

The zone of parental discretion: An ethical tool for dealing with disagreement between parents and doctors about medical treatment for a child

Lynn Gillam

Abstract

Dealing with situations where parents' views about treatment for their child are strongly opposed to doctors' views is one major area of ethical challenge in paediatric health care. The traditional approach focuses on the child's best interests, but this is problematic for a number of reasons. The Harm Principle test is regarded by many ethicists as more appropriate than the best interests test. Despite this, use of the best interests test for intervening in parental decisions is still very common in clinical settings and can lead to confusion. In this paper, I propose the Zone of Parental Discretion as a means of putting into practice the key ideas of the Harm Principle, in a clear, step-by-step process. The Zone of Parental Discretion provides a tool for ethical deliberation by clinicians and ethicists about all situations in which parents and doctors disagree about treatment of a child, whether parents are refusing medically recommended treatment, or requesting non-recommended treatment.

Keywords

Children, Harm Principle, parental refusal of treatment, best interests

Introduction

Providing health care for children brings with it a number of ethical challenges. Dealing with situations where parents' views about treatment for their child are strongly opposed to doctors' views is one major area of challenge, not only in the hospital, but also in out-patient and community settings. The traditional approach to dealing with these situations focuses on determining whether the course of action wanted by the parents is in the child's best interests. In particular, this is the way in which the issue is framed in the law, when such disagreements reach court. However, the best interests approach is problematic for a number of reasons, not least of which is that it does not always mean what it seems to mean, namely accepting only the absolute best for the child.^{1,2} Best interests, even when used in legal context by a judge, is notoriously subjective and grey concept.^{3–5} The Harm Principle, which focuses on whether the child will be harmed, is regarded by many ethicists as more appropriate than the best interests test.^{5–10} However, best interests approaches are still commonly used in clinical

practice and sometimes lead to confusion for doctors and clinical ethics committee. This paper aims to further direct attention to possible harm to the child, and the moral claim of parents to be the decision-makers for the child, as the two features that matter most in deciding whether the parental decision should stand in the many and varied situations in which parents and doctors disagree about medical treatment for a child.

The archetypal instance of parents disagreeing with doctors is the Jehovah's Witness parent refusing a life-saving blood transfusion, but there are very many others. Parents refuse blood transfusion for a number of reasons, including concerns about the safety of the blood supply, preference for natural medicines or simply not believing that their child's condition is

Children's Bioethics Centre, Royal Children's Hospital, Melbourne School of Population and Global Health, University of Melbourne, Australia

Corresponding author:

Lynn Gillam, Children's Bioethics Centre, Royal Children's Hospital, 50 Flemington Road, Parkville Vic 3052, Australia.

Email: l.gillam@unimelb.edu.au

serious enough to need this treatment. These refusals are not always in life-or-death situations, such as an eminently treatable cancer or a correctable heart defect requiring surgery. Parents may refuse blood transfusions for a chronic anaemia, where there are feasible alternative treatments to sustain life, but blood transfusion is regarded as medically preferable because it offers fewer side-effects. Parents also refuse other types of medical treatment. Parents with a strong belief in natural therapies may refuse anti-epileptic medication for a child with mild, probably self-limiting, seizure disorder. Anxious parents in an emergency department may refuse supra-pubic aspiration to obtain a urine sample from an infant with suspected urinary tract infection. Parents also 'demand' treatment. The parents of a child with a neurodegenerative condition may want her doctors to administer an experimental drug. When a child is dying or irreversibly dependent on ventilation, parents sometimes want to continue treatment, which doctors believe should be ceased because it is 'medically futile' or causing more harm than good in the face of inevitable death.

The situations described above have all been the subject of formal referrals to the clinical ethics service at our centre^{11,12} or raised in ethics rounds. Although they differ in many ways, these situations have in common one key ethical feature. They are all instances of parents disagreeing with medical recommendations for treatment of their child. Despite their variety, and despite the fact that some are refusals of treatment and some are demands for treatment, I argue that, in the first instance, this common feature means that they can all be dealt with in the same way, ethically speaking. Other ethical considerations may arise, as I will explain below, but they are not primary. In this paper, I put forward a systematic way of approaching disagreements between doctors and parents, specifically where the child is too young to have a meaningful view of their own about treatment. This approach puts into practice the Harm Principle.⁶ It uses a concept that I have called the 'Zone of Parental Discretion' (ZPD) as a tool for clinicians and ethicists to use in ethical deliberation in these situations. In what follows, I will first explain briefly why a tool is needed, then set out the meaning, scope and theoretical basis of the ZPD and describe how to use it. The idea of the ZPD has grown out of my experience in clinical ethics case consultation, and I am indebted to my colleagues for their role in testing out and refining it as we have gone along.

The need for a conceptual tool for deliberation

In 2004, the US paediatric ethicist Diekema⁶ argued that 'Continued reference to a best interest standard

simply confuses physicians and others who must determine when parental refusals of consent should be tolerated'. Baines³ came to a similar conclusion in the UK context in 2008, specifically in relation to end-of-life treatment. Diekema's⁶ articulation of the Harm Principle was intended to remove this confusion. However, reference to best interests of the child in disagreement situations continues. In our experience of doing clinical ethics in a major paediatric hospital, a very common first response, especially by clinicians, is to ask what is in the child's best interests. If used in formal ethical deliberation, this best interests approach often leads us to get stuck on the question of what actually is *best* for the child. Either there are competing views, which cannot be adjudicated, or there is paralyzing uncertainty: evidence is lacking, equivocal or not directly relevant, and there is no obvious way to resolve the question of what would be optimal for the child.⁶ Not only does the discussion bog down, but, I suggest, it focuses on the wrong thing. The Harm Principle, properly understood, means that the focus should be first whether the child would be *harmed* if the parents' wishes were followed, not on what is *optimal* for the child. The Harm Principle approach recognizes that there is morally significant gap between what is in the best interests of the child (i.e. optimal for the child) and what will cause harm to child.^{3,6} As a normative tool, the Zone of Parental Discretion draws attention to this difference and provides a systematic way to think through these situations. It also accords appropriate moral weight to parents as the decision-makers for the child,^{3,8} weight which is often not properly taken into account when using the best interests test.

The Zone of Parental Discretion

I use the term 'Zone of Parental Discretion' to refer to the ethically protected space where parents may legitimately make decisions for their children, even if the decisions are sub-optimal for those children (i.e. not absolutely the *best* for them). The ethically acceptable zone for parents' decisions about young children is broader than the single point at the top of the scale where the child's absolute best interests lie (if that point could ever be determined) and extends down to the cut-off line, or threshold, where the child will be harmed if the parents' decision is followed.⁶ In this space, 'good enough' parental decisions should be tolerated, until the point where they would cause harm to the child. The meaning of the term 'harm' here is not conceptually separate from the idea of 'interests'. Drawing on Feinberg's classic definition, I am using 'harm' to refer a 'serious set-back to interests'⁸ and interests to refer to the various components of well-being⁸ (such as continued life, freedom from pain,

relationships with others and experience of happiness). Different interests can be set-back to different degrees by the same action. Harm occurs when one course of action causes a *serious* set-back to interests *overall*, when compared to the other possible courses of action. The difference between asking whether a course of action harms a child and asking whether it is in the child's best interests lies in recognizing that there can be set-backs to some interests, which are not significant enough to count as harm, even though, as set-backs, they clearly are not the best possible outcome of the child. Decisions that fall within the ZPD range from those that are absolutely optimal for the child's interests, to those which do not fully meet some or all of the child's interests, but are not so bad as to constitute harm to the child. Quite a number of different courses of action, each with somewhat different effects on the child, could fall inside the ZPD. In contrast, there is presumably only one course of action that is in absolute best interests of the child. This is why it is easier to determine whether something is inside or outside the ZPD than it is to determine whether or not it is in the child's best interests. When parents disagree with the doctors, the first question to ask is whether the parents' decision falls within the ZPD, not whether their decision is in the best interests of the child.

Using the ZPD for ethical analysis

The ZPD is intended for use when parents' views remain opposed to doctors' recommendations about treatment, even after usual attempts at providing further explanation, more information and time to consider. It involves a step-by-step approach, using a short series of key questions, in two stages. These questions cover similar ground to that covered in the first six of Diekema's eight conditions under the Harm Principle⁶ (conditions which would justify state intervention in parents' decisions). This is to be expected, as the Zone of Parental Discretion is intended as tool for putting the Harm Principle into practice. However, the ZPD is addressed to a broader range of situations than Diekema addresses, so the ZPD questions are framed somewhat more broadly. Diekema⁶ focuses only on delineating situations in which state intervention to compel medical treatment is ethically justified, in the face of parental refusals, but the ZPD is aimed at answering the question about whether doctors should accede to or reject parental decisions, when those decisions are contrary to medical recommendation. This covers requests for treatment as well as refusals and envisages not just court intervention, but any number of avenues for not acting in accord with parental wishes, many of which involve no coercive intervention by any authority.

Stage 1: Harm from parents' decisions

1. What are the parents' wishes or decision? (This is not always clear, but must be clarified.)
2. What would be the effects on the child of carrying out the decision? (This needs to be thoroughly explored, considering the full range of possible benefits and burdens to the child, and may not be clear cut.)
3. Are these effects so bad as to constitute probable significant harm to the child? (This may also not be clear cut and can be contentious).

As noted earlier, 'harm' refers to harm *overall*; that is, taking into account potential benefits to the child as well as burdens and risks. Both the magnitude and probability of the effects on the child must be considered. If on balance, the likely burdens and risks of what the parents want significantly outweigh the likely benefits, this constitutes probable significant harm to the child. It is important to note that 'weighing up benefits and burdens' is just another way of describing the process of assessing the extent to which all of the child's interests are advanced or set-back by the course of action wanted by the parents. This is essentially the same type of thinking that occurs when attempting to determine the best interests of a child. The difference is that the threshold is set at a different level. In the best interests test, only a "score" of 100% on advancement of interests is acceptable, whereas in determining the cut-off point for harm, the score can be lower than 100% and still not count as harm. Note that all the interests of the child are to be included, not just their 'medical interests' in narrow sense, but their social, psychological and emotional interests as well. For example, negative psychological and emotional effects of prolonged hospitalisation on a child need to be taken into account, just as much as the positive medical effects such as improved physiological functioning or protection from infection.

In practice, much will turn on assessing whether the negative effects or the degree of set-back to interests is 'significant'. There is no precise consensus in the paediatric ethics literature on how to define 'significant' or to specify the threshold. Diekema⁶ states that the harm needs to be 'serious, imminent and preventable', and the risk of it occurring 'non-trivial'. Ross⁹ specifies situations that would result in deprivation of the child's basic needs if the parents' wishes were followed, such as a chance for normal, healthy growth or life. These formulations give some indication of where to draw the line, but both Diekema⁶ and Ross⁸ acknowledge that there will always be an element of interpretation involved, no matter how 'significant harm' is defined. Using the ZPD does not change this. Interpretation and

judgement is at play here, just as it is in determining whether something is in a child's best interests. In both cases, one has to grapple with problems known to be associated with decision-making in these situations: degrees of probability associated with various possible outcomes, rather than certainty; assessing the degree of an effect when there are no simple numerical scales; and trying to compare effects and outcomes of qualitatively different kinds. For example, when the question of whether to attempt curative treatment for an advanced cancer is raised, the effects on the child that must be taken into account might include the probability of extra years of life, psychological distress, relief of pain, prolonged hospitalisation, salvaging of a limb, altered body image, nausea and temporary hair loss, damage to eyesight and possibility of treatment failure. There is no algorithm for comparing these, and no meaningful way to set numerical levels of probabilities of any of these that would indicate 'significant harm'. The whole picture must somehow be put together and assessed. This is an unavoidable part of clinical ethics in general.

Once this complex assessment, with its inevitable lack of certainty, is made, the next step is clearer. If the effects on the child of the course of action wanted by the parents do not constitute probable significant harm, the parents' decision falls within the Zone of Parental Discretion: it should be acceded to, even if it is sub-optimal for the child. If the effects do constitute probable significant harm, the parents' decision falls outside the Zone of Parental Discretion, and *prima facie*, it should not be acceded to. Going against parents' wishes may sometimes require taking action in court or notification to child protective services, but there are other mechanisms available, some of which simply involve doctors standing firm and forcefully stating what they believe must be done for the child's sake (with institutional support, where available), relying on the considerable influence they have over parents.

Stage 2: Harm from overriding the parents' decision

However, before proceeding to override or reject the parents' decision, a second stage of deliberation is required. This is because attempting to override parents' decisions (whether this is successful or not) may in itself cause harm to their child. This sort of harm to the child, such as being removed from daily care and presence of parents, or being taken away from hospital by parents, might be indirect and unintended from the perspective of those taking the actions needed to override the parents, but, I argue, must still be considered. These outcomes have real effects on the child and so are not ethically less important, just because they are

indirect or unintended. Avoiding harm to the child is the ethical foundation of the ZPD approach, so it is vital to consider all forms of potential harm to the child at every step. In order to work out whether overriding the parents' decision is the right thing to do, not just *prima facie*, but *all things considered*, there are two more questions to ask:

4. What would be the effects on the child of attempting to or succeeding in resisting or overriding the parents' decision?
5. If there are likely to be negative effects on the child, would this constitute greater harm to the child than the harm expected from the parents' original decision?

If there are minimal negative effects on the child of overriding the parents, or if the benefits to the child of overriding outweigh the harm, then the *prima facie* position holds, and the decision to override is ethically confirmed. However, if the effects of overriding are likely to be worse for the child than the effects of the parents' original decision, then the *prima facie* position does not hold. Attempts to override the parents' decision should not be made. For example, getting a court order or calling in child protection, in an attempt to enforce treatment for cancer may result in the parents removing the child from hospital and essentially going into hiding, losing all contact with the health care system. This would mean that the child gets no health care of any sort, not even symptom management and pain relief. If the cancer treatment has a relatively low chance of success, so that the child may die anyway, this could be the worse for the child than missing out on the treatment. In these sorts of circumstance, the plan of overriding should not proceed, and alternatives or compromises should be sought, at least until the foreseeable harms of attempting to override can be protected against or mitigated.

Understanding the ZPD

At the heart of the ZPD is the concept that decisions made by parents about medical treatment for their children may be *sub-optimal*, especially in the eyes of clinicians, but still not count as *harmful* to child. Clinicians may reasonably disagree with parental decisions, even though those decisions actually fall within the ZPD. There are three main explanations for this. First, the concept of interests is multi-dimensional, covering different domains of life.¹² A number of authors have attempted to produce list of the many domains of life, which 'interests' cover. A recent and very plausible list of the interests of the child, developed by Binik,¹³ includes fulfilment of basic biological needs (food,

water, sleep), intellectually engaging activities, good health, meaningful relationships and opportunities for imaginative play. In many situations, no course of action will maximise every one of these different interests; all options will have some loss in at least one of the domains. When parents and clinicians disagree, it may be because clinicians prioritise one domain of the child interests over another, in a way that parents do not and hence come to a different view about best interests overall (This is recognized by Diekema⁶). Doctors and parents are valuing the various aspects of a good life to different degrees. For example, it would not be surprising if clinicians valued functional ability or cognitive capacity most highly, since this is what is needed to do they work which they do, and presumably value highly. Parents may put a greater value on social interaction and participation in family life as a more important component of the child's interests than cognitive capacity. This difference may lie behind disagreements over continuation of life-sustaining treatment when the child has major physical and cognitive disabilities.

Second, disagreement may also be due to different evaluation of probability of outcomes. Parents may feel that a 5% chance that a transplant will save their child's life is good chance, worth pursuing, whereas a transplant surgeon may see a transplant in these circumstances as virtually futile. Third, parents may be making a decision, which they view as best for their family as whole, rather than best for that individual child. That is, they may acknowledge that they are not deciding in a way that totally prioritises the best interests of that individual child; rather, they are taking into account the needs of siblings, extended family and even themselves.⁸ This may often be the basis, for example, of disagreements over whether a child should stay in a tertiary metropolitan hospital for management or be transferred to a smaller, less-specialized regional hospital.

The idea of the ZPD is that decisions based on all these sorts of considerations are legitimate and should not be overridden simply because doctors disagree with them. Doctors may think parents' decisions not optimal for child, but overriding the parents is only ethically justified if their decision is likely to cause significant harm to the child and hence falls outside the ZPD. However, if doctors, alone or in conjunction with clinical ethicists, come to believe that following the parents' wishes would or is likely to cause significant harm to the child, then they are obliged to resist that course of action. This may involve going to court to seek an order, or making a notification to Child Protection, but, as noted above, often this degree of coercive intervention will not actually be required. A firm refusal or strong persuasion may be sufficient.

Note that the ZPD is not just a zone of medical uncertainty. There will be no medical uncertainty at all about some decisions, which may nevertheless be within the ZPD. The refusal of blood transfusions for a child with a chronic anaemia, which was mentioned earlier, is a good example of this. Given the child's diagnosis and current condition, there was medical agreement that the condition could be well managed with the current drug treatment. However, regular blood transfusion was regarded as medically superior at this point, because it would avoid the main side-effect of the drug therapy, which is growth retardation. There was no uncertainty about differential effect on the child between the treatment recommended by doctors and the treatment wanted by parents. Blood transfusion was known to be the optimal treatment; drug therapy was known to be effective in managing the condition, but not optimal. The child would not grow to as great a final height if the current drug treatment were continued, rather than moving to regular blood transfusion. However, the parents' decision fell within the ZPD, because it was not sufficiently detrimental to constitute harm to the child. The loss of several centimetres of final height, in a child who would in any case be very short due to the anaemia, does not constitute significant harm to the child, even though maximizing final height would be optimal. Small loss of final height is not a significant enough set-back to a central interest or basic need of the child to count as a harm. The ZPD is also quite different from, and wider than, the 'grey zone' in neo-natal medicine. The neo-natal grey zone allows for parents to make their own decision about resuscitation for a very premature new born, but only between specified gestational ages or birthweight.^{14,15} These cut-offs are based on medical data about survival and long-term outcomes.¹⁶ The grey zone, where parents may make a decision, is the range where the medical data are equivocal and clinicians are uncertain about outcomes. Outside this range, there is sufficient medical certainty, and parents get no choice.

Finally, it is also important to note that parents' motivations or reasons for their decisions are not in themselves relevant to determining whether their decision falls within the ZPD.⁶ Their decisions may be based on religious beliefs, cultural norms and practices, beliefs in traditional or alternative medicines, persistent fear or irremediable lack of understanding. These are important to understand and discuss with parents but when an impasse is reached, the only thing that ultimately matters is the effect on the child of the parents' decision. The decision falls within the ZPD as long as it is not likely to cause significant harm to the child. In almost all instances, the nature of the parents' reasons does not influence the degree of negative effect on the child caused by the parents' decision.

However, parents' reasons may turn out to be relevant in the second stage of deliberation using the ZPD, when considering what effect the attempt at overriding the parents' decision may have on the child. The parents' response to that attempt may well be influenced by their religious views (or those of their community), or the views about dangers of biomedical interventions, to give two obvious examples.

Scope of the ZPD tool – 'Refusals' and 'demands'

The ZPD is the relevant tool to use, whether the parents' decision is a refusal (a decision not to have treatment that has been medically recommended) or a 'demand' (a decision or desire to have a treatment which is not medically recommended). The nature of the course of action, which the parents want (whether it would constitute an act or an omission), does not itself make any ethically significant difference. The theoretical rationale for this is that there is not a clear and consistently relevant difference between acts and omissions, either in ethical theory or in practice, as many moral philosophers and ethicists have argued.^{17,18} In practice, it may appear that demands for treatment are ethically different from refusals, because demands require resources and refusals do not; and demands require clinicians to do something, whereas refusals just require them to refrain from doing something. However, it is often not so straightforward. For example, refusal of blood transfusion usually means a decision *for* another form of treatment, so clinicians are still doing something. Other forms of treatment may involve other blood products or drugs, which may be more costly than blood transfusion and less effective, hence requiring that the child stay in hospital longer. Conversely, a demand for treatment may be cost-neutral. For example, the parents, who wanted an experimental drug given, had sourced and paid for it themselves and only wanted hospital staff to administer it by intramuscular injection once daily for a week were seeking something that would require almost no extra resources.

So, whether it is a refusal or a request, when parents want something for their child that goes against medical recommendations, the first question to be answered is whether it would be ethically permissible to do what parents want. If it is, then, there may be further questions to be asked, in particular in relation to fair use of limited resources. Resource allocation issues raised by parental wishes regarding treatment should in principle be dealt with in the same way as other situations in which the proposed treatment for a child involves use of expensive and/or scarce resources. It is beyond the scope of this paper to consider this any further. But the

important point here is this: if what the parents want is so detrimental to the child's interests that it counts as causing harm, and hence is not within the ZPD, then it is not ethically acceptable to do it, even if there are no implications for use of health care resources.

Theoretical basis for the ZPD

Zone of parental discretion is based on the following ethical claims:

1. Parents have an ethical right to make medical decisions for their children, based on their own conception of the good life.
2. Parents are not morally obliged to maximise the well-being of their child.
3. The limit to parental authority lies at the point where significant harm is likely to be caused to the child. Parents' decisions should only be overridden if the child is likely to suffer significant harm from the decision.

The first of these claims is not controversial. The moral claim of parents to be decision-makers for their children is widely recognized and argued for by a number of prominent moral philosophers and ethicists.^{1,6,7,8} Brock and Buchanan,¹ for example, argue that parents have a right (within limits) to raise their children according to their own values. This right is not based on the idea that parents own their children in the way that they own property or have some sort of sovereign authority over children. The primary ethical relationship is one of obligation. Parents have an obligation to care for their children to promote their welfare and interests. The right of parents is to fulfil that obligation according to their own values.⁶ Ross^{7,8} argues that parents form the basis of the family, the unit that provides for the well-being of children, and some degree of parental autonomy is needed for the family to do this job effectively.

The second claim, which parents do not have an obligation to act in the *maximal* best interests of their children, may sound controversial, but is again widely supported. Blustein¹⁹ makes this case strongly, arguing that 'parents do not have an obligation to do what is best, but what is good enough'. His argument is founded on Salter's⁵ analysis and rejection of best interests standard. Kopelman²⁰ also argues the appropriate standard to hold parents to is 'adequate parenting'.

The more controversial issue is where the limit to parental authority to decide for children lies. Claim 3, based on the Harm Principle, is that the limit lies at the point where the child is likely to suffer significant harm. In essence, this puts the same ethical limit on parental autonomy as the limit on the autonomy of all

individuals: it stops where the exercise of autonomy risks causing harm to others. It might be objected that adopting the Harm Principle as the place to draw the line on intervening in parents' decision sets the bar too low. It does not meet the 'best interests' standard used in law in many jurisdictions. However, the ZPD is not intended to address legal decision-making. It is a tool for ethical decision-making. Clinicians and/or ethicists should assess the *ethical* acceptability of acting on the parents' wishes, using the Harm Principle test embodied in the ZPD. If they decide that the parents' wishes fall outside the ZPD, then they should not do what the parents want. If it is necessary to go to court in order to achieve this, then the court will use legal standards related to the child's best interests to make its decision. It is highly likely, though, that when the court uses this 'higher' standard of the child's best interests, it will come to the same conclusion as clinicians or ethicists, who have used the 'lower standard of avoiding harm to the child – the conclusion that the parents' wishes should be overridden.

The apparently more problematic implication of accepting that clinicians and ethicists can and should use a 'lower' standard than that used by the court is that they will decide to accede to or tolerate parental decisions, which a court may override. The ZPD process as I have presented in this paper does indeed imply this, but two points must be made. First, we should not accept too readily that courts actually do use a strict best interests standard, even though court decisions are couched in these terms. There is some evidence and analysis to show that in practice, courts' judgements are at least sometime more consistent with a harm threshold than a best interests standard.^{3,5,6,21} Second, and more fundamentally, I suggest that it is the job of ethicists and clinicians to make ethical decisions, not legal ones, and the sounder ethical basis for decisions about acceding to parents' wishes or not is the Harm Principle. Knowing that courts use a higher standard and will override parents' wishes more readily just makes the ethical challenge in the clinical setting more sharply defined. Doctors and clinicians must decide whether it is ethically appropriate to take a case to court, when they are aware that the decision is likely to go against the parents. If they believe that this would not be the ethically appropriate outcome, they should not seek to take the matter to court in the first place.

Conclusion

The ZPD provides a clear and practical way of operationalising the Harm Principle to guide ethical decision-making when parents and doctors disagree about the treatment of a child. I argue that there are two

main advantages of using the ZPD, over the more instinctive approach of focusing on best interests. The first lies in avoiding the 'best interests bog', which I described earlier. Finding the one right answer to the question of what is in child's best interests can be virtually impossible. Using the ZPD circumvents this by going straight to the question of whether the parents' decision will harm the child. This is a negative rather than a positive question and can be easier to answer. We do not have to agree on which course of action is best for the child, merely recognising whether the course of action wanted by the parents is harmful to the child. Second, using the ZPD sets the ethically appropriate presumption about parents' decisions: they should be respected, unless there is good reason not to. The burden of proof lies with those who would override: when clinicians and ethicists are uncertain or disagree among themselves about what is best for the child, this is usually a reliable sign that this burden of proof has not been met, and the parents' decision should be acceded to.

Using the ZPD does not take away greyness in ethical deliberation. The question of whether the parents' decision is likely to cause harm to the child will often not be black and white. It will still be necessary to worry about how probable any negative effects on the child must be in order to count, and whether these effects would be of sufficient magnitude to constitute harm. It might be argued that the ZPD has merely moved the difficulty, not resolved it. But moving it is a significant step – at least we are now worrying first about the correct ethical issue and giving ourselves a better chance of resolving it. Using the ZPD will not necessarily produce a different outcome to the 'best interests of the child' approach. In practice, that approach does sometimes include consideration of the parents' decision or wishes, and flexibility around values and the need to maximise, as noted above,^{3,5,6,21} so it may well produce same, ethically appropriate, outcome as using the ZPD. But it is less well set up to do so and gets there by an unnecessarily circuitous route.

Insofar, as this is an argument for the practical advantages of using ZPD rather than a best interests approach, empirical evidence (e.g. of less time spent resolving disagreement situations) would be needed to validate it. However, I am also arguing that the ZPD has ethical advantages over best interests approaches. The ZPD puts into practice well-founded, widely accepted ethical positions regarding parental rights and decision-making authority. And it focuses attention directly on the most important ethical issues when parents and doctors disagree about medical treatment for children – which is the potential harm to the child, rather than maximization of the child's interests.

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References

- Buchanan E and Brock W. *Deciding for Others: The Ethics of Surrogate Decision Making*. Cambridge: Cambridge University Press, 1998.
- Beauchamp TL and Childress JF. *Principles of Biomedical Ethics*, 6th ed. New York: Oxford University Press, 2009.
- Baines P. Death and best interests. *Clin Ethics* 2008; 3: 171–175.
- Kopelman LM. Using the best interests standard in treatment decisions for young children. In: Miller G (ed.) *Pediatric Bioethics*. Cambridge: Cambridge University Press, 2010.
- Salter EK. Deciding for a child: a comprehensive analysis of the best interest standard. *Theor Med Bioeth* 2012; 33: 179–198.
- Diekema DS. Parental refusals of medical treatment: the Harm Principle as threshold for state intervention. *Theor Med* 2004; 25: 243–264.
- Feinberg J. *Harm to Others*. New York: Oxford University Press, 1984.
- Ross LF. *Children, Families, and Health Care Decision Making*. Oxford: Oxford University Press, 1998.
- 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.
- Gold H, Hall G and Gillam L. Role and function of a paediatric clinical ethics service: experiences at the Royal Children's Hospital, Melbourne. *J Paediatr Child Health* 2011; 47: 632–636.
- McDougall R, Delany C, Spriggs M, *et al*. Collaboration in clinical ethics consultation: a method for achieving "balanced accountability". *Am J Bioeth* 2014; 14: 47–48.
- Degrazia D. Value theory and the best interests standard 1. *Bioethics* 1995; 9: 50–61.
- Binik A. On the minimal risk threshold in research with children. *Am J Bioeth* 2014; 14: 3–12.
- Singh J, Fanaroff J, Andrews B, *et al*. Resuscitation in the gray zone of viability: determining physician preferences and predicting infant outcomes. *Pediatrics* 2007; 120: 519–526.
- Leuthner SR. Borderline viability: controversies in caring for the extremely premature infant. *Clin Perinatol* 2014; 41: 799–814.
- Seri I and Evans J. Limits of viability: definition of the gray zone. *J Perinatol* 2008; 28: S4–S8.
- Rachels J. Active and passive euthanasia. *N Engl J Med* 1975; 292: 78–80.
- Takala T. Acts and omissions. In: Ashcroft RE, Dawson A, Draper H, *et al* (eds) *Principles of Health Care Ethics*, 2nd ed. Wiley: Chichester, 2007.
- Blustein J. Doing the best for one's child: satisficing versus optimizing parentalism. *Theor Med Bioeth* 2012; 33: 199–205.
- Kopelman LM. The best interests standard as threshold, ideal, and standard of reasonableness. *J Med Philos* 1997; 22: 271–289.
- Lyons B. Children, best interests and the courts: a response to Bridgeman. *Clin Ethics* 2010; 5: 188–194.