medical opinion, with scant regard for the wider considerations, such as social relationships and spiritual beliefs that are central to the current approach assessment of best interests. *Re AB*, on appeal, was eventually resolved with more sensitivity to the parents. Not all cases reach appeal, as *Re R* shows.⁹² It is possible therefore, that the harm threshold may have a chilling effect upon parental autonomy.

Part of the problem in both these instances is the definitionally problematic nature of both harm and best interests. As I indicated in the discussion of the empirical picture in part 1, it is unclear where the border lies between where treatment is harmful and beneficial. Treatments such as intensive care and oncology involve inflicting both limited (pain, discomfort, fear, upset) and sustained (sterility, heart problems, lung problems, psychological dysfunction) harms on children in an attempt to benefit them. Moreover, some treatments, just don't fall into a straight forward harm/benefit dichotomy. Demanding unnecessary antibiotics, or refusing a vaccine, for example, may neither significantly harm, nor benefit a child, although they may have harms and benefits to the wider community. In most cases, harm doesn't any better specify where the line for court intervention should be drawn.⁹³

This notwithstanding, because the harm threshold is used within social welfare, some have argued the harm threshold to bring a more consistent approach to social and medical welfare.⁹⁴ Yet it is fitting to raise concerns about whether such consistency is desirable. Rather than asking for parity between medical and social standards about children, we might ask why decision-making for children should be different from the way any person who relies on others to make decisions on their behalf. Like other forms of care, parenting involves compromise and dutiful sacrifice of our heartfelt aims and life plans. The broad acceptance of welfare as a basis of parental rights suggests that good parenting is fittingly signalled by a system that overly prioritises what is best for children. The harm threshold seems to break the link with the necessity to act in a child's welfare. The reasons for breaking this link in social welfare are both historical and expedient. The historical welfarist project of removing children from predominantly poor parents in order to improve children's

⁹⁰ G. Birchley, 'Harm is all you need? Best interests and disputes about parental decision-making' (2016) 42 *J Med Ethics* 111

⁹¹ Bester, 'The Harm Principle Cannot Replace the Best Interest Standard: Problems With Using the Harm Principle for Medical Decision Making for Children'

⁹² Katie Gollop and Sarah Pope, 'Charlie Gard, Alfie Evans and R (A Child): Why A Medical Treatment Significant Harm Test Would Hinder Not Help' (2018) <<http://www.transparencyproject.org.uk/charlie-gard-alfie-evans-and-r-a-child-why-a-medical-treatment-significant-harm-test-would-hinder-not-help/>> accessed 27th September 2018

⁹³ Birchley, 'Harm is all you need? Best interests and disputes about parental decision-making'

⁹⁴ Wilkinson and Savulescu, *Ethics, Conflict and Medical Treatment for Children: From Disagreement to Dissensus*

welfare, was, even in its own terms, a failure.⁹⁵ Social intervention struggles with both the strict limits to the resources provided by the state for social welfare provision. There are also a lack of effective interventions that mean, unfortunately, outcomes for many children raised outside families are mediocre.⁹⁶ For these reasons social intervention remains a last-ditch activity. It seems that we lack the resources,⁹⁷ and perhaps the know-how, to have significant confidence that changing a child's living arrangements will produce significant benefit. So long as these factors remain in place, this uncertainty suggests the cautionary approach emphasised by the harm threshold is justified in social welfare.

A survey of the same reasons – resources and confidence in outcomes – of medical decisions, suggest decisions about medical welfare are quite different. The totality of current levels of social care and healthcare spending are similar, but the social care spend is spread much more thinly.⁹⁸ Investments in children's healthcare dwarf the resources that are available for children in care. Moreover, we can have far more confidence when trying to predict the likely outcomes of healthcare interventions. Huge investments continue to be made in research to better understand the risks and benefits inherent in medical decisions. Although there are numerous areas where better evidence is required, the situation is constantly improving. On top of this, quantitative, basis for medical intervention, clinicians will accumulate a wealth of qualitative knowledge that they can bring to bear to make informed judgements on the basis of their close familiarity with the situations they encounter. Importantly, to recognise this difference in social and medical judgments is not to make an unguarded plea for hard paternalism. There are numerous features of human judgment that suggest that decision-making is fallible, especially where values are at stake.⁹⁹ Nor are we necessarily able to disentangle the dense web of facts and values in order to permit an authoritative evaluation of facts on the basis of value.¹⁰⁰ Without deeply engaging in the complex philosophical and epistemic issues involved in claims of fact-value separation (it would be difficult to do so briefly), we can note that a naïve separation between facts and values is far from universally accepted among philosophers and bioethicists.¹⁰¹ These challenges to reasoning are why a shared decision-

⁹⁵ P. Bean and J. Melville, *Lost Children of the Empire* (Routledge 2018)

⁹⁶ P. Roy, M. Rutter and A. Pickles, 'Institutional care: risk from family background or pattern of rearing?' (2000) 41 *J Child Psychol Psychiatry* 139A. Goemans, M. van Geel and P. Vedder, 'Over three decades of longitudinal research on the development of foster children: a meta-analysis' (2015) 42 *Child Abuse Negl* 121

⁹⁷ Or at least the political will to provide them.

⁹⁸ See: Elaine Kelly and others, *Public Spending on Children in England: 2000 to 2020*, 2018) available from: <https://www.childrenscommissioner.gov.uk/wp-content/uploads/2018/06/Public-Spending-on-Children-in-England-CCO-JUNE-2018.pdf> ; NHS Digital, 'Hospital admissions hit record high as population ages' (*NHS*, 2016) <<https://digital.nhs.uk/news-and-events/news-archive/2016-news-archive/hospital-admissions-hit-record-high-as-population-ages>> accessed 31st January ; Office for National Statistics, *Households below average income: 1994/95 to 2016/17*, 2018)

⁹⁹ Experimental psychology suggests that moral reasoning closely maps people's immediate emotional reactions. Although the ability to use reasoned argument plays an important part in moral deliberation, reasoning generally seeks to confirming evidence, and fails to seek evidence that challenges, these emotional reactions. Indeed, in experiments where participants initial emotional reactions are manipulated to produce unfounded moral objections, a significant minority of these participants adhere to their initial emotional reactions even when presented with strong arguments contrary. See: G Harman, K Mason and W Sinnott-Armstrong, 'Moral Reasoning' in J Doris (ed), *The Moral Psychology Handbook* (The Moral Psychology Handbook, Oxford University Press 2010)

¹⁰⁰ Such an approach is suggested by e.g. Wilkinson and Savulescu, *Ethics, Conflict and Medical Treatment for Children: From Disagreement to Dissensus*

¹⁰¹ E.g. Hilary Putnam, 'Beyond the Fact-Value Dichotomy' (1982) 14 *Crítica: Revista Hispanoamericana de Filosofía* 3A. M. Hedgcock, 'Critical bioethics: beyond the social science critique of applied ethics' (2004) 18 *Bioethics* 120R. De Vries and B. Gordijn, 'Empirical ethics and its alleged meta-ethical fallacies' (2009) 23

making approach is desirable, particularly one that goes beyond the parent-doctor dyad and brings a plurality of views. Yet this approach should be focused on ensuring that the child's welfare is as well served as possible under the circumstances, even if this means taking an alternative view to parents of what is good for their child. Attending to the child's overall good will usually mean a need to maintain clinical dialogue with the parents, and, on balance, this may entail some degree of sub-optimisation of treatment goal. Yet at no point should it mean simple capitulation to obviously poor parental judgements. While the authority or otherwise of expert decisions requires an account legitimate political authority¹⁰² that shall not be discussed here, the nature and extent of knowledge about medicine clearly distinguishes medical decisions from decisions about parenting style, involvement in contact sports or a host of other social decisions that are commonly considered by proponents of the harm threshold.¹⁰³

We might argue that such concerns do not matter. The empirical data in part 1 indicates that the best interests standard does not align strongly to actual decision-making. If the practical approach to decision-making is necessarily different from the law, then the harm threshold might essentially mean that business carried on as usual. In this scenario the harm threshold would be part of the law's role of signalling the boundaries of acceptable behaviour to the wider public. In this case, it would signal that society values and, except in exceptional cases protects, parental autonomy as a means to advance the welfare of children. Yet it is worth noting that the use of the harm threshold in determining the social welfare of children is by no means unproblematic, as the regular drip of appalling cases where children die as a result of their parents' mistreatment attests. In most of these cases, members of the public, social workers, teachers or doctors note the signs of neglect or abuse but judge it insufficient to breach the harm threshold. Signals are important, and we should take serious stock of the failures of social welfare in this regard.

I have so far considered whether there is a strong case for the harm threshold in current clinical practice and whether we might want to introduce a more consistent approach to social and medical welfare. But this might not be the end of the story. Recently, some have argued that a harm threshold will require greater attention to resource limitations. Before I conclude, I would like to consider the potential for unintended consequences of the harm threshold.

One of the motivations of the harm threshold as it is seen within Charlie's law is to reduce conflict.¹⁰⁴ Some have also suggested that the harm threshold may enjoy public support,¹⁰⁵ and if this were so,¹⁰⁶ it might also indicate that the adoption of the harm threshold would reduce instances of

Bioethics 193J. McMillan, 'Empirical Bioethics and the fact value distinction' in J. Ives, M. Dunn and A. Cribb (eds), *Empirical bioethics: Theoretical and Practical Perspectives* (Empirical bioethics: Theoretical and Practical Perspectives Cambridge University Press 2017)

¹⁰² D. Estlund, *Democratic Authority: A Philosophical Framework* (Princeton University Press 2008)

¹⁰³ Wilkinson and Nair, 'Harm isn't all you need: parental discretion and medical decisions for a child'

¹⁰⁴ The Charlie Gard Foundation, 'Charlie's Law'

¹⁰⁵ Nair, Wilkinson and Savulescu conducted an online survey of the views of 178 visitors to a U.S. crowdsourcing website. They found almost 60% of participants were willing to support a hypothetical parental demand for a substitute treatment that increased the risk of their child's death by 4%. The authors concluded that the harm threshold is more representative of public opinion, and that, given the weight of bioethical commentators supportive of the harm threshold, the harm threshold should therefore be adopted - albeit with a lower risk threshold than that supported in the survey. See: Nair and others, 'Settling for second best: when should doctors agree to parental demands for suboptimal medical treatment?'

¹⁰⁶ There is some reason to question the representativeness of these findings: Crowdsourced samples are not representative of general populations, and thus any claim that Nair et al.'s research offers a balanced view of public attitudes is suspect. See: J. Chandler and D. Shapiro, 'Conducting Clinical Research Using Crowdsourced Convenience Samples' (2016) 12 *Annu Rev Clin Psychol* 53

conflict in paediatric healthcare. However, the harm threshold may have the unintended effect of bringing deeper conflicts about resource limitation to the fore, at least in the United Kingdom (UK). Medical decisions in the UK are capable of commanding extensive levels of resources irrespective of ability to pay. Healthcare spending on the range of therapies that are offered by local commissioners is putatively allocated on the basis of individual. In other words, whether an individual child receives a therapy for five days or fifty will be determined clinically rather than by any limit of individual funding. In practice, widespread shared decision-making means that need is determined between a parent and a doctor. Resource limitations, as we saw in the empirical data in part 1, may be a consideration, but they are rarely an explicit one. Resources that might be available to parents and doctors in individual cases, while not unlimited, are extremely extensive nevertheless. Under a putative harm threshold, the clinical recommendation against a treatment that is harmless, but of no particular benefit, must take a back seat to parental demand for a treatment. For a costly but harmless treatment, very large amounts of resource may be thus be concentrated on meeting that parental demand with little clinical justification.

Advocates of the harm threshold have been alert to this problem, and suggest a central role for resource limitation. Wilkinson and Savulescu¹⁰⁷ spend considerable energies arguing that it is financial resources, rather than best interests, that should demarcate the limit on children's treatment. Whatever it's ethical merits, there is a practical problem to this solution: making decisions to limit treatment solely on the basis of resources is extremely unpopular with the British public.¹⁰⁸ The apparent political toxicity of this strategy is highlighted by reviewing the outcome of attempts at fair resource allocation by the National Institute for Health and Care Excellence (NICE). NICE decisions have been undermined by both public campaigns (often bankrolled by companies with a financial interest in overturning NICE's decision)¹⁰⁹ and government policy.¹¹⁰ The overall impression is that an era of bald resource allocation ushered in by a harm threshold seems likely to be a significantly more divisive way to demarcate the limits of treatment than the current system that gives weight to clinical expertise. Indeed, it is likely that, under a harm threshold, health and governmental authorities will come under significant public pressure to raise or remove caps to resources in high profile cases. Without a major change in public and political attitudes to health rationing, the harm threshold seems to raise potential for significant conflicts in this area.¹¹¹

For children, for parents or for society at large, it is clear that there are significant risks to adopting a harm threshold. There are good reasons to be dissatisfied with the opacity of the best interests test, and it is correct to investigate apparent inconsistencies in the law as well as the significant concerns raised by supporters of the Charlie Gard's parents. While the harm threshold usefully focuses attention on these areas, it is not the answer to the apparent deficiencies in the current approach.

¹⁰⁷ Wilkinson and Savulescu, *Ethics, Conflict and Medical Treatment for Children: From Disagreement to Dissensus*

¹⁰⁸ H. McKenna, *Are we expecting too much from the NHS?*, 2018) Available from:

<https://www.health.org.uk/sites/default/files/NHS-70-Are-we-expecting-too-much-from-the-NHS.pdf>

¹⁰⁹ M. Wood, 'Depoliticisation, Resilience and the Herceptin Post-Code Lottery Crisis: Holding Back the Tide' (2015) 17 Br J Polit Int Relat 644

¹¹⁰ V. Kirkbride, 'Health Economics: Decisions and Choices at the End of Life' in L. Hagger and S. Woods (eds), *A Good Death? Law and Ethics in Practice* (A Good Death? Law and Ethics in Practice, Ashgate Publishing Ltd. 2013)

¹¹¹ While the harm threshold might threaten the current way that socialised healthcare is organised in the UK, there is clearly a constituency for which this is an acceptable price, or even a goal. For example, groups that are highly critical of the NHS as an institution played a vocal role in the campaign to continue the active treatment of Charlie Gard, See: R. Hurley, 'How a fight for Charlie Gard became a fight against the state' (2017) 358 BMJ j3675

Without a specification of the harms it intends to limit, it will not bring transparency. It is true, it could bring a veneer of consistency to social and medical decision making – but to what end if the factors involved in these decisions are fundamentally different? It seems likely that any conflict ameliorated by the harm threshold will redouble in other areas. Nevertheless it is true that a systematic revision of healthcare decision-making is timely. A central concern should be our approach to power relations in decision-making.¹¹² To this extent, as JS Mill recognised,¹¹³ questions of parental autonomy (as well as medical authority) are questions of the power of each party over a child, rather than questions of individual liberty. Most apparently agree that the welfare of the child recipient of a decision is central. Welfare must be contingent on facts rather than fictions. Yet, given the very amorphous nature of welfare when facts are in short supply, any approach that concentrates power with a parent, a doctor, or any other party risks failing to take account of important perspectives. What is needed is some way of diffusing power among a plurality of stakeholders to increase the perspectives consulted in a decision. Shared decision-making is a good start, yet risks excluding consideration of the child.¹¹⁴ Developing better approaches remains contingent on improving our understanding of the interaction between policy and practice in children’s healthcare. Academics are fond of stating that ‘more research is needed’. As there is clearly a dearth of empirical research into practice, and, importantly, into a range of practice settings to capture more everyday experiences, on this occasion the adage seems especially apt. These issues are simply too important to proceed without a sound empirical basis.

Conclusion

There is a peak of interest in the harm threshold following the Charlie Gard case. In this chapter I have sought to consider the harm threshold through the prism of decision-making in a clinical setting. These show the breadth of considerations that decision-makers take into account. Proponents for a harm threshold are likely to take succour from findings that suggest features of the harm threshold are in operation in practice. Yet, for reasons I have outlined in my analysis, I believe the picture is rather more complicated. The broader literature seems to indicate that, rather than simply allowing parents autonomy so long as their decisions are not harmful, clinicians try to steer a path that balances benefits and harms to both the child in their care, and to the child’s parents. True, this fits the conventional account of the best interests test rather poorly. Yet it is no better a fit to the harm threshold. Of course, this is unlikely to convince those who argue that there are nevertheless strong normative reasons to support the harm threshold: to some of these scholars, the case of Charlie Gard was emblematic of a wider abuse of parental autonomy. To others the natural need for consistency in the law is offended by the differing clinical and social standards by which children’s welfare is judged by the law. Others, including the authors of chapters in this book, offer a normative justification based on a supposed parental right to autonomy.

I have argued that parental autonomy is not widely abused in contemporary healthcare. In the case of Charlie Gard, parent objections were met, not with clinical obduracy, but a willingness to seek other opinions and make sustained attempts to overcome misunderstandings, albeit within lines that were drawn by the clinical evidence about Charlie’s medical welfare. What we know of the wider empirical picture indicates that parental wishes are treated sympathy and respect. Moreover, the nature of clinical and legal interventions is quite different. The differences between this clinical picture and the apparent intent of the legal test of best interests test should therefore not

¹¹² M. Quigley, 'Best Interests, the Power of the Medical Profession, and the Power of the Judiciary' (2008) 16 Health Care Analysis 233

¹¹³ See note n.25

¹¹⁴ Birchley, 'Deciding together? Best interests and shared decision-making in paediatric intensive care'

necessarily inspire changes in the law. Nor should the inconsistency between the social and clinical standards of welfare intervention necessarily be undesirable. Differences between the apparent political willingness to pay for clinical interventions, and the much greater clinical knowledge of the efficacy of medical interventions markedly reduces the degree of uncertainty about the impact of clinical decisions. This reduces the degree of caution with which we should otherwise approach decisions that seek the best for a child. While it is possible that the harm threshold could have minimal effects on decision-making in practice, it is equally possible that a switch to the harm threshold signal would involve radical changes. These may involve unintended consequences both to parental autonomy, since the harm threshold may invite a much more clinically dominated approach to welfare than the current system. It may also open decision-making up to greater conflicts, since limits in resources would play a much more overt part in limiting children's treatment. New approaches to decision-making are needed, but liberal welfare should be based on pluralised decisions, rather than concentrating power in one group or another. Even if best interests is not the perfect standard in which to express such ideals, the harm threshold does not advance the process of reform.

Word count: 9764

Appendix

Table 2: Parent characteristics

<i>ID</i> ¹	Present at interview	Age of child	Admission type	Length of Admission ²	LLC ³	Outcome of Admission ⁴
P40	Both parents	<1 month	Emergency	>1 month	Yes	Ongoing ill-health
P41	Both parents	<1 month	Emergency	>1 month	Yes	Death
P42	Mother and relative	1 – 12 months	Emergency	<2 weeks	Yes	Death
P45	Both parents	1 – 4 years	Emergency	2 – 4 weeks	No	Ongoing ill-health
P55	Mother	1 – 4 years	Emergency	2 – 4 weeks	No	Recovery
P56	Both parents	1 – 12 months	Elective	<2 weeks	No	Recovery
P58	Mother	1 – 4 years	Emergency	<2 weeks	No	Ongoing ill-health
P59	Both parents	1 – 4 years	Emergency	<2 weeks	Yes	Ongoing ill-health
P60	Mother	<1 month	Emergency	2 – 4 weeks	No	Recovery
P61	Mother	1 – 4 years	Emergency	<2 weeks	No	Ongoing ill-health
P62	Mother	1 – 4 years	Elective	<2 weeks	No	Recovery
P63	Mother and friend	1 – 4 years	Elective	<2 weeks	No	Recovery
P64	Mother	<1 month	Emergency	<2 weeks	No	Recovery
P65	Both parents	1 – 12 months	Emergency	<2 weeks	No	Recovery

1. Participant identifier

2. Period of time given to aid anonymity

3. Life Limiting Condition, as categorised by

4. Recovery is where child leaves PICU with an improvement in their pre-admission baseline health, Ongoing ill-health is where the child leaves PICU with a deficit to their baseline health

Table 3: Clinician characteristics

<i>ID</i>	Designation ¹	Years of experience of PICU decisions
D27	Trainee	5-10
E28	Chaplain (clinical ethics committee)	3-5 ²
N29	Senior Nurse	>10
D30	Consultant	10-20
N31	Staff Nurse	5-10
E32	Doctor (clinical ethics committee)	3-5

E33	Nurse (clinical ethics committee)	3-5
D34	Consultant	10-20
N35	Staff Nurse	<5
E36	Doctor (clinical ethics committee)	<3
N37	Staff Nurse	<5
N38	Staff Nurse	<5
E39	Lay member (clinical ethics committee)	3-5
N43	Staff Nurse	5-10
D44	Consultant	>20
D46	Consultant	10-20
D47	Trainee	5-10
N48	Senior Nurse	>10
D49	Consultant	10-20
D50	Trainee	<5
E51	Doctor (clinical ethics committee)	3-5
D52	Consultant	10-20
E53	Lay member (clinical ethics committee)	3-5
N54	Senior Nurse	5-10
D57	Trainee	<5

- 1. Doctors were either intensive care consultants or “trainees”; experienced doctors below consultant level who were on training in paediatric intensive care. Nurses from Agenda for Change band 6 and above were classified as senior nurses. Ethics committee members are identified by profession rather than seniority.**
- 2. Participant could not recall actual length of service**

Study methodology:

Participants were approached with a letter from an intensive care consultant (in the case of parents) or by email from a manager or a direct approach by the author in the case of clinicians. Participants were invited to respond to the author and those that did were given an opportunity to discuss the study and decide if they wished to take part. Before interview, participants gave written, informed consent. With participants permission, interviews were audio recorded and transcribed, before being analysed using the thematic method. This analysis took place in the first instance in 2014-2015, where it informed several papers.¹¹⁵ Permission to conduct the research was granted by the Research Plymouth and Southwest Ethics Committee (approval reference 12/SW/0210).

¹¹⁵ Birchley G. ‘You Don’t Need Proof When You’ve Got Instinct!’: Gut Feelings and Some Limits to Parental Authority,. In: Huxtable R, Meulen RT, eds. *The Voices and Rooms of European Bioethics*. London: Routledge; 2015:120-35; ; Birchley G, Huxtable R. *Critical Decisions for Critically Ill Infants: Principles, Processes, Problems*. In: Stanton C, Hervey T, Farrell A, Mullock A, eds. *Pioneering Healthcare Law: Essays in Honour of the Work of*

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