

# Children, futility and parental disagreement: The importance of ethical reasoning for clinicians in the paediatric intensive care setting

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[journals.sagepub.com/home/cet](https://journals.sagepub.com/home/cet)**Chiara Baiocchi<sup>1</sup>**  and **Edmund Horowicz<sup>2</sup>**

## Abstract

The provision of intensive care enables the lives of neonates, infants and children to be sustained or extended in circumstances previously regarded as impossible. However, as well as benefits, such care may confer burdens that resultingly frame continuation of certain interventions as futile, conferring more harm than or any, benefit. Subsequently, clinicians and families in the paediatric intensive care unit are often faced with decisions to withdraw, withhold or limit intensive care in order to act in the best interests of the child. An integral consideration in respect of these decisions is that futility is a concept that has to be contextualised for all those involved. Recent high-profile legal cases highlight the professional, clinical, legal and social conflicts that can arise when parents and clinicians have different interpretations of futility. In acknowledging the complexity of these conflicts for clinicians, this paper aims to support a better understanding of futility as an integral concept in such difficult and emotive decisions within professional practice. We utilise the concept of futility to frame how these decisions to withdraw or withhold certain invasive life-prolonging interventions are ethically and legally justifiable, even when they disagree or conflict with parental views. To support clinicians in understanding these decisions, we in part use the familiar bioethical framework of Principlism developed by Beauchamp and Childress. We suggest that understanding legal and ethical analysis of futility ultimately will help clinicians in approaching and reflecting on such decision-making.

## Keywords

Withdrawal of care, medical futility, paediatric intensive care, critical care, parental disagreement, decision-making

## Introduction

In recent years, the high-profile cases of Charlie Gard, Isaiah Haastrup and Alfie Evans have highlighted the complexity of determining the best interests of children with life-limiting conditions, where continuation or provision of medical interventions are considered as futile by clinicians.<sup>1</sup> Each infant had sustained devastating, unrecoverable brain damage and the English courts were asked to determine whether the continuation of life-prolonging medical interventions was in the best interests of the child where there were no chances of any meaningful recovery. Whilst these cases are complex and deeply tragic, they are not extraordinary by themselves in the Paediatric Intensive Care Unit (PICU) environment. What sets them apart, is the international widespread media attention as to whether continuation or even provision of life-prolonging interventions are futile and therefore not in the best interests

of the child. Moreover, these cases demonstrate the fragility of the relationships between clinicians, organisations and parents, which can have a profound impact on both clinical practice and the way in which the public perceives the care of these children.<sup>2–4</sup>

In the PICU, where the majority of patients are not competent to voice their decisions because they are often impaired through their condition or are simply too young

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to take part, parents work together with healthcare professionals to make appropriate decisions that have to promote the child's best interests above all.<sup>5</sup> Where there is disagreement, healthcare professionals must act in accordance with the legal framework, professional codes of conduct and clinical guidelines to care for and safeguard the interests of the child.<sup>6,7</sup> Although the obligation to work in partnership with carers and families is an integral feature of paediatric intensive care, because of the parents' role recognition and the promotion of family-centred care,<sup>8</sup> the above-mentioned recent cases demonstrate that the professional and legal position is that the best interests of the child are always paramount. Yet, a significant concern is that as a result of these high-profile cases and the public disagreements they involved, health professionals may develop reluctance in confronting the reality of futility, when continued intervention may support the wishes of parents.<sup>9,10</sup>

In this paper, we seek to offer a pragmatic and accessible approach to understanding how futility is professionally, ethically and legally approached and understood when there are disagreements as to what is in the best interests of the child with a life-limiting condition. It is not our intention to address specific individual issues within the aforementioned cases, but rather explain that these cases have challenged paediatric intensive care practice and therefore that they highlight the importance of moral and ethical reasoning in contextualising futility as an integral part of this complex area of clinical care.

In the first instance, we attempt to rationalise the concept of medical futility, before going on to consider futility within the English legal framework, highlighting that the courts will always have to consider futility on a case-by-case basis. In acknowledging that these legal cases are inherently addressing ethical issues of futility within PICU practice, we utilise the well-established Principlism lens; encompassing autonomy, beneficence, non-maleficence, and justice, developed as a framework for bioethical reasoning by Beauchamp and Childress.<sup>11</sup> We use Principlism in recognition of the universal application of this pragmatic and applied framework to better promote the importance of clinical bioethical reasoning in these cases. The ultimate aim of this paper is to promote a better practical understanding of futility for clinicians, through ethico-legal analysis and their application to withdrawal or non-provision of treatments and interventions for children with life-limiting conditions.

### *Defining medical futility*

Although lawyers, judges, ethicists and clinicians have contributed to the analysis of what in fact futility means, it remains that our understanding of futility may vary depending on culture and context but more specifically individual interests within such decisions, whether they be

professional or relational.<sup>12</sup> The challenges in defining the concept of futility within health are explained by Morata<sup>13</sup> as being that whilst futility can be seen as determining which acts are meaningful and which are not, futility is subjective and influenced by values, beliefs, experience and perceptions. A starting point for understanding futility within the PICU context is that it is pragmatic, as Lippe<sup>14</sup> explains, 'drawing the line between hope and false expectations'. Futility could therefore here be understood as being focused on the treatment or intervention goal.<sup>15</sup>

Whilst advances in medical research and technology have given paediatric intensivists the potential to prolong children's lives, for some children it is important to consider futility as being whether life-prolonging medical interventions are in fact non-beneficial and thus where it is then appropriate to discuss and consider the end of life decision-making.<sup>16</sup> Therefore, even where disagreements over the provision of life-sustaining treatment arise, the focus in decision-making must be whether such interventions are futile and if they are then they cannot be in the best interests of the child.<sup>17</sup> Determining the futility of interventions in the PICU is, as Wilkinson<sup>18</sup> explains, complex and in the first instance can be informed by drawing from established clinical guidelines in respect of withholding or withdrawing clinical treatment.

In 2015, the Royal College of Paediatrics and Child Health (RCPCH)<sup>19</sup> revised the already published framework for practice, indicating where withholding or withdrawal of treatment can be considered ethically justifiable. Larcher and Hird<sup>20</sup> identified three circumstances that apply to paediatric care: life limited in quantity, in quality and informed competent refusal of treatment. When the decision to withdraw or not provide such treatments is made, this will almost always be based on its futility rather than the intention that the withdrawal will bring death to the child.<sup>19</sup>

In providing care for children in the PICU, clinicians and parents often have to consider a range of interventions, however, in the case of children with poor prognosis, these have to be balanced against the chances of any meaningful recovery and conversely any continued experienced pain or suffering.<sup>18</sup> Some treatment options can more easily be considered too burdensome or inappropriate because they are a limited resource, like organ transplantation and extra-corporeal membrane oxygenation (ECMO).<sup>21</sup> Yet less resource-restricted treatments and interventions, like active cardiopulmonary resuscitation, prolonged parenteral nutrition and prolonged artificial ventilation, have been the focus of futility discussions in these recent cases because they are for many patients, interventions that maintain life in the PICU.<sup>22</sup> Decisions not to provide these interventions on the basis of futility are therefore extremely emotive, complex and therefore require a reasoned and transparent decision-making process.<sup>23</sup>

### The decision-making process

In approaching decision-making in the PICU, clinicians are required to explain the intended benefits of any considered treatment or intervention, contextualised by clinical guidelines and the limits of clinical practice.<sup>24</sup> Before giving an evaluation of all the possible therapeutic intervention options, the clinical team has to start from the position of an understandable diagnosis and awareness of the probable prognosis.<sup>25</sup> According to Larcher and Hird,<sup>20</sup> when the decision to withhold or withdraw treatment is considered to be in the best interests of the child, the medical and nursing professionals are expected to have transparent and meaningful discussions with parents. These discussions may also be held in conjunction with and form part of the role of clinical ethics advisory groups, highlighting the importance of clinical ethicists and decision-making support for both clinicians and families.<sup>26</sup>

The shared decision-making model in the PICU highlights a shift away from paternalistic approaches and the significance of providing family-centred care as an ethical and professional obligation.<sup>27</sup> Although family-centred care is widely adopted in the majority of clinical settings, there can be concerns as to whether the needs of the child and not of the family are the primary focus of concern for parents.<sup>22</sup> However, we must accept just how extremely difficult these situations might be for parents and families when approaching such challenging decisions that will result in a shift to palliative care.

One way to understand the needs of parents is to consider how they may approach futility. According to Barnes *et al.*,<sup>28</sup> despite trust and comprehension between parents and the health team often being well established, the concept of futility can be misinterpreted by the different parties in shared decision-making.<sup>22</sup> In fact, as highlighted by the mainstream and social media, the concept of letting die rather than killing someone, is not always comprehended by parents and consequently, the public, who have more than once showed their hostility against healthcare professionals.<sup>29</sup> Under these arduous circumstances, it is essential that healthcare professionals understand the legal framework behind how decisions to withdraw or withhold treatment in cases of parental disagreement are considered.

### The legal framework

In the first instance, it is fundamental to consider the rights afforded to children through international law. Children's rights are provided foremost by the UN Convention on the Rights of the Child (UNCRC), ratified by the United Kingdom in 1991.<sup>30</sup> Of significance in decisions of futility is Article 3, which states that all decisions concerning a child must be made in their best interests. Hammond<sup>31</sup> argues that Article 3 is pivotal for acknowledging the needs of an individual child because best interests can be

conflated with the interests of others, including society. Despite the 'best interests principle' being used universally and playing a decisive role in children's decision-making, the UNCRC, does not give a clear, or even conceptual, the definition of what is meant by best interests, instead, this has been left to states to determine.<sup>32</sup> Therefore, even when we acknowledge the UNCRC as the leading authority on international children's rights, they cannot be considered independently as a legal authority, as both international and individual State jurisdictional legal frameworks have to be interconnected.<sup>33</sup>

In England and Wales, the Children Act 1989<sup>34</sup> is the primary piece of legislation that encompasses the principles set out in the UNCRC. Francis J explained in *Great Ormond Street Hospital NHS Trust v Yates and Gard*<sup>35</sup>:

Our law in relation to children in circumstances such as this is governed by section 1 of the Children Act 1989 which contains a proposition which I suggest would be hard to criticise. Section 1 provides as follows: when a court determines any question with respect to the upbringing of a child the child's welfare shall be the court's paramount consideration.

Specifically, section 1(3) of the Act<sup>34</sup> sets out the considerations that the Court will have in determining the welfare of the child:

- a) the ascertainable wishes and feelings of the child concerned (considered in the light of his age and understanding);
- b) his physical, emotional and educational needs;
- c) the likely effect on him of any change in his circumstances;
- d) his age, sex, background and any characteristics of his which the court considers relevant;
- e) any harm which he has suffered or is at risk of suffering;
- f) how capable each of his parents, and any other person in relation to whom the court considers the question to be relevant, is of meeting his needs;
- g) the range of powers available to the court under this Act in the proceedings in question.

Whilst the considerations set out in the Children Act 1989<sup>34</sup> offer a broad approach to what must be considered to determine a child's welfare, there are no definitive guiding principles as to how these should be navigated in complex healthcare decisions in order to establish what is in the best interests of the child. Hedley J in *Portsmouth Hospitals NHS Trust v Wyatt*<sup>36</sup> explained the reason for this as being, 'The infinite variety of the human condition never ceases to surprise, and it is that fact that defeats any attempt to be more precise in a definition of best interests'. However, in *Alder Hey Children's NHS Foundation Trust v Evans*<sup>37</sup> Hayden J utilised the Supreme Court's approach to

determining best interests, although in the context of the Mental Capacity Act 2005,<sup>38</sup> set out by Lady Hale in the Supreme Court case of *Aintree University Hospital NHS Foundation Trust v James*.<sup>39</sup> Lady Hale<sup>39</sup> explained that ‘the focus is on whether it is in the patient’s best interests to give the treatment rather than whether it is in his best interests to withhold or withdraw it’. Later Lady Hale<sup>39</sup> went on to explain that:

the most that can be said, therefore, is that in considering the best interests of this particular patient at this particular time, decision-makers must look at his welfare in the widest sense, not just medical but social and psychological; they must consider the nature of the medical treatment in question, what it involves and its prospects of success; they must consider what the outcome of that treatment for the patient is likely to be; they must try and put themselves in the place of the individual patient and ask what his attitude towards the treatment is or would be likely to be; and they must consult others who are looking after him or are interested in his welfare, in particular for their view of what his attitude would be.

Whilst the Supreme Court’s approach to determining the best interests for older individuals is important to consider, we must acknowledge that in determining the best interests of children there are often specific difficulties, notably what the role of parents should be in such decisions. This question was indeed addressed by Francis J in *Great Ormond Street Hospital NHS Trust v Yates and Gard*<sup>35</sup>:

Some people may ask why the court has any function in this process, why can the parents not just make the decision for themselves? The answer is that, although the parents have parental responsibility, overriding control is by law vested in the court exercising its independent and objective judgment in the child’s best interests.

Perhaps, the most straightforward way in which to understand this answer is to acknowledge that in such decisions the best interests of the child may be difficult for parents to determine and thus the courts have a duty to ensure that the child’s best interests are considered as paramount.

The courts though are not themselves removed from the same difficulties in determining a child’s best interests. In *Portsmouth City Council v King*,<sup>40</sup> Baker J recognised such challenges in determining a child’s best interests:

Whilst the approach to consider the welfare of a person in the ‘wider sense’ is easier in an adult with more lived experience, it is more difficult for infants but nonetheless must ensure thorough consideration of the views of the parents. It is a fundamental principle of family law in this jurisdiction that responsibility for making decisions about a child rest with his parents. In most cases, the parents

are the best people to make decisions about a child and the State – whether it be the court, or any other public authority – has no business interfering with the exercise of parental responsibility unless the child is suffering or is likely to suffer significant harm as a result of the care given to the child not being what it would be reasonable to expect a parent to give.

The consideration of significant harm is further apparent in the recent cases involving parental disagreement, whereby the courts seemingly focus on the medical evidence and any harm that the child has suffered or is at risk of suffering.

The concept of harm, therefore, has to be carefully examined in scenarios of parental disagreement, as despite it being referred to in the Children Act 1989,<sup>34</sup> there is no measurable threshold of what is harmful, it is only defined as ‘a compromised health state (mental or physical) or the altered emotional, physical and cognitive development’.<sup>41</sup> The Children Act 1989<sup>34</sup> does however use the threshold of ‘significant harm’ to seemingly justify state intervention but this is without a clear definition. Defining the threshold of significant harm is further complicated when we consider the current shared decision-making framework for children and the role of parents in making decisions when the child is unable to participate given that parents may not or are not always able to make the right choice in the best interests of the child.<sup>1</sup> In opposition to this position was a proposal for legal reform, named Charlie’s Law, put forward to the House of Commons by the Labour politician Bambos Charalambous in 2019.<sup>42</sup> The central idea of the proposed law was to introduce a new harm threshold legal test preventing cases from ending up in the courts. This significant amendment would only allow the courts to intervene with decisions that cross a certain and determinable threshold level of harm.

Proponents of a harm-based approach to justifying court intervention argue that harm is defined in the Children Act 1989 and thus avoids the broad and less defined best interests test that may in fact reflect the interests of parents.<sup>43</sup> Therefore, according to Wilkinson,<sup>44</sup> there are good reasons to focus the ethical attention on harm. We will go on to analyse the concept of harm later but at present, the UK legal approach to parental and clinician disagreements is through determining the best interests of a child, as opposed to attempting to define a harm threshold in each case. McFarland J in *Gard* explained the reason for this as being that: ‘Best interests is the established yardstick which applies to all cases and there is no justification for this court now to endorse the creation of a sub-set of cases based upon establishing significant harm’. Furthermore, in *Evans*, Hayden J reaffirmed that in such decisions: ‘the sole principle is that the best interests of the child must prevail and that must apply even to cases

where parents, for the best of motives, hold on to some alternative view’.

In understanding the challenges for the courts in approaching how to determine the best interests of children in these cases where parents and clinicians disagree, we should acknowledge that there is a tension between futility and harm. In one sense futility can be medically determined but it is important to understand that futility can be interpreted by parents and society in other ways. Moreover, the courts only consider individual cases and futility for that individual child, which Burns *et al.*<sup>45</sup> highlight as in some ways further confounding clinical practise. By acknowledging that the courts and professional guidelines cannot offer a universal approach to determining futility, we now, therefore, turn to addressing the crux of our paper: the role and value of ethical reasoning in navigating and determining the best interests of the child where there is parental disagreement with clinicians. In using the four principles, we enable the ethical issues associated with futility to be clarified, analysed and applied in the context of the courts, in order to provide clinicians with a rationalistic but familiar way to understand these ethically contentious aspects of PICU care.<sup>46</sup>

### *Application of the four principles*

*Respect for autonomy.* The concept of autonomy, in bioethics, should be understood as self-governance, through the right to make individual free choices.<sup>47</sup> To be autonomous, an individual has to be in a condition of liberty (freedom from dominating influences) and agency (have the potential for actions).<sup>48,49</sup> Children present various degrees of independence and competence in respect of health decision-making, dependent on intellectual, psychological and emotional maturity.<sup>50</sup> However, for children unable to participate in decision-making, a substituted judgement is required.<sup>51,52</sup> The substituted person, a parent, legal guardian or clinician should, as we have highlighted, make healthcare decisions in the child’s best interests to promote their welfare.<sup>51,53</sup> There are two pertinent issues though that arise in substituted decision-making; the conflation between parental views and parental autonomy and how the child’s future autonomy is considered.

There is a common understanding that parents ‘know’ their children best but there is undoubtedly a combination of protective factors that make it extremely difficult for parents to objectively approach the child’s best interests in such difficult and emotional circumstances, even when the futility of treatment or interventions are explained by clinicians.<sup>52</sup> Within the highlighted legal cases earlier, part of the basis of parental refusal to withdraw intensive care treatment was that it was not the right choice for their child as death would follow and that continued or further interventions and treatments should be provided to maintain life.<sup>52</sup> Although democracy permits different

values and beliefs of parents that may influence their position, clinicians must be committed to focussing on the needs of the child with life-limiting disease.<sup>54</sup> By acknowledging suffering and futility in the context of autonomy, there is significance in recognising the limitations of the relational autonomy of parents.

While the role of the child in decision-making within the PICU setting is often very limited or non-existent, decision-making should not preclude consideration of the child’s future autonomy. We should accept that respect for future autonomy is a significant part of the moral and indeed legal notion of parental responsibility. Children do not belong to their parents, instead, they are part of a continued progressive transition to adulthood and parents have a responsibility to respect their child’s future capability to make their own choices in the healthcare settings.<sup>55</sup> By recognising that children in the PICU still have future autonomy, clinicians should perceive them as persons whose potential views matter, enjoying the same status as other rational agents.<sup>44</sup> A significant question therefore emerges, how can we determine the potential views of children in the PICU with life-limiting conditions where continued intervention is considered as being futile? There is no singular answer but consideration of how a child may view their continued suffering, pain or reduced quality of life are at the very forefront of approaching an answer for each child. Subsequently, consideration of the principles of beneficence and non-maleficence aids in identifying the best interests of the child with a life-limiting condition in the PICU setting.

### *Beneficence*

In healthcare, the principle of beneficence is the moral commitment and positive obligation of clinicians to benefit patients.<sup>56</sup> Beneficence in the context of decision-making is supported through healthcare policy and practise, to ensure that individuals are faced with reasoned choices balancing intended benefits and risks.<sup>11</sup> This fundamental principle is simplified in the paediatric context by assuming that every decision should follow the paramount positive obligation of acting in the child’s best interests.<sup>57–60</sup>

Kopelman<sup>61</sup> refers to best interests as being a challenging umbrella term because it conceptually encapsulates differences in societal, parental, clinical, and legal interpretations. Therefore, in the context of substituted decision-making, the morally expected standard of decision-making without the express wishes of the child must weigh all the relevant factors to decide upon what is in the child’s best interest, all things considered.<sup>51</sup> Given that futility of interventions for children with life-limiting conditions has to be contextualised by the intended benefit of the intervention being considered, we should ethically frame them.

One way of ethically framing interventions is to differentiate ordinary from extraordinary care. Kelly<sup>62</sup> emphasises

that ordinary interventions are medicines or treatments made in an attempt to reach some important health objectives, based upon diagnosis and prognosis. Whilst extraordinary interventions are treatments and medicines only obtained with excessive costs, risks and pain which may or may not offer a reasonable chance of benefit.<sup>62</sup> The provision of ordinary care and interventions is the mainstay responsibility for healthcare professionals and organisations; whereas extraordinary care and interventions may be delivered by healthcare professionals and organisations but may not always be considered morally right.<sup>63</sup> We should however highlight that the way in which ordinary and extraordinary interventions may be considered is influenced by advances in medical science and clinical care. Children with life-limiting conditions may now be provided with what might once have been considered extraordinary interventions that are now regarded as being ordinary, even delivered in their own homes. Yet even if we still regarded extraordinary interventions as being such, justification for provision must be that they are in the best interests of the child.<sup>64</sup>

Bowden<sup>65</sup> explains how we differentiate between ordinary and extraordinary care and the best interest of a person is through using the example of a ventilator. The use of a ventilator on postoperative patients who may need respiratory support until they recover from the effects of anaesthesia would not be considered extraordinary care, but a ventilator used for a patient with such severe brainstem infarction that they are unable to breath unaided would certainly be considered as an example of extraordinary care that raises ethical issues. Such differentiation between ordinary and extraordinary care in the context of beneficence has been utilised by the courts. Hayden J in *Evans v Alder Hey NHS Trust*<sup>37</sup>: 'Alongside all this, it must be remembered that Alfie cannot sustain life on his own. It is the ventilator that has been keeping him alive for many months, he is unable to sustain his own respiratory effort'. It, therefore, becomes obvious that categorical distinctions as to what we deem beneficial treatment (and thus being a beneficent consideration) must be evaluated on a case-by-case basis but understanding the notion of extraordinary interventions is helpful in our ethical reasoning.

A notable challenge to the way in which extraordinary treatment and care is considered through beneficence comes from those who argue that the sanctity of life is the overriding issue.<sup>66</sup> These proponents believe that a child's right to life is more important than any judgement as to the benefits of any interventions made by someone else and therefore nothing should be considered extraordinary if death is the alternative.<sup>67</sup> However, whilst the sanctity of life arguments represents an important value that is placed on the role of medicine in preserving life, this cannot prevail against scientific assessment as to the futility of treatments and interventions in an individual case. As

Hayden J<sup>37</sup> went on to explain in respect of Alfie Evans, 'the continued provision of ventilation, in circumstances which I am persuaded is futile, now compromises Alfie's future dignity and fails to respect his autonomy. I am satisfied that continued ventilatory support is no longer in Alfie's best interest'. Professionals, therefore, have a duty to only offer treatment that is appropriate to the diagnosis and prognosis based on all available evidence, whereas the provision of extraordinary treatment outside of this based on parental demand should not be considered compatible with the principle of beneficence. In fact, such interventions should be framed as being futile and harmful.

### Non-maleficence

The principle of non-maleficence is the ethical obligation to not cause harm to patients or to prevent harm by inaction, avoiding unnecessary harm.<sup>68</sup> The potential for clinicians to cause harm through medical interventions in paediatric care is widely appreciated in the context of patient safety,<sup>69</sup> however clinicians in the PICU are also inherently concerned with whether an intervention itself confers more harm than, or even if, any benefit at all for the child and is therefore futile.<sup>70</sup> Deciding upon the futility of continued interventions for a child in the PICU may clinically be agreed but may not be shared by parents, for whom the focus is more complex than medical facts and opinions.<sup>71</sup>

Although clinicians may demonstrate the futility of treatment through evidence and clinical opinion, the way in which complex and invasive care is provided in the PICU may give parents the view of their child being serene and peaceful, making it difficult to demonstrate how ongoing consideration or provision of invasive care constitutes harm.<sup>72</sup> Therefore, the principle of non-maleficence may not be universally applied in cases of the futility of treatment and subsequently has to be subjectively defined.<sup>73</sup>

We should then return to analyse in more depth how harm can be interpreted. Harm could be regarded as an appropriate and logical threshold for state intervention when parental decision-making places the child at risk of suffering harm.<sup>74,75</sup> However, despite harm as a threshold being seemingly well adopted by clinicians and the courts, Birchley<sup>76</sup> highlights that the harm threshold is less clear in complex ethical dilemmas. In fact, Birchley<sup>76</sup> argues that it is questionable to focus on harm as it may not capture all the aspects of a complex and intricate moral dilemma, particularly where there is clinical uncertainty. A further criticism is that the harm seemingly can present a narrow view of a child's best interests, which suffers from inadequate attention to normative grounding.<sup>59</sup> We could then argue that a focus on harm in complex and uncertain clinical circumstances should be better understood as having potentially limited value on its own in establishing a child's best interests. It is not that harm should not be considered but in order to establish futility,

and thus that continued provision of interventions is not in the child's best interests, the way in which harm is interpreted by external influences becomes an important consideration.

Stewart and De Marco<sup>77</sup> promote a 'microeconomic' model that considers the interests of external influences and their compatibility in ensuring that the best interests of the child are met. Although the strict application of Stewart and De Marco's approach would also consider the significance of causing the least harm to all parties, we suggest that this approach better identifies how the interests of others can be conflated with the best interests of the child. In fact, this microeconomic approach resonates with the dilemma clinicians and the courts face in PICU disagreements with parents as to the futility of interventions. Subsequently, consideration of external influences, such as parental views, clinical guidelines and professional codes of conduct, may help to better rationalise why an intervention is not in the best interests of a child and conversely why external influences may not always promote these. Importantly, such an approach to harm allows for a broader understanding of different views, in order to ethically reason with them and to better establish what the best interests of the child are.

### Justice

The principle of justice refers to different types of obligations to equality and fairness, commonly grouped in the three big areas of right-based justice, legal justice and distributive justice.<sup>57</sup> The dramatic increase in the cost of healthcare has resulted in inequalities in the access to healthcare and, in the context of the futility of care, it must be explored if the resources are distributed fairly (distributive justice).<sup>78</sup> We do not dispute the position of clinical and professional guidelines, in that a decision to withdraw or withhold a treatment should be based on analysis of the intended benefits versus risks and burdens, however in a public health system, financial considerations cannot be ignored.<sup>20</sup> Allocating costly financial resources to the provision of futile care for children becomes ethically problematic in itself. These are problems of contemporary health policy and are extremely complex, but it is important to set priorities and to allocate resources fairly and after considering the futility of treatment it is legitimate to argue that this would be unjust on the basis of parental demand.<sup>24</sup>

The issue of deficient resources may not apply to the paediatric cases where parents raise independent funds to travel abroad for treatment, however, the same concern is legitimate considering the use of public facilities until a solution is reached as this may take several months.<sup>79</sup> Moreover, clinicians working in the UK are subject to professional standards and legal frameworks that may differ from other jurisdictions. Perhaps consideration of the differing jurisdictional professional and legal positions was best

demonstrated in the arguments put forward in the case of Alfie Evans, where it was put to the Court that care could and would be provided in another country. As Hayden J<sup>37</sup> held, the decision to allow the transfer of care had to be made within the UK legal framework, which found that this was not in Alfie's best interests.

Finally, publicly funded health systems should provide effective treatments that should respect and serve patients and families wishes as long as these wishes do not cause harm to others. The current Covid-19 pandemic resulted in a huge need of specialised high-resource clinical settings with highly trained clinicians and has demonstrated the difficulty in allocating the resources fairly.<sup>80</sup> In fact, despite the need to adhere to the ethical principles of beneficence and non-maleficence, clinicians have had to prioritise some patients over others to maximise the benefits of the treatment and to reduce mortality due to the saturation effect.<sup>81</sup> The fair distribution of critical care resources has as yet not been the focus for the courts and there is no legal way for courts to establish the limitations of public resources.<sup>70</sup> However, we argue that the phenomenon of prolonged intensive care treatment, in cases where there is no chance of survival, can represent an unfair allocation of resources, potentially resulting in inequalities in the access to healthcare. The reduction of inequalities among patients is an essential principle for the fulfilment of the universal right to health and must be taken into consideration.<sup>73</sup> Futility should therefore be considered in a broader sense. Whilst the focus of whether to continue with or provide treatment or interventions must be made on an individual basis, with the best interests of the child being paramount, there is value in appreciating that when this is decided upon as being futile then there are further obligations for clinicians to consider.

### Conclusion

The decision to withdraw, withhold or limit intensive care treatment for children raises profound clinical, ethical, and legal questions as to how to determine what course of action is in the best interests of children. Such decisions are made using a shared decision-making approach that involves clinicians, parents, carers, and families to ensure that the child's interests are paramount. However, where parental disagreement arises, recent high-profile legal cases highlight the very public challenges faced by clinicians in the PICU setting. One concern is that clinicians may develop reluctance in confronting the reality of futility, when continued intervention may support the wishes of parents. To support clinicians, we hope to have offered an accessible analysis of the concept of futility through ethico-legal analysis and specifically using the four principles approach, with the aim of promoting an understanding of ethical reasoning in these complex and challenging decisions. Furthermore, by drawing on judgements from these

high-profile cases, we demonstrate a practical and pragmatic judicial application of futility. It is fundamental to responsibly and empathetically approach these decisions through a shared decision-making approach, but we must accept that there are times when the views of clinicians and parents differ. Futility, therefore, becomes a central focus of determining the best interests of a child in the paediatric intensive care. Yet, whilst futility is conceptually complex, using a widely understood framework to develop ethical analysis in the context of pragmatic considerations, at the very least offers greater clarity to articulate, communicate and share clinical ethical reasoning in clinical practice.

### Ethical statement

The authors consciously assure that for the manuscript Children, Futility and Parental Disagreement: The Importance of Ethical Reasoning for Clinicians in the Paediatric Intensive Care Setting the following is fulfilled:

1. This material is the authors' own original work, which has not been previously published elsewhere.
2. The paper is not currently being considered for publication elsewhere.
3. The paper reflects the authors' own research and analysis in a truthful and complete manner.
4. The paper properly credits the meaningful contributions of co-authors and co-researchers.
5. The results are appropriately placed in the context of prior and existing research.
6. All sources used are properly disclosed.
7. All authors have been personally and actively involved in substantial work leading to the paper and will take public responsibility for its content.
8. All the research meets the ethical guidelines, including adherence to the legal requirements of the study country.
9. The paper does not infringe on any rights of others, including privacy rights and intellectual property rights.
10. The data is true and not manipulated.
11. There aren't any conflicting or competing interests.
12. Guidelines on patient consent have been met and any details of informed consent obtained are indicated within the text of the submitted manuscript.

The authors agree with the above statements and declare that this submission adheres to all research ethics guidelines.


### Declaration of conflicting interests

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### References

1. Wilkinson D and Savulescu J. Hard lessons: learning from the Charlie Gard case. *J Med Ethics* 2018; **44**: 438–442.
2. Tripp J and McGregor D. Withholding and withdrawing of life sustaining treatment in the newborn. *Archives of disease in childhood. Fetal and Neonatal Edition* 2005; **91**: F67–F71.
3. Das R. Populist discourse on a British social media patient-support community: the case of the Charlie Gard support campaign on Facebook. *Discourse, Context & media* 2018; **24**: 76–84.
4. Song IG, Kang SH, Kim MS, *et al.* Differences in perspectives of pediatricians on advance care planning: a cross-sectional survey. *BMC Palliat Care* 2020; **19**: 45.
5. Close E, Willmott L and White BP. Charlie Gard: in defence of the law. *J Med Ethics* 2018; **44**: 476–480.
6. Nursing and Midwifery Council (NMC). *The Code*. London: NMC, 2018.
7. General Medical Council (GMC). *Good Medical Practice*. London: GMC, 2019.
8. Richards CA, Starks H, O'Connor MR, *et al.* Elements of family-centered care in the pediatric intensive care unit: an integrative review. *J Hosp Palliat Nurs* 2017; **19**: 238–246.
9. Dyer C. NHS Urged to help reduce conflicts between staff and parents of critically ill children. *Br Med J* 2019; 11625.
10. Moore B and Lantos JD. Healthcare organizations and high profile disagreements. *Bioethics* 2020; **34**: 281–287.
11. Beauchamp T and Childress J. Principles of biomedical ethics: marking its fortieth anniversary. *Am J Bioeth* 2019; **19**: 9–12.
12. Leslie P, Rourke N and Sacks T. Doing what works: a discussion of medical futility. *Perspectives on Swallowing and Swallowing Disorders (Dysphagia)* 2014; **23**: 72–79.
13. Morata L. An evolutionary concept analysis of futility in health care. *J Adv Nurs* 2018; **74**: 1289–1300.
14. Lippe M. Drawing the line between hope and false expectations. *Reflect Nurs Leadersh* 2018; **44**: 74–78.
15. Shah SK, Rosenberg AR and Diekema DS. Charlie Gard and the limits of best interests. *JAMA Pediatr* 2017; **171**: 937–938.
16. Longden JV and Mayer AT. Family involvement in end-of-life care in a paediatric intensive care unit. *Nurs Crit Care* 2007; **12**: 181–187.
17. Lantos J. Intractable disagreements about futility. *Perspect Biol Med* 2018; **60**: 390–399.
18. Wilkinson D. *Futility*. International Encyclopedia of Ethics, 2016.
19. Royal College of Paediatrics and Child Health. *Making Decisions to Limit Treatment in Life-Limiting and Life-Threatening Conditions in Children: A Framework for Practice*. London: Royal College of Paediatrics and Child Health, 2015.
20. Larcher VF and Hird MF. Withholding and withdrawing neonatal intensive care. In: P Cartlidge (ed) *Ethical, Legal and Social Aspects of Child Healthcare*. Philadelphia: Elsevier, 2007, pp.125–128.



21. Robinson S and Peek G. The role of ECMO in neonatal and paediatric patients. *Paediatr Child Health (Oxford)* 2019; **29**(5): 218–223.
22. Isaacs D. Trust me I'm a doctor: making decisions about children's direction of care. *J Paediatr Child Health* 2019; **55**: 1411–1413.
23. Hon KLE, Poon TCW, Wong W, et al. Prolonged non-survival in PICU: does a do-not-attempt-resuscitation order matter. *BMC Anesthesiol* 2013; **13**: 43.
24. McDougall RJ and Notini L. Overriding parents' medical decisions for their children: a systematic review of normative literature. *J Med Ethics* 2014; **40**: 448–452.
25. Vernon DD, Dean JM, Timmons OD, et al. Modes of death in the pediatric intensive care unit: withdrawal and limitation of supportive care. *Crit Care Med* 1993; **21**: 1798–1802.
26. Birchley G and Huxtable R. Clinical ethics committees' advice when deciding for critically ill infants: an answer to a problem or a problem to answer? *Institute of Medical Ethics* 2015 Jun 18.
27. Hill C, Knafl KA and Santacroce SJ. Family-centered care from the perspective of parents of children cared for in a pediatric intensive care unit: an integrative review. *J Pediatr Nurs* 2018; **41**: 22–33.
28. Barnes J, Kroll L, Burke O, et al. Qualitative interview study of communication between parents and children about maternal breast cancer. *Br Med J* 2000; **321**: 479–482.
29. Burke D. Straight-up execution: Alfie Evans' dad claims doctors could be prosecuted for murder if life support switched off. *The Mirror*, 23 April 2018.
30. The United Nations. Convention on the Rights of the Child. (1989, Accessed 20 March 2022).
31. Hammond SL. *Children's Rights, Educational Research and the UNCRC: Past, Present and Future Jenna Gillet-Swan and Vicki Coppock (eds)*. Oxford: Symposium Books, 2016.
32. Skivenes M and Sørdsal LM. The child's best interest principle across child protection jurisdictions. In: A Falch-Eriksen and E Backe-Hansen (eds) *Human Rights in Child Protection*. Cham: Palgrave Macmillan, 2018, pp.59–88.
33. Corradi G and Desmet E. A review of literature on children's rights and legal pluralism. *The Journal of Legal Pluralism and Unofficial Law* 2015; **47**: 226–245.
34. Children Act 1989 (UK).
35. Great Ormond Street Hospital NHS Trust v Yates and Gard [2018] EWHC 1909. <https://www.judiciary.uk/wp-content/uploads/2017/07/gosh-v-gard-24072017.pdf> (2018, Accessed 20 March 2022).
36. Portsmouth Hospitals NHS Trust v Wyatt [2005] EWHC 117.
37. Evans V Alder Hey NHS Trust [2018] EWHC 308 <https://www.judiciary.uk/wp-content/uploads/2018/02/alder-hey-v-evans.pdf> (2018, Accessed 20 March 2022).
38. Mental Capacity Act 2005 (UK).
39. Aintree University Hospital NHS Foundation Trust v James. [2013] EWCA CIV 65. *Med Law Rev* 2013; **21**: 622–631.
40. Portsmouth City Council v King [2014] EWHC 2964.
41. Birchley G. The harm threshold and parents' obligation to benefit their children. *J Med Ethics* 2016; **42**: 123–126.
42. Charalambous B. Introducing Charlie's Law, Bambos Charalambous MP (Labour, Enfield Southgate). *Practical Ethics* 2019. Weblog. [Online] Available from: <http://blog.practicaethics.ox.ac.uk/2019/10/guest-post-introducing-charlies-law-bambos-charalambous-mp-labour-enfield-southgate/> [Accessed 23 March 2022].
43. McDougall RJ. Indeterminacy and the normative basis of the harm threshold for overriding parental decisions: a response to Birchley. *J Med Ethics* 2016; **42**: 119–120.
44. Wilkinson D. Tafida Raqeeb and Charlie's Law. *Practical Ethics* 2019. Weblog. [Online] Available from: <http://blog.practicaethics.ox.ac.uk/2019/10/tafida-raqeeb-and-charlies-law/> [Accessed 23 March 2022].
45. Burns K, Pösö T and Skivenes M. *Child Welfare Removals by the State: A Cross-Country Analysis of Decision-Making Systems*. New York: Oxford University Press, 2017.
46. Pritchard I. Using Principlism to resolve the ethical dilemma of withdrawing treatment from a neonate diagnosed with spinal muscular atrophy. *J Neonatal Nurs* 2015; **21**: 186–194.
47. Campbell L. Kant, autonomy and bioethics. *Ethics, Medicine, and Public Health* 2017; **3**: 381–392.
48. Beauchamp TL and Walters L. *Contemporary Issues in Bioethics*. 5th ed. Belmont, CA: Wadsworth Publications, 1999.
49. Reis-Dennis S. Understanding autonomy: an urgent intervention. *The Journal of Law and the Biosciences* 2020; **7**: 1–10.
50. Parsapoor A, Parsapoor M, Rezaei N, et al. Autonomy of children and adolescents in consent to treatment: ethical, jurisprudential and legal considerations. *Majallah-'i būmārīhā-yi kūdakān-i Īrān = Iranian Journal of Pediatrics* 2014; **24**: 241–248.
51. Ross LF. *Children, Families and Health Care Decision Making*. New York: Oxford University Press, 1998.
52. Archard D. 'My child, my choice': parents, doctors and the ethical standards for resolving their disagreement – NILQ 70 1 (93). *Northern Ireland Legal Quarterly* 2019; **70**(1): 93–109.
53. Bester J and Kodish E. Children are not the property of their parents: the need for a clear statement of ethical obligations and boundaries. *Am J Bioeth* 2017; **17**: 17–19.
54. Auckland C and Goold I. Resolving disagreement: a multi-jurisdictional comparative analysis of disputes about children's medical care. *Med Law Rev* 2020; **28**: 643–674.
55. Thomson M. A capabilities approach to best interests assessments. *Legal Studies* 2021; **41**(2): 276–293.
56. Varkey B. Principles of clinical ethics and their application to practice. *Med Princ Pract* 2020; **30**: 17–28.
57. Sokol DK. *Doing Clinical Ethics: A Hands-on Guide for Clinicians and Others*. London: Springer, 2012.
58. Diekema DS. Revisiting the best interest standard: uses and misuses. *J Clin Ethics* 2011; **22**: 128–133.
59. Bester JC. The harm principle cannot replace the best interest standard: problems with using the harm principle for medical decision making for children. *Am J Bioeth* 2018; **18**: 9–19.
60. Staford H and Hollingsworth K. "This case is about you and your future": towards judgments for children. *Modern Law Review* 2020; **83**: 1030–1058.
61. Kopelman LM. The best-interests standards as threshold, ideal, and standard of reasonableness (children and bioethics: uses and abuses of the best interests standards). *J Med Philos* 1997; **22**: 271–289.
62. Kelly G. *Medico-moral Problems*. St Louis: The Catholic Health Association of the United States and Canada, 1958.
63. Fost N. Ethical issues in the treatment of critically ill newborns. *Pediatr Ann* 1981; **10**: 16–22.

64. Pruski M and Gamble NK. Reasonable parental and medical obligations in pediatric extraordinary therapy. *Linacre Q* 2019; **86**: 198–206.
65. Bowden VR. Selective nontreatment of handicapped newborns: how do we decide? *Child Health Care* 1988; **17**: 12–17.
66. Lazaridis C. Ending life in the ICU: the vacuity of sanctity. *Crit Care Med* 2017; **45**: 28.
67. Kitzinger J, Kitzinger C and Cowley J. When ‘Sanctity of Life’ and ‘Self-Determination’ clash: Briggs versus Briggs [2016] EW COP 53 – implications for policy and practice. *J Med Ethics* 2017; **43**: 446–449.
68. Gillon R. "Primum non nocere" and the principle of non-maleficence. *Br Med J (Clin Res Ed)* 1985; **291**: 130–131.
69. Mueller BU, Neuspiel DR and Fisher ERS. AAP council on quality improvement and patient safety, committee on hospital care. Principles of pediatric patient safety: reducing harm due to medical care. *Pediatrics* 2019; **143**: 20183649.
70. Kirsch RE, Balit CR, Carnevale FA, *et al.* Ethical, cultural, social, and individual considerations prior to transition to limitation or withdrawal of life-sustaining therapies. *Pediatr Crit Care Med* 2018; **19**: S10–S18.
71. Bennett RA and LeBaron VT. Parental perspectives on roles in end-of-life decision making in the pediatric intensive care unit: an integrative review. *J Pediatr Nurs* 2019; **46**: 18–25.
72. Truog RD. Is ‘best interests’ the right standard in cases like that of Charlie Gard? *J Med Ethics* 2020; **46**: 16–17.
73. Boles J. Everyday ethics for every child. *Pediatr Nurs* 2016; **42**: 308–311.
74. Diekema DS. Parental refusals of medical treatment: the harm principle as threshold for state intervention. *Theor Med Bioeth* 2004; **25**: 243–264.
75. Bridgeman J. A threshold of significant harm (f) or a viable alternative therapeutic option? *J Med Ethics* 2018; **44**: 466–470.
76. Birchley G. Harm is all you need? Best interests and disputes about parental decision-making. *J Med Ethics* 2016; **42**: 111–115.
77. Stewart DO and De Marco JP. Evaluating the harm principle and the best interest of the child: a case resolved using standard microeconomics principles. *Am J Bioeth* 2018; **18**: 76–78.
78. Wilkinson D and Savulescu J. Cost-equivalence and pluralism in publicly-funded health-care systems. *Health Care Anal* 2018; **26**: 287–309.
79. Elhadi M, Msherghi A, Alkeelani M, *et al.* Concerns for low-resource countries, with under-prepared intensive care units, facing the COVID-19 pandemic. *Infection, Disease & Health* 2020; **25**: 227–232.
80. Leclerc T, Donat N, Donat A, *et al.* Prioritisation of ICU treatments for critically ill patients in a COVID-19 pandemic with scarce resources. *Anaesthesia Critical Care & Pain Medicine* 2020; **39**: 333–339.
81. Lopes L, De Melo N, Acurcio FDA, *et al.* (Un)Equitable distribution of health resources and the judicialization of health-care: 10 years of experience in Brazil. *Int J Equity Health* 2019; **18**: 10.