In defense of a conditional harm threshold test for paediatric decision-making

Dominic Wilkinson[1,2,3,*]

The case of Charlie Gard raises a number of serious ethical questions, including how a child's best interests should be assessed, the role of parents in decision-making for a child, the appropriateness of trying untested experimental treatment in a serious ill child, and the allocation of limited healthcare resources. Elsewhere, I have reviewed these questions in some detail and explored the implications for future disputes over medical treatment for children.[1] In this chapter, I will focus on one of the questions that arose in the Gard case and was also raised in the subsequent case of Alfie Evans. If there is disagreement between parents and health professionals about treatment for a child, should courts overrule parents on the basis of an assessment of what would be *best* for the child, or only if what the parents propose would be *harmful* for the child? I will largely focus on the ethical question (and leave the more specific legal questions to other commentators in this volume).[2] I outline the ethical case for using a harm threshold test rather than a best interests test, identifying a set of cases where these tests may yield different decisions. I respond to a series of counterarguments against the use of harm thresholds. In the last part of the chapter, I propose a compromise, a conditional harm threshold test that would apply only if there is a question of preventing parents from pursuing treatment that other health professionals are offering

Author Affiliations: 1 Oxford Uehiro Centre for Practical Ethics, Faculty of Philosophy, University of Oxford, UK. 2 John Radcliffe Hospital, Oxford, UK. 3 Murdoch Children's Research Institute, Melbourne.

* Correspondence: Prof Dominic Wilkinson, Oxford Uehiro Centre for Practical Ethics, Suite 8, Littlegate House, St Ebbes St, Oxford, OX1 1PT, UK. Tel: +44 1865 286888, Fax: +44 1865 286886 Email: dominic.wilkinson@philosophy.ox.ac.uk

Publication details: Wilkinson D. (2019) In defense of a conditional harm threshold test for paediatric decision-making. In *Parental Rights, Best Interests and Significant Harm. Medical decision-making on behalf of children post Great Ormond St vs Yates*, ed Goold I, Herring J, Auckland C. (Hart Publishing)

https://www.bloomsburyprofessional.com/uk/parental-rights-best-interests-and-significant-harms-9781509924912/

This is the manuscript of a chapter accepted for publication by Hart Publishing in the book *Parental Rights, Best Interests and Significant Harms: Medical decision-making on behalf of children post Great Ormond St vs Yates* published in 2019.

1 D. Wilkinson & J. Savulescu. 2018. *Ethics, conflict and medical treatment for children: from disagreement to dissensus*: Elsevier.

2 Goold I Evaluating 'Best Interests' as a Threshold for Judicial Intervention in Medical Decision-Making on Behalf of Children. In *Parental Rights, Best Interests and Significant Harm. Medical decision-making on behalf of children post Great Ormond St vs Yates*, ed Goold I, Herring J, Auckland C. Hart 2019

to provide. I explore the implications of this test for a set of challenging cases similar to the Gard/Evans cases, setting out two different alternatives for evaluating the harm of prolonging life in children with absent consciousness.

1. Harm or best interests in the case of Charlie Gard?

In the Gard case, part of the first legal appeal focused on when courts may override parental wishes. The high court had previously heard evidence about the risks and benefits of prolonging life-sustaining treatment (and seeking experimental therapy) for Charlie Gard. Justice Francis had cited the previous case of Wyatt, noting that "the intellectual milestones for the judge in a case such as the present are, therefore, simple, although the ultimate decision will frequently be extremely difficult. The judge must decide what is in the child's best interests."[3] Justice Francis concluded that it would be in Charlie's best interests to withdraw treatment and allow him to die.

However, Charlie's parents argued in the Court of Appeal that this was the wrong standard to apply. Their lawyers claimed that:

> "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*."[4]

One of the arguments that the legal team drew on in support of this claim drew an analogy with the legal approach to placing children in care. The UK 'Children Act' sets out when public authorities can remove a child from their parents. Social services in the UK can obtain a court order only if:

> "the court is satisfied that the child concerned is suffering or is likely to suffer significant harm, and that the harm, or likelihood of harm, is attributable to parental care or the child being beyond parental control"[5]

But if the 'harm threshold' is the standard for the state intervening in parental everyday decisions – why shouldn't that also apply to medical decisions? The legal team representing Charlie's parents suggested that in cases where parents have an alternative viable treatment option to that proposed by doctors, the test shouldn't be whether one of these is 'better'. Instead, the parents' wishes should be overridden only if their preferred treatment plan would be significantly harmful.

That was the argument put to the Court of Appeal. The judges in that court ultimately rejected it. As a point of law in the UK, medical treatment cases *are* treated differently from decisions about when local authorities can take over the care of a child. In the case of Alfie Evans, the Supreme Court reached a similar conclusion.[6]

That still leaves the ethical question unanswered – *should* we use the harm threshold for deciding when parents' wishes about medical treatment should be respected or refused? If we think the answer to that is right, it may be that the law should change.

3 Portsmouth NHS Trust v Wyatt [2005] 1 FLR 21.

4 Yates & Anor v Great Ormond Street Hospital For Children NHS Foundation Trust & Anor (Rev 1) [2017] EWCA Civ 410. Para 54 [emphasis added]

5 The Children Act, 1989. https://www.legislation.gov.uk/ukpga/1989/41/section/31

6 In the matter of Alfie Evans UKSC [2018] Permission to appeal determination 20 March.

2. Definitions, distinction

In order to be clear about what is at stake, it would be useful to clarify the two different ways of resolving disputes about medical treatment between doctors and parents.

> *Best interests test*: A decision should be reached based on an assessment of which course of action would promote the best interests of the child. Parents' wishes about treatment should be followed only if they are consistent with the child's best interests
>
> *Harm Threshold test*: A decision should be reached based on an assessment of whether the default decision-maker's chosen course of action would be harmful. Parents' wishes should ordinarily be respected, unless what they are requesting will cause the child to suffer or is likely to cause the child to suffer significant harm.

One important issue, if a harm threshold is employed, is what would count as a sufficient magnitude of harm, or a sufficient chance of harm, for intervention to be justified. Different accounts of the harm threshold employ different language. For example, The Children Act refers to "significant harm". Diekema refers to a "significant risk of serious preventable harm".[7] For this chapter, I will employ the language used in the Children Act, however, will largely set aside what level of harm this refers to.

There are two different settings in which disputes may occur. Parents may be refusing a recommended course of treatment for the child. Alternatively, they may be requesting or demanding that treatment be provided or continued for their child. Important ethical differences between these two types of conflict will become apparent.

3. Three ethical arguments in defense of the harm threshold

While the Gard case is the first court case in the UK (to my knowledge) where the issue of harm thresholds has been raised directly, there has been active debate over the best interests test within bioethics for more than two decades.[8] There is wide agreement that 'best interests' represents a laudable *goal* for decision-making about children. The United Nations declaration on the rights of the child states the child's best interests should be a "primary consideration" when decisions are made about them.[9] However, it seems more problematic to use best interests as a *threshold* for deciding whether courts should overrule parents.[10] Here are three reasons for this concern.

---

7 D.S. Diekema. Parental refusals of medical treatment: the harm principle as threshold for state intervention. *Theoretical Medicine and Bioethics* 2004; 25: 243–264. PubMed PMID: 15637945.

8 L.M. Kopelman. The best-interests standard as threshold, ideal, and standard of reasonableness. *J Med Philos* 1997; 22: 271–289 PubMed PMID: 9232512.; Diekema. *op. cit.* note; R. McDougall, et al. eds. 2016. *When doctors and parents disagree: ethics paediatrics and the zone of parental discretion*. Sydney: Federation Press; R.J. McDougall & L. Notini. Overriding parents' medical decisions for their children: a systematic review of normative literature. *J Med Ethics* 2014; 40: 448–452 PubMed PMID: 23824967.; J.C. Bester. The harm principle cannot replace the best interest standard: Problems with using the harm principle for medical decision making for children. *The American Journal of Bioethics* 2018; 18: 9–19 PubMed PMID: 30133393.; G. Birchley. Harm is all you need? Best interests and disputes about parental decision-making. *J Med Ethics* 2016; 42: 111–115 PubMed PMID: 26401048.. R. Dresser. Standards for family decisions: replacing best interests with harm prevention. *Am J Bioeth* 2003; 3: 54–55.

9 D. Archard. 2008. Children's Rights. Available at: http://plato.stanford.edu/archives/win2008/entries/rights-children/ [Accessed 23/09/2009].

10 Diekema. *op. cit.* note.

3.1. Moral uncertainty

Critics of the best interests standard have argued that it is unknowable or "vague".[11] This points to the difficulty in many cases of knowing what, exactly, would be best for a child. When it comes to a decision about medical treatment (should it or shouldn't it be provided), the best interests test appears to imply that there is a simple yes or no answer to the question. If treatment is in a child's best interests, it should be provided, if it isn't in the child's best interests, it shouldn't (Figure 1).

That answer, however, appears hopelessly simplistic when we reflect on the typical cases where medical treatment is under dispute. Cases of conflict have often arisen over life-sustaining treatment for a child. They are often situations where parents wish for treatment to continue, but health professionals believe that this offers no benefit to the child (and may be harmful). The assessment of best interests in such cases involves weighing up the benefits of life (including an assessment of the quality of a child's life) against the harms of invasive medical treatment. This is a profoundly difficult assessment to make, partly because of uncertainty about what might lie ahead for the child. Yet, the difficulty also arises from the fundamentally value-laden nature of the decision. Even if a child's future quality of life were known with certainty, even if we could predict accurately the amount of pain/pleasure they would experience, the ethical difficulty would remain.[12] How much weight should we give to different benefits or harms? How should we weigh up the benefit of continued existence (for example in a state of minimal consciousness) against the discomfort of medical treatment? These are questions of substantial moral uncertainty, on which there can be a range of different reasonable viewpoints.[13]

The challenge for the best interests test in the setting of moral uncertainty is that there can be, and often are, competing views about what would be best for the child. In that setting, it seems a problem for courts to be tasking themselves with identifying a single 'best' course of action.

Moral uncertainty does not always undermine decisions made on the basis of best interests for a child. There are some cases that are clear-cut. For example, paradigm cases include parental refusal of a blood transfusion for a child (for example because of their religious belief), or parental requests for mutilating female circumcision. In those instances, there is not genuine moral uncertainty about the benefits and harms of the requested treatment. There is not reasonable disagreement about the pros and cons of intervening in such instances.

Clear cases (such as parental refusal of a transfusion) do sometimes reach the court. However, perhaps predictably, the most contentious cases are not so clear (Figure 2). The cases where moral uncertainty raises problems are those where the benefits or harms of treatment are relatively small or uncertain. Table 1 identifies a set of possible cases of this type. Case A (Transfusion) and F (Infibulation) are clear cases, while cases B-E are ones where there is more uncertainty. It is relevant that the benefits/harms are relatively small in magnitude in these cases. That is because there is more scope for reasonable disagreement about the balance of benefits and burdens. Others may reasonably reach a different conclusion about whether treatment is overall in the interests of the child.

11 R.M. Veatch. Abandoning informed consent. *Hastings Cent Rep* 1995; 25: 5–12. H. Brody & W.G. Bartholome. In the best interests of. Ibid. 1988; 18: 37–40; Kopelman. *op. cit.* note..

12 D. Wilkinson. 2013. *Death or disability? The Carmentis Machine and treatment decisions for critically ill children.* Oxford: OUP.

13 Wilkinson & Savulescu.

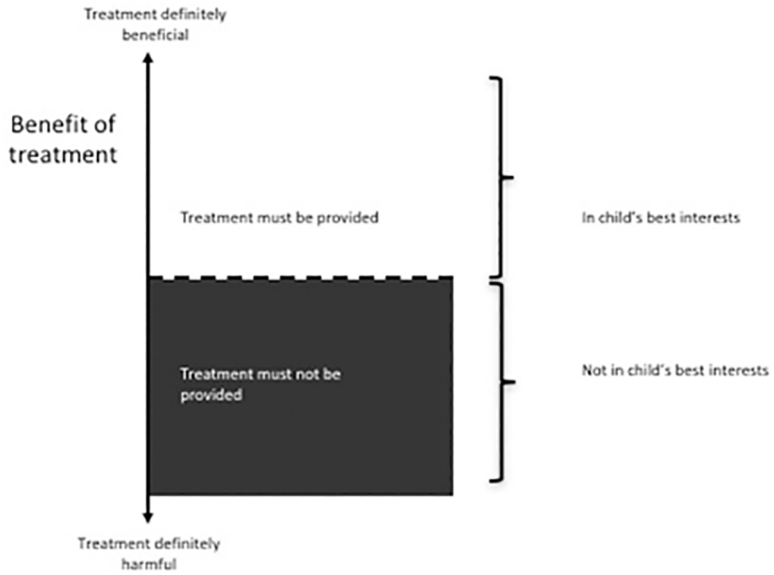

Figure 1. **The best interests test.**

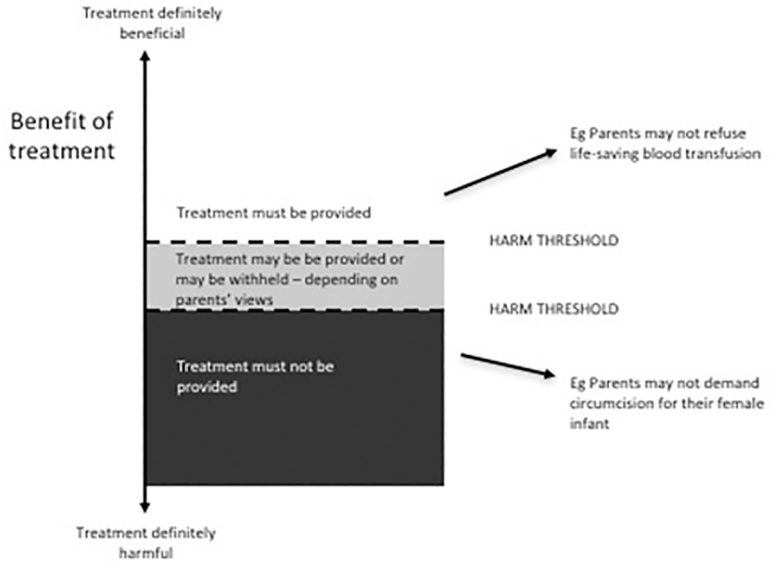

Figure 2. **Harm Thresholds.**

Table 1. **The spectrum of decisions.** Rows highlighted in grey are those where there is plausibly moral uncertainty about providing treatment. Case X appears in multiple rows as, depending how the harms and benefits of treatment are evaluated, it may be considered to fit into several different categories (see text)

	Example
Refusal of medical treatment where benefit is certain and significant	A. Blood transfusion in a child following trauma (parents Jehovah's witness)
Refusal of medical treatment where benefit is certain, but is small	B. Immunisation against a common childhood illness (chance of severe complications is very small)
Refusal of medical treatment where benefit is uncertain	C. Life prolonging treatment in a newborn with severe brain injury[14] (X. Prolonged life-sustaining treatment – absent consciousness)

Table 1 continued from previous page.

	Example
Request for medical treatment without benefit	D. Complementary medicine (no scientific evidence to substantiate, but risks negligible) (X. Prolonged life-sustaining treatment – absent consciousness)
Request for medical treatment where harm is certain, but is small	E. Male circumcision. Minimal forms of female circumcision[15]
Request for medical treatment where harm is uncertain	(X. Prolonged life sustaining treatment - absent consciousness)
Request for medical treatment where harm is certain and significant	F. Infibulation (X. Prolonged life sustaining treatment - absent consciousness)

3.2. Value of parental freedom

If there is genuine moral uncertainty about whether a proposed course of action is in the best interests of a child, whose view should be followed? One intuitive response to that question is that parents' wishes should usually be respected.

There are several reasons to give weight to parents' interests and views in decision-making.[16] One reason is that the interests of the child and those of parents often overlap and are interdependent. Parents may be in a unique epistemic position to assess the interests of the child – they may be in a better position than the health professionals to assess the child's quality of life and predict their ability to cope with treatment.[17] Beyond that though, we usually think that it is good for parents to have significant latitude in deciding how to bring up their child. After the child, they are the ones likely to be most affected by those decisions. Parents may seek guidance and advice in how to raise their children. It is, though, a necessary part of parenthood for parents to make ethical evaluations and choices.

Parental freedom to make decisions for and about their children is closely linked to respect for individual autonomy. However, parents' freedom to decide about treatment for their children is more constrained than their freedom to decide about their own health. That constraint is the important concern to avoid causing harm to the child. Yet, if parents' decision about medical treatment for a child would *not* cause significant harm to the child, what business is it of doctors, or of the state to intervene?[18]

14 D. Wilkinson. A life worth giving: the threshold for permissible withdrawal of treatment from disabled newborn infants. *Am J Bioeth* 2010; 11: 20–32.

15 Ritual genital cutting of female minors. *Pediatrics* 2010; 126: 191. PubMed PMID: 20530070.

16 D. Wilkinson. How much weight should we give to parental interests in decisions about life support for newborn infants?. *Monash Bioeth Rev* 2010; 29: 13.11–13.25.

17 Ibid..

18 Similar points are raised in the chapters by Imogen Goold and Rachel Taylor in this volume. Goold Op cit note 2. Taylor R Parental Decisions and Court Jurisdiction: Best Interests or Significant Harm? In *Parental Rights, Best Interests and Significant Harm. Medical decision-making on behalf of children post Great Ormond St vs Yates*, ed Goold I, Herring J, Auckland C. Hart 2019

3.3. Consistency

Finally, the harm threshold should apply to legal disputes about medical treatment as a matter of simple ethical consistency. This is the threshold that applies elsewhere in life and in medicine.[19]

As already noted, the harm threshold is used in cases where there are decisions about taking a child into care. Children will only be removed from their parents if remaining with the parents would pose a significant risk of serious harm. More generally, though, parents make a wide range of decisions that are sub-optimal. Whether deciding what to feed their children, what school to send them to, how much screen-time they should be permitted, or what activities or interests to encourage or support, parents constantly fail to maximise their children's interests. That reflects, in part, the fallibility of parents. Parents do not always know what would be best, or (even when they know better) make the right choices. It reflects, too, the necessary conflict between the interests of family members. When parents have more than one child, there are often decisions that may be better for one child, but worse for another. There is simply no way to maximise all of their interests. Moreover, the interests of children compete with those of parents. Optimal choices for children may require very substantial sacrifice of the parents' own wellbeing. How much sacrifice must parents make? Our society does not appear to think that the state should interfere whenever parents fail to optimise the child's wellbeing.

In medical decisions, it isn't thought that doctors' views about treatment should always predominate and that parents' wishes should be ignored. Paediatricians and general practitioners spend a good deal of time counselling parents and encouraging them to make health care decisions for their children that are likely to promote the child's interests. However, if parents make suboptimal decisions, professionals will usually only seek to override parents if what parents have decided poses a real risk of harming the child. Table 1 indicates some examples where, in fact, parents may not be making decisions in the best interest of a child, but those decisions are usually respected. In practice, in cases like B-E, treatments/interventions are sometimes provided and sometimes not provided, largely on the basis of parents' wishes. For example, it is not in a child's interests to receive a complementary medicine that has no scientific or medical basis and offers no plausible benefit. However, so long as there is no reason to think that it would be harmful, such treatments are commonly given to children, and health professionals do not oppose this. It is in a child's interests to be immunised, to have vitamin K prophylaxis or to have newborn screening tests. Yet, health professionals do not normally invoke child protection proceedings if parents refuse these interventions.[20] While paediatricians are often discomfited and disquieted when parents decline their recommendations, they do not seek to impose their own views for the reasons already highlighted: there is often some degree of moral uncertainty about how to weigh up the risks and benefits of treatments; there is clear social value in allowing parents (within reason) broad discretion to make decisions about their children; there would be significant harm, both to children and to families, and substantial costs (in time and resources) if legal mechanisms were employed to enforce mandatory treatment against parental opposition.

19 Taylor argues [op cit note 18] that the law is not inconsistent in its use of these thresholds. The courts apply the harm threshold to situations where local authorities are seeking "ongoing state involvement in the life of the child…[and] ongoing discretional authority over the child's life". In contrast, for specific decisions, the court can make decisions on the basis of the welfare of the child under its 'inherent jurisdiction', or under section 8 of the Children Act. My argument here is not that the law is inconsistent, or being applied inconsistently – rather that there is ethical inconsistency in overruling parents decisions about medical treatment if they are not in the child's best interests, but only overruling other decisions (for example around education, diet, religious practice etc) if they would be significantly harmful.

20 Giles Birchley's empirical research, described in his chapter, supports the notion that something like a harm threshold is, in fact, employed by clinicians in deciding whether to respect, or oppose parental wishes about treatment. Birchley G. The Harm Threshold: A View from the Clinic. In *Parental Rights, Best Interests and Significant Harm. Medical decision-making on behalf of children post Great Ormond St vs Yates*, ed Goold I, Herring J, Auckland C. Hart 2019.

4. Counterarguments to the harm threshold

4.1. No difference

Some critics of the harm threshold argue that it is unnecessary to seek any change in the threshold for intervention since harm is already incorporated into the best interests test as it is applied by courts.[21] On this view, a change in the threshold would make no difference. In the Gard case, it was suggested in the Court of Appeal that a decision based on harm would have been identical to the decision that was made on the basis of best interests.

> "the judge was not invited to consider the law in the way that it is now put before this court, let alone to consider the existence of 'Category 2' cases with the need to establish a threshold for significant harm. …It is clear, in my view, that if the judge had been invited to form a conclusion on whether Charlie was or was not suffering significant harm currently, that finding would have been made." Para 114[22]

One way of understanding this argument is conceptual. Harms and benefits can be seen as opposite sides of a coin. If an intervention would be in someone's interests, it would be harmful to withhold that intervention. Conversely, if it would be harmful to provide a particular treatment, it would be in the patient's best interests not to do this.

However, on conceptual grounds this seems to be a mistake. First, harms are typically understood as a thwarting or a set-back in someone's interests.[23] That is different from failing to promote or enhance an interest. (Compared with a neutral reference point, one makes the child worse, the other fails to make them better). Second, harms and benefits are often thought to be asymmetric. The claim (consistent with many people's intuitions) is that it is *worse* to harm than to fail to benefit.[24] This necessarily implies that failure to benefit does not (always) constitute harm. Third, the harm threshold (but not the best interests test) includes an assessment of the magnitude of change for the child. There must be *significant* harm. It might be in a child's best interests to have a second helping of supper (because, for example, they are still hungry and desire it) – but it seems to be a quite different claim to suggest that they would be harmed by not having an additional serving.

It is worth pointing out that the fact that best interests and harm *converge* in some cases does not prove that the two tests are coterminous. While it is *not* the case that withholding treatment that is in the child's interests is necessarily a significant harm, the opposite does hold. *If* a particular course of action would pose a significant risk of serious harm, it must be the case that this would not be in the child's best interests. It may be that in many cases of disputed treatment that come before the courts, the harm threshold has been crossed. If so, the same decision would be justified using either the harm threshold test or best interests test. Yet that does not prove that in *all* cases the two tests would reach identical conclusions.[25]

---

21 C. Foster. Harm: as indeterminate as 'best interests', but useful for triage. *J Med Ethics* 2016; 42: 121–122 PubMed PMID: 26670670.. T.M. Pope. The Best Interest Standard for Health Care Decision Making: Definition and Defense. *The American Journal of Bioethics* 2018; 18: 36–38.

22 Yates & Anor v Great Ormond Street Hospital For Children NHS Foundation Trust & Anor (Rev 1) [2017] EWCA Civ 410.

23 J. Feinberg. 1984. *The moral limits of the criminal law: Harm to others*. Oxford: Oxford University Press.

24 D. Alm. Deontological restrictions and the good/bad asymmetry. *Journal of Moral Philosophy* 2009; 6: 464–481; F.M. Kamm. 2007. *Intricate ethics : rights, responsibilities, and permissible harm*. Oxford: Oxford University Press: p17; D. Benatar. 2006. *Better never to have been: the harm of coming into existence*. Oxford: Clarendon: 30–36.

25 I will return in section 5 to specifically discuss the question of whether applying a form of Harm Threshold test to the Gard and Evans cases would have led to a different decision.

As highlighted above in section 3.1, it seems too simplistic to claim that treatment must be either in or against a child's interests. Given moral uncertainty, there are situations where it may or may not be in the child's interests to provide treatment.

Furthermore, where the benefits or harms of treatment are small, there are clear cases where a determination of the child's best interests, and assessment of significant harm diverge. One example is that of routine immunisation. There have been some cases that have come before the court where those with parental authority have disagreed about whether their child should be immunised.[26] In those cases, the courts have consistently concluded that immunisation *would* be in the child's interests.[27] However, it does not seem at all likely that a court would (in a situation where parents are in agreement) conceive that refusal of a routine childhood immunisation, constitutes significant harm. It seems highly unlikely that a court would (in the absence of other, more clearly harmful behaviour) authorise immunisation against the parents' wishes.

4.2. Harm (to children, to families)

A second potential objection to the harm threshold is that this would be damaging to both children and families. For example, it could be claimed that use of the harm threshold rather than the Best Interests test would threaten the wellbeing of children, allowing their interests to be compromised for the sake of the interests of parents or other family members. (We might imagine, for example, that parents do not wish a child to have surgery because it would interfere with their professional career). Yet the harm threshold, *by definition*, does not permit children to receive (or be denied) treatment where that would be harmful to them. It does not mean that the interests of the child are ignored; where treatment is clearly in the interests of the child, it must be provided. Furthermore, as noted in section 3.3 above, the harm threshold already applies to parental care of children in most circumstances and to most medical decisions. That is not thought to constitute a breach of children's rights.

The harm threshold might be damaging in a different way if it led to families (in cases of disputed medical treatment) being treated as though they seek to deliberately harm their children.[28] For example, if a court decided that the course of action favoured by parents represented a significant harm to the child, would that mean that the family's care of other children would be examined by social services, or their children would be removed from their care?

Barristers Katie Glossop and Sarah Pope have advanced this argument against a Harm Threshold, drawing on a case of disputed treatment for a child where a Local Authority had applied a significant harm test and taken a child protection approach.[29] When a mother disagreed with health professionals about provision of antibiotics for her severely disabled daughter, the Local Authority obtained an interim care order, and "used every occasion on which R's mother had not accepted medical advice to build its case on significant harm".[30] The child was placed in residential care, with restricted access from her mother over a period of six months while a final hearing was awaited

26 Re SL (Permission to Vaccinate) [2017] EWHC 125 (Fam). B (A Child: Immunisation) [2018] EWFC 56.

27 R. English. 2017. https://ukhumanrightsblog.com/2017/02/08/should-courts-order-vaccination-against-parents-wishes/. Available at: https://ukhumanrightsblog.com/2017/02/08/should-courts-order-vaccination-against-parents-wishes/ [Accessed 12/12/18].

28 Birchley. *op. cit*. note 20. Taylor op cit note 18.

29 P.S. Glossop K. 2018. Charlie Gard, Alfie Evans and R (A Child): Why A Medical Treatment Significant Harm Test Would Hinder Not Help. Available at: 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 15/3/19].

30 ibid

If families were to be stigmatised, scrutinised or unfairly treated as a consequence of using the Harm Threshold for treatment decisions, this would unquestionably be of concern.

However, it is worth pointing out that this sort of problem depends entirely on how a Harm Threshold test were applied to medical treatment decisions. There is nothing intrinsic in the test itself that means that families would be so treated, and some reason to think that they wouldn't.

The Children Act stipulates a presumption (unless shown otherwise) that involvement of parents in the life of the child will further the child's welfare (s2A). The courts aim to make orders that will cause the least disruption to the child's life. Where parents have requested a treatment, and a court has found that this treatment should not be provided, (because it would be harmful) there is no reason to think that it would be in the child's best interests to be removed from the parents' care. This would certainly not count as being the least disruptive course for the child.

Secondly, it is the case at present in UK law, that the Harm Threshold test is primarily invoked in situations where there is concern that the child should be removed from parents' care. That means that Local Authorities, health professionals and the courts currently focus on whether remaining in parents' custody would pose a risk to the child. If the test were to be applied, however, to *specific* medical treatment issues, there would be a different focus of enquiry. The question would be on whether the treatment (or refusal of it) poses a risk of significant harm – not whether the *parents* pose a risk of significant harm. For that reason, such an enquiry need not be inquisitorial, stigmatising[31], and contrary to the ideal of seeking consensus between professionals and parents in the way that Glossop and Pope fear.

4.3. Indeterminacy

One counter-argument to the harm threshold has been that the concept of harm is just as vague and indeterminate as 'best interests'.[32] If it is difficult to work out whether it would be best to continue or to withdraw life-prolonging treatment in a seriously ill child, it may also be difficult to decide if it would be harmful to do this. The harm threshold incorporates an assessment of the magnitude of harm ("significant"). Yet, there is then a challenge in determining how to define or determine the significance of a putative harm.[33]

However, while the Harm Threshold may be vague, there is no reason to think that it is any more vague that the Best Interests test.[34] Indeterminacy would not provide an argument against the Harm Threshold – merely undermine one possible argument in its favour. If the Harm Threshold were only being used in place of the BIT because of its putative ease of use, or because the BIT were 'vague' – these objections would be particularly

31 One separate argument against a Harm Threshold, is that the language of 'harm' is itself stigmatising or damaging to parents. Birchley. *op. cit.* note 20; Glossop K. It is an open empirical question whether parents would find it more difficult or just as difficult to come to terms with a court decision that continued life-sustaining treatment for their child is "significantly harmful" rather than "not in their best interests". Glossop and Pope note that "[p]erhaps no linguistic usage or avoidance helps, when the person who is yours to care for is taken away from you against your will" (I would add – 'or when a loved child is allowed to die when you had desperately hoped that they would survive').

32 Birchley. *op. cit.* note 20; Bester. *op. cit.* note 8.

33 T. Nair, et al. Settling for second best: when should doctors agree to parental demands for suboptimal medical treatment? *J Med Ethics* 2017; (forthcoming); L. Gillam. The zone of parental discretion: An ethical tool for dealing with disagreement between parents and doctors about medical treatment for a child. *Clinical Ethics* 2015; 11: 1–8. As noted in section 2, it is beyond the scope of this paper to set out where exactly the Harm Threshold should be drawn. In my book on the Gard case, I set out a process (the dissensus framework) that might be employed to determine whether the course of action pursued by parents should be permitted. Wilkinson & Savulescu.

34 Shah, Rosenberg and Diekema have argued that while the Harm Threshold remains vague, it is *less vague* than Best Interests. S.K. Shah, et al. Charlie Gard and the Limits of the Harm Principle-Reply. *JAMA Pediatr* 2018; 172: 301. PubMed PMID: 29309494.

important. However, as noted above, there are several arguments in favour of the HT that do not depend on it being clear or determinate (consistency, the importance of respecting parents' wishes, moral uncertainty).

4.4. Requiring professionals to provide treatment against better judgment

In cases that have come to the court (including Gard and Evans), paediatricians have felt strongly that life prolonging treatment should be withdrawn because it was not in the child's best interests. However, if the harm threshold had been applied by the court, it is possible that the court would have concluded that treatment did not constitute a significant harm to the child.[35] What should happen then?

Should professionals be compelled to treat the child against their considered view of what would be helpful for the child? That may, understandably, lead to significant moral distress. Courts have traditionally been loath to impose on health professionals an obligation to provide medical treatment. (For example, a court order may provide permission to withdraw treatment, though professionals are not obliged to do so). Professionals may feel that continuing treatment would be contrary to their professional role, and conscientiously object to providing the treatment.[36] Furthermore, a requirement to continue treatment in such cases could lead to harm in other ways, even if it wouldn't risk significant harm to the child. Requests for sub-optimal treatment may harm other children through consuming limited medical resources[37]. I have elsewhere highlighted the significance of resource limitations in judgments about futility in intensive care.[38] In my book on the Gard case, I outline the importance of separating out consideration of limited resources in treatment disputes.[39] Even if treatment would not be harmful to the child, it would be wrong to continue to provide that treatment if that would thereby mean that other children are unable to access intensive care.

5. The Conditional harm threshold

I have defended the idea that the harm threshold provides the correct normative test for overruling parents decisions about medical treatment for a child. Yet, there is still an important role for the best interests test in relation to medical treatment for children. That is, firstly, because some situations cannot be resolved by invoking the concept of harm. Table 2 illustrates situations where it would be ethically inappropriate to invoke a harm threshold. In those situations, decisions must be based on a consideration of what would be best for the child. For example, in situations where parents are in conflict about treatment for a child, it is not possible to apply a harm threshold.

Second, the *ideal* is for the child's interests to guide decision-making and for those making decisions to make the best available choice for the child. The best interests test is what parents and health professionals *should* apply in order to reach decisions about treatment. Doctors should recommend courses of action that would be best for the child, and discourage choices that would be sub-optimal.

35 Shah and co-authors argued in the wake of the Gard case, that the Harm Threshold, correctly applied to that case, would have permitted treatment S.K. Shah, et al. Charlie Gard and the Limits of Best Interests. *JAMA Pediatr* 2017; 171: 937–938. PubMed PMID: 28800374.. I will return shortly to assess this specific question in more detail.

36 D. Wilkinson. Conscientious Non-objection in Intensive Care. *Camb Q Healthc Ethics* 2017; 26: 132–142 PubMed PMID: 27934573.. The courts in the UK have usually, in disputed treatment cases, indicated that they will not (and are unable to) take into account these sorts of issues.

37 Nair, et al. *op. cit.* note.

38 D. Wilkinson, et al. Expensive care? Resource-based thresholds for potentially inappropriate treatment in intensive care. *Monash Bioeth Rev* 2018; (forthcoming).

39 Wilkinson & Savulescu.

Thirdly, as argued above, it would be ethically problematic for doctors to be required to provide treatment that they believe would not be in a child's best interests, or would be contrary to the interests of other patients.

For these reasons, it may be appropriate for the default legal test to remain best interests. However, this could be supplemented by a harm threshold in some specific situations. In the following sections I will set out both when a Harm Threshold should be applied, and what the implications might be.

Table 2. Situations where a harm threshold test cannot apply to medical decisions.

a. Absent decision-maker.	Where both parents (and anyone else with parental responsibility) are incapacitated or absent, and a decision needs to be made. The court may need to make a decision on behalf of the child (or appoint a surrogate to do this).
b. Conflict between parents.	Those with parental responsibility to make decisions on behalf of a child are unable to reach agreement
c. Conflict between health professionals	Health professionals are in conflict about what would be best for a child, and parents are unable to decide.
d. Health professional/ parental uncertainty	Health professionals are uncertain about whether a particular course of action would be best for a child (or legal) and have sought a court determination.

5.1. Refusal of treatment

Where parents are declining medical treatment that health professionals believe would be in the best interests of the child, parents may enact their refusal by not presenting the child to medical care or by removing the child from a healthcare environment. Consider the following example:

> **Refusal**: A newborn infant is born following a normal delivery and an uncomplicated pregnancy. The infant is due to be discharged home, but one of the midwives calls the paediatric team as the parents have declined prophylaxis with vitamin K. (Intramuscular vitamin K injections are provided to newborns to prevent a rare life-threatening complication – haemorrhagic disease of the newborn.) Should the doctor seek a court order to compel vitamin K prophylaxis?

In Refusal, the parents are declining a routine intervention that is part of normal newborn care. The paediatricians may try to persuade the parents that their child should have the injection. There is good reason to think that this would be in the best interests of the child. However, if the parents continue to refuse, they may decide to leave the hospital. For the child to receive the Vitamin K, the doctors would need to restrain the parents from leaving hospital, or remove the child from the parents' care. That would be possible, but would be require making an urgent application to the court for an Interim Care Order[40]. The legal threshold for care proceedings would be the Harm Threshold. (In my personal experience of such cases, social workers or hospital lawyers would almost certainly not pursue a court order unless there was good reason to fear significant harm from the refusal of treatment.)

Because parents can simply remove the child from a place of treatment, in cases of parental refusal of treatment, a dispute about treatment would already be likely to involve the Harm Threshold if health professionals seek court intervention. There would be no need for a supplementary test.

40 This was what happened in the case of Ashya King, a 5-year old boy with a brain tumour, whose parents did not wish him to have conventional radiotherapy (they sought a new treatment – proton beam therapy). When his parents removed him from Southampton hospital, the local authority filed an application in the high court to make him a ward of court, on the basis that he was a significant risk of harm. In the matter of Ashya King (A child) [2014] EWHC 2964.

5.2. Demands for treatment

Where parents are demanding medical treatment, the ethical considerations are slightly different. For a health professional to withhold the treatment would not involve physically restraining the parents or removing the child from the child's care. Moreover, as highlighted above, it would be problematic if the Harm Threshold meant that professionals felt compelled to provide treatment that they feel is of no or minimal benefit to the child. That would potentially be harmful to other children – by consuming limited resources. Consider the following case:

> **Provision**: A newborn infant is born following a normal delivery and an uncomplicated pregnancy. The child's parents have been reading about haemorrhagic disease of the newborn and had a friend whose baby tragically died from this complication despite normal preventative measures.[41] They have accepted routine vitamin K for their child, however, they are requesting the paediatrician to take blood for a full set of coagulation studies on their child, and to give their child an additional intramuscular dose of vitamin K at 4 weeks of age, in order to reduce even further the risk of this complication.[42] Should the paediatrician provide the treatment?

In Provision, the paediatrician may believe that what the parents are requesting is not in the child's best interests. There is no reason to think that the child is at increased risk of this rare condition (notwithstanding the parents' concern). The downsides of what the parents are requesting are relatively small (an extra blood test and an extra injection), but the benefits of doing so seem negligible.[43] However, even if what the parents are requesting does not constitute a significant harm, it does not seem that the paediatrician should be obliged to do what the parents are asking. The paediatrician may be mindful that it would constitute a waste of limited medical resources to be performing a blood test and providing a medication without any reason to think that these would be of benefit. In this case, the resource implications of providing the treatment are small – the cost of these interventions is pretty minimal. However, in other cases (for example in intensive care cases), provision of treatments that have no evidence of benefit would clearly have significant resource implications. Furthermore, allowing, as a general principle, parents to demand medical treatments that have no scientific evidence to support benefit, would have enormous implications for a publicly-funded healthcare system.

We might consider, though, a variation of the case where the situation is different.

> **Preventing Provision**. A newborn infant is born following a normal delivery and an uncomplicated pregnancy. The child's parents wish the child to have an additional blood test and injection because of their fear of haemorrhagic disease of the newborn. The paediatrician refuses to offer this intervention, and parents leave the consultation dissatisfied. Subsequently, the paediatrician learns that the child's GP has agreed. Should the paediatrician seek court intervention to prevent the GP from performing the blood test/giving the additional injection?

41 V.H. Flood, et al. Hemorrhagic disease of the newborn despite vitamin K prophylaxis at birth. *Pediatric blood & cancer* 2008; 50: 1075–1077. PubMed PMID: 17957759.

42 M.S. Elalfy, et al. Intracranial haemorrhage is linked to late onset vitamin K deficiency in infants aged 2–24 weeks. *Acta Paediatr* 2014; 103: e273–276. PubMed PMID: 24528309.

43 One estimate puts the risk of vitamin K deficiency bleeding in infants who have received the standard prophylaxis as <1 in a million A.W. McNinch & J.H. Tripp. Haemorrhagic disease of the newborn in the British Isles: two year prospective study. *BMJ (Clinical research ed)* 1991; 303: 1105–1109..

In Preventing Provision, the paediatrician would not be refusing to provide treatment, but would be seeking to limit the parents' freedom to access treatment (as well as impacting on the freedom of the other health care provider).

Perhaps the GP is aware of evidence that the paediatrician has not considered? The paediatrician may have reason to reconsider her views about the child's best interests. However, even if the paediatrician is right that these interventions are not in the child's interests, it seems a further step is required to justify intervening. The harm threshold (in a more restricted form) should apply to cases like Preventing Provision.

Since it applies only to cases where additional conditions apply, I have denoted it the Conditional Harm Threshold.

> *Conditional Harm Threshold test*: A decision to prevent parents from accessing a particular treatment option should be based on an assessment of whether the chosen course of action would be harmful. Where the following conditions apply, parents' wishes should ordinarily be respected, unless what they are requesting will cause the child to suffer or is likely to cause the child to suffer significant harm.

i. The parents are requesting provision or continuation of a medical treatment for the child
ii. the child's health professionals do not support that treatment
iii. other suitably qualified health professionals are prepared to provide that treatment and any ongoing care necessary (including if necessary, transfer of the child to another health facility)[44]

The Conditional Harm Threshold restricts parents' seeking of medical treatment in cases like Preventing Provision. It is similar to the test that the Gard parents' lawyers had argued should apply in their case. It would not require health professionals to provide treatment that would be contrary to their professional judgement or would harm other patients. It would sanction courts overriding parents on the same basis as court intervention in other parental decisions.

5.3. Implications of the conditional harm threshold – prolonged unconsciousness

I have elsewhere (with Julian Savulescu) explored in detail when treatment requested by parents would or would not cross the harm threshold.[45] In particular, we defend the importance of reasonable disagreement in establishing the moral uncertainty that underpins parental discretion over treatment. If there is reasonable disagreement about whether treatment would be in a child's best interests, parents' views should be decisive. In that work, we set out some characteristics that would help identify whether disagreement is reasonable or unreasonable.

For the final part of this chapter, however, I wish to focus on a distinctive type of situation where disagreement may occur. If a child has a severe disorder of their brain such that they are unconscious and have no prospect of recovering consciousness, is it a significant harm to prolong their life?

In table 1, I refer to this situation as condition X: "Prolonged life-sustaining treatment – absent consciousness". This includes children in a persistent vegetative state, and closely related conditions (for example minimally

44 As noted at the start of this chapter, my focus here is largely on ethics rather than law. I set aside for those with legal expertise whether a conditional harm threshold would require a change to the Children Act. One possibility, is that no change would be required. Parents could request and arrange transfer of their child's care to another health professional. If a health care team wished to prevent this, they could seek a care order (using the Harm Threshold).

45 Wilkinson & Savulescu.

conscious state). It is important, because this state (or a variation of it) was potentially the situation of the children in all three of the recent UK disputed cases (Gard, Haastrup, Evans). It is also ethically contentious since it is difficult to evaluate the putative harm of treatment in condition X. In the table, I indicate that there are four possible views about such cases. Treatment might be regarded as offering an uncertain benefit (since it prolongs life in the absence of consciousness), as offering zero benefit (since the child has no experience and no conscious interests), as offering uncertain harm (since the child might experience pain or discomfort), or offering certain harm (since it extends the dying process, risks causing suffering, and does not benefit the child). There are two possible ways that the Conditional Harm Threshold might impact on future cases involving condition X.

5.3.1. No significant harm

One response to condition X is to suggest that treatment in such cases would offer uncertain benefit or harm. If the child truly is completely unconscious, the child would not suffer pain or discomfort, however, neither would they ever experience any conscious benefit from continuing to live. That might support a view that treatment would be neither beneficial, nor harmful. However, the neuroscientific literature from adults in persistent vegetative state points to the challenge in distinguishing between patients with completely absent consciousness and those with some minimal level of consciousness.[46] A child in a condition like Alfie Evans or Charlie Gard might experience intermittent pain or discomfort, might have some awareness of their parents' presence, or they might experience none at all.

Given such a state, it appears unclear whether it would be in the child's best interests to prolong their life. It would be permissible to withdraw life prolonging treatment and allow the child to die, and health professionals may also decline to provide treatment on the basis that they do not consider it to be in the child's best interests. However, if parents have identified alternative health professionals who are prepared to provide treatment, the conditional harm threshold would, on this view, allow parents to pursue that treatment.

On this understanding of condition X, the Best Interests test and the Conditional Harm Threshold Test would diverge. Treatment would be withdrawn if courts assess best interests, but may be permitted if they apply a conditional harm threshold and the family are able to find another health provider willing to continue treatment.

5.3.2. Significant harm

However, it is not inevitable that the Conditional Harm Threshold would permit treatment in condition X. As noted above, in the Court of Appeal, Justice MacFarlane indicated his belief that the initial judge (Justice Francis) would have regarded continued treatment (and experimental treatment) for Charlie Gard as being harmful.

There are two different ways of substantiating such a claim. The first would be to focus on the possibility of significant physical discomfort without corresponding benefit. That claim would depend on the child's specific circumstances. Intensive care and the forms of life-prolonging treatment that are often under dispute cause children to experience pain. For example, children who are dependent on mechanical ventilation require regular suctioning of tracheal secretions (which is potentially painful) and experience intermittent sensations of dyspnoea or choking. There are ways of alleviating those symptoms for patients in the short term, but it is more challenging to do this over a prolonged period, and it is likely that even with the best symptom management that children with condition X (if they are capable of perceiving anything at all) would experience some pain and discomfort. If there is a low magnitude of benefit from prolonging life, or there is a low probability of benefit, most children kept alive in such circumstances may be harmed. On that basis, I argued, at the time of the Gard

46 M.M. Monti, et al. Willful modulation of brain activity in disorders of consciousness. *N Engl J Med* 2010; 362: 579–589 PubMed PMID: 20130250.; R.M. Gibson, et al. Somatosensory attention identifies both overt and covert awareness in disorders of consciousness. *Annals of neurology* 2016; 80: 412–423 PubMed PMID: 27422169.. To my knowledge, there have been no studies investigating covert consciousness in children with brain disorders

case, (and based on evidence as presented to the court) that it would be harmful to pursue experimental treatment.[47] This argument would be strongest in cases where there is evidence that a child is experiencing pain/discomfort, or there is good reason to suspect that they are. (Children with severe brain injury, or who are paralysed, may be unable to manifest usual signs of distress).

The second justification for claiming that it would be a significant harm to keep a child alive with condition X is that this would compromise the child's wellbeing even if it did not lead to physical suffering. For example, it may be regarded as bad to prolong a child's dying phase if there is no realistic prospect of them recovering, or of gaining benefit from continued life. Alternatively, reference might be made to the child's dignity. The claim would be that it is undignified to prolong life artificially (for example with mechanical ventilation or other invasive medical treatment) if the child has no capacity for conscious awareness.

There is some reference to non-subjective harms of this sort in the Gard and Evans cases. Justice Hayden rejected an argument that Alfie Evan's life lacked dignity. Nevertheless, he held that continuing treatment might compromise that value:

> "He requires peace, quiet and privacy in order that he may conclude his life, as he has lived it, with dignity…The continued provision of ventilation, in circumstances which I am persuaded is futile, now compromises Alfie's future dignity" para 62, 66[48]

In an earlier case of a child with severe hypoxic brain injury (as well as underlying physical disability), Justice Macdonald made it clear how he understood the concept of dignity:

> "when it is recognised that life is ending, for many the concept of dignity becomes encapsulated by the idea of a 'peaceful' or 'good' death." Kings College and MH [2015] EWHC 1920 (Fam)

The courts may, therefore, regard it as a significant harm to prolong life in future cases of disputed treatment in condition X.[49] Such a determination would be consistent with the approach that UK courts have taken to end of life decisions in children with severe brain injury. I have elsewhere noted, however, that this line of argument is also challenging to defend because of the contested and conflicting accounts of what 'dignity' means at the end of life.[50]

6. Conclusions

The ethical and legal challenges raised by cases like that of Charlie Gard or Alfie Evans are vexing and profound. They relate to the role of parents in decision-making for a child, the role of the state in overruling parents, and the role of courts in arbitrating disputes. There are conflicting interests at stake – the interests of parents, the interests of the child, the interests of wide society. And there are, inevitably, conflicting views about what would be best for the child. Any response to those challenges involves compromises, and will mean that some views are respected while others cannot be.

47 D. Wilkinson. Beyond resources: denying parental requests for futile treatment. *Lancet* 2017; 389: 1866–1867. PubMed PMID: 28478971.

48 Alder Hey Children's NHS Foundation Trust v Evans & Anor [2018] EWHC 308 (Fam).

49 In the seminal case relating to treatment of an adult with absent consciousness – the case of Tony Bland, it was argued that it was a damage to his dignity to prolong his life by artificial means. Airedale NHS Trust v Bland [1993] AC 789.

50 Wilkinson & Savulescu. p34–35

In this chapter, I have argued that as a general ethical principle, parents' views about medical decisions for their children should be respected, unless their choices would risk significant harm for their child. That does not dismiss the importance of 'best interests'. Health professionals and parents should continue to seek treatment that would be in a child's best interests. There is no obligation for health professionals to provide treatment that they reasonably judge to be not in the child's best interests, or an unjust use of limited medical resources. The best interests test may be applied by courts in cases where there is conflict between those with parental responsibility, or health professionals are uncertain which course to pursue. Where treatment is judged not to be in a child's best interests, health professionals may be given permission by the court to withdraw or withhold it.

I have articulated a form of compromise, a restricted role for the harm threshold in disputes about medical treatment: this should be applied in situations where health professionals or others wish to prevent parents from pursing treatment that other professionals are prepared to provide. In such cases, the harm threshold is the correct normative threshold for over-ruling parents. However, the implications of such a test will depend on how courts understand harm. In some of the most difficult cases, those relating to children with severe disorders of consciousness, that will depend on an evaluation of the value of dying well, and the disvalue of possible suffering.