

Harm isn't all you need. Parental discretion and medical decisions for a child

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How should we make decisions about medical treatment for a very young child? What should we do when there is a disagreement between parents and clinicians about what would be best for the child? The conventional answer, as found in textbooks, professional guidelines, and the law, is that decisions should be based on the best interests of the child. However, as noted by Giles Birchley in an article in this issue<sup>1</sup>, a number of ethicists have argued that the focus should instead be on harm; parents should be overruled where their decision would cross a threshold level of harm<sup>2 3</sup>. Birchley, in his article, disagrees. He argues that the harm threshold suffers from problems of negative connotations, narrow scope and indeterminacy, and that it would be better to clarify the values that should inform best interests.

### What is the question?

Before addressing whether Birchley is right, we should clarify the type of question that we are dealing with. Is this a legal question, or is it an ethical question? If it is a legal question, are we asking what is currently lawful, or what the law should be? The question of what the law currently *is* will depend on the jurisdiction, as well as perhaps on the specific scenario. As Birchley notes, UK law includes both a harm threshold and a best interests standard, though for medical treatment decisions it is the latter that is usually applied<sup>1</sup>. Here we will focus on the question of wider relevance – of what the law should be in this area. Second, we should distinguish between what should happen, and what is permissible. Not everything that ought to happen is a matter for the law. As we will see, the argument in favour of the Harm Threshold draws specifically on the gap between what parents ought to do, and what they must not be permitted to do.

Third, when we are trying to work out what standard to apply we should distinguish between different types of case (Table 1). Are we dealing with a situation where parents' wishes are unknown, or are we dealing with a situation where parents are in direct conflict with medical professionals? We will argue that the Harm Threshold should apply only to the latter cases.

### An example

All of this might seem very theoretical, so it may be helpful to focus our attention on a specific case.

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Some years ago, I [DW] was contacted by one of my registrars about a newborn infant, Jasmine, who had just been born. It is routine care for newborn infants to receive intramuscular vitamin K after birth to reduce the risk of a rare but serious bleeding disorder (haemorrhagic disease of the newborn)<sup>4</sup>. The parents of Jasmine had declined the vitamin K injection on the grounds that it was unnatural, and they had read about possible risks of later cancer or leukaemia. They had also declined routine newborn screening, (involving a heelprick blood test for rare but treatable disorders that can cause serious illness in babies). I spoke with Jasmine's parents, and explained the benefits of both of these routine interventions. I also explained that the question of vitamin K and cancer had been carefully studied, and it had been shown clearly that there was no connection<sup>5</sup>. The parents remained clear that they did not want either intervention for their child (they also declined an oral preparation of vitamin K). Later that night, I received another call. Jasmine remained well, but had developed a fever. My registrar had planned to admit the baby to the special care nursery, and commence antibiotics. However, her parents were adamant that this was unnecessary, and refused consent for this to happen. They planned to discharge themselves from the hospital, and take Jasmine home. What should I have done in this case? If I were unable to resolve my disagreement with the family and sought an emergency court order, what should the court do?

### Best Interests vs Harm Threshold

One answer in this situation is to act in the best interests of the child. What do we mean by this? Birchley does not define 'best interests', but here is one definition

**Bests Interests Principle:** Decision-makers should take whichever course of action would maximally promote the wellbeing of the child<sup>6</sup>.

As stated, the best interests principle refers to the decision that parents or other decision-makers *should* make. But thinking about the dilemma described above, the critical question is whether or not the doctor is justified in going against parents' wishes. Here is a version of the Best Interests Principle applied in a negative way:

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<sup>i</sup> This is a composite case experienced by DW. Details have been altered.

**Best Interests Threshold (BIT):** Parents should be overruled if they are making decisions that would *not* maximally promote the wellbeing of the child compared with other available options

We could contrast this with the Harm Threshold as set out by American paediatrician Doug Diekema<sup>2</sup>.

**Harm Threshold (HT):** Parents should be overruled if they are making decisions that significantly increase the risk of serious harm to the child compared with other available options

One possibility is that the BIT and the HT would yield the same answer. Birchley appears to believe that this is the case. He argues that in adopting the HT “[a]ll we have done is rename the best interests test while dealing with none of its failings.”<sup>[1 p 4]</sup>. If the HT and the BIT are identical, then the question of which we should use is simply a question of semantics. Furthermore, if Birchley is correct in asserting that the HT has pejorative overtones, and is harder for clinicians or the judiciary to understand, then perhaps it would be preferable to use the BIT.<sup>ii</sup> However, thinking about the case example above may perhaps make clear why the BIT is not identical to the HT. Both intramuscular vitamin K, and newborn screening tests potentially prevent serious harm to a newborn infant, while imposing on the child only the risk of a brief painful injection or blood test. It would be clearly in the best interests of Jasmine for her to have these interventions. If we were in a situation where parental wishes were unknown or contradictory (type A or B cases, Table 1), there is little doubt that a court would favour providing intramuscular vitamin K as well as the heel-prick test for newborn screening. Yet, this does not mean that doctors would be justified in overruling parental objections in the case above. The harms prevented by vitamin K prophylaxis, or by newborn screening, though serious, are rare. For example, the rate of haemorrhagic disease of the newborn in UK infants who did not receive intramuscular vitamin K is approximately 1 in 10,000<sup>7</sup>. That is why in the case of Jasmine, it would not be appropriate to obtain a court order when her parents declined vitamin K or newborn screening.

In contrast, in the case example, the presence of fever suggests a risk of bacterial sepsis that may be as high as 10%<sup>8</sup>. At that point, it appears justified to invoke a court order if necessary, in order to provide antibiotics.

### In defense of the Harm Threshold

But why *should* we use the HT rather than the BIT for decisions about children? Why should parents be given discretion to make decisions that are less than the best for their child?

#### 1. Uncertainty

One reason to defer to parents for a medical decision is because of *medical uncertainty*. Existing evidence may suggest that a particular intervention is of

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<sup>ii</sup> Birchley is correct in this sense – all cases that fall above the HT would also sit above the BIT (choices that impose a significant risk of serious harm by definition do not maximally promote the wellbeing of the child). However, the reverse does not apply.

overall benefit, and on that basis it would appear to be potentially in a child's interests to provide it. However, the evidence may not be clear-cut, and accordingly it would be reasonable to not provide the treatment if that is parents' wish.<sup>iii</sup>

More commonly though, decisions may be affected by a different type of uncertainty – *value uncertainty*. Determining whether or not treatment is in a child's best interests involves placing weight on the different possible outcomes. There is no value-neutral way of doing this. For some decisions the values at stake are widely shared, and it is highly unlikely that there would be disagreement. For other decisions, values may be highly contested. Where there are a range of different reasonable views about whether or not a particular treatment is in a child's best interests, it is unfair to impose one set of values on all parents.

## 2. The interests of parents

Although the main impact of medical decisions will be on the child, these decisions may affect others – for example the child's parents. This is perhaps most vividly seen in disputes around life-sustaining treatment, where the life or death of a child will have profound and long-lasting impacts on the family<sup>6</sup> (p113-124). However, in other decisions, for example those around immunization, or circumcision or blood transfusion, there may also be significant impact on the parents. In the example above, Jasmine's parents had an interest in caring for her in a particular way. They had a strong desire to avoid medical interventions, and to nurture her in a more natural way. We could expect that if doctors go against her parents' wishes that will cause some significant negative effect for them.

Birchley rejects parental autonomy because children have rights on their own account<sup>1</sup> (p2). However, a view that children's rights should be protected does not mean that these should always take precedence over other interests at stake. Conversely, giving some ethical weight to the autonomy or interests of parents does not mean that they will be given free rein to make any decision they like. Plausibly, where the benefit to child is statistically unlikely or small in magnitude it is reasonable to give parents' interests (or rights) some weight. Yet where there is a sufficient level of potential harm for the child (as in the case of blood transfusion for severe anaemia or antibiotics for suspected neonatal sepsis), parents should be overruled.

## 3. Consistency

Finally, the above approach to parental decision-making is consistent with the approach taken in other areas of life. Parents make suboptimal decisions about their children all the time. For example, they make decisions about what to feed their child, what type of car to drive, which school to enroll their child in. They might choose to install the latest safety equipment to protect their child from

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<sup>iii</sup> One example, is the difference between oral and intramuscular preparations of vitamin K. Although it appears from epidemiological studies that IM vitamin K is more effective than oral vitamin K in preventing haemorrhagic disease<sup>7</sup>, there have been no randomized controlled trials that have looked at this question<sup>4</sup>.

accidents around the home, or they may not. They may enroll the child in classes to learn a sport, or musical instrument or second language, or not. In all of these domains, and in many more, parents make decisions that are not in the best interests of their children. Yet, we do not think that the state should be in the business of interfering with these everyday decisions. Rather, in those other areas of life parents are given a degree of freedom. We accept that it is important to allow parents to make decisions, good and bad, for themselves and their children. Only if their decision-making risks serious harm to the child will the state step in to intervene.

One argument that is sometimes advanced in favour of the HT over the BIT is on the basis of indeterminacy. 'Best Interests' has been criticized as vague and difficult to apply in practice<sup>2</sup>. Birchley correctly notes that the HT, as articulated above, is also indeterminate. What constitutes a "significant" risk, or "serious harm" is still going to be a matter of judgement, and it is likely that there will be differing views about particular cases. Birchley points to apparent inconsistencies in the application of the HT in case law as evidence of problems with this standard<sup>1</sup> (p4) However, this argument does not provide any reason to favour the BIT. At best, it undermines one reason for preferring the HT (and as set out above, and articulated by Diekema this is not a principle reason in favour of the HT). Furthermore, it remains possible (and we would suggest plausible) that even if the HT remains somewhat indeterminate, it may be less so than the BIT. One possibility would be to clarify the probability of harm that would count as 'significant', or the degree of harm as 'serious'. Although such evidence would not be definitive, it would be possible to test empirically the views of professionals or the general public about the harm threshold in a way that we contend would be easier than the BIT.

Birchley suggests that the concept of 'harm' is more pejorative than 'best interests', and that the judiciary prefers the latter term in order not to offend families<sup>1</sup> (p3) Yet, it is difficult to place much weight on this argument. A decision by a health professional or by the court to go against the express and sincerely held wishes of parents will *necessarily* cause offence and distress. It hardly seems to lessen the blow for parents if courts or doctors cloak their reasoning in the vague language of best interests rather than that of harm. Furthermore, since it appears that the BIT licenses far more interference in parental decision-making than the HT it seems plausible that parents would prefer more latitude in decision-making (at the cost of more explicit language).

### Beyond harm

We have argued that the Harm Threshold is the correct normative level for state intervention to overrule parental wishes about treatment. Yet, as we have already intimated, a full account of medical decision-making for children needs *more* than the concept of harm. First, this is because we still need the Best Interests Principle. In situations where parents views are unknown, or conflicting (type A or type B cases), courts or surrogates *should* decide based on what in their judgement would be best for the child. Furthermore, even if parents views are clear, best interests remains important as an ideal and normative guide<sup>9</sup>. In the example of Jasmine, the paediatrician should ultimately

respect the parents' refusal of vitamin K and newborn screening. However, that does not mean the paediatrician should remain neutral. He or she should advocate for the best interests of the child, attempting to persuade the parents that their concerns are misplaced, and that it would be best for the child to have both interventions.

Second, as Birchley notes, the Harm Threshold may have too narrow a scope and ignore other relevant factors in some instances<sup>1</sup> (p2). The HT permits overruling parents if their decision risks serious harm to the child. Yet there may be some parental decisions that should be overruled even if the potential harm is less than this threshold, indeed, even if the treatment would be of overall benefit. The most obvious example of that is where parents are requesting highly expensive treatment. In such cases, (particularly common in intensive care or oncology) providing treatment may risk harm to others (by using limited medical resources)<sup>10</sup>. In such situations (type C2 cases), we need both a harm threshold and a cost threshold. If the requested treatment is not expensive, and does not risk serious harm it may be ethical to provide it or to continue providing it (where already started), even if this would not be condoned or recommended by the medical professional. However, where the treatment exceeds either the cost threshold or the harm threshold, parents should be overruled (Table 1).

Discussion of cases like that of Jasmine sometimes gives the impression that parents and physicians are at loggerheads, and that conflicts are frequent. In reality, such conflicts are rare. In almost all cases, both health professionals and parents are focused on what would be best for the child and agree on how to go about promoting this. The difficulty comes where there are different views. Then we need to change our focus to the harms, and the costs, at stake.

| Type of case | Parental wishes            | Nature of request            | Normative principle               |
|--------------|----------------------------|------------------------------|-----------------------------------|
| A            | Unknown                    | -                            | Best Interests Principle          |
| B            | Conflicting                | -                            |                                   |
| C1           | Contrary to medical advice | Parents refusing treatment   | Harm Threshold                    |
| C2           | Contrary to medical advice | Parents requesting treatment | Harm Threshold and Cost Threshold |

Table 1: Decisions about medically recommended treatment for a young child: types of cases based on parental wishes, and the normative principle that should be applied

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