

## CLINICAL ETHICS

# Is it in the best interests of an intellectually disabled infant to die?

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One of the most contentious ethical issues in the neonatal intensive care unit is the withdrawal of life-sustaining treatment from infants who may otherwise survive. In practice, one of the most important factors influencing this decision is the prediction that the infant will be severely intellectually disabled. Most professional guidelines suggest that decisions should be made on the basis of the best interests of the infant. It is, however, not clear how intellectual disability affects those interests. Why should intellectual disability be more important than physical disability to the future interests of an infant? Is it discriminatory to base decisions on this? This paper will try to unravel the above questions. It seems that if intellectual disability does affect the best interests of the child it must do so in one of three ways. These possibilities will be discussed as well as the major challenges to the notion that intellectual disability should have a role in such decisions. The best interests of the child can be affected by severe or profound intellectual disability. It is, though, not as clear-cut as some might expect.

that if she survives, she will be severely cognitively impaired. Further discussions are held with the child's parents about whether it is in her interest to continue with active treatment.

### INTRODUCTION

Neonatal intensive care is barely 40 years old. The technological change and medical advances made in this time have meant that many babies who would previously have died can now be saved. Some of these infants, however, will survive with severe and sometimes overwhelming disabilities, and parents and neonatal teams must grapple with the question of whether prolonging the life of the infant is the right thing to do. As early as 1973, some neonatologists were willing to publicly express their concerns for those infants and for their families in public, and suggest that perhaps not all should be actively treated.<sup>1</sup> Despite the controversial nature of such decisions, and ongoing legal uncertainty, life-sustaining treatment continues to sometimes be withheld or withdrawn from infants who might otherwise survive.<sup>2–4</sup>

In my experience of neonatal and paediatric intensive care, the single most important factor in discussions on withdrawal of treatment is the presence (or predicted presence) of severe intellectual disability.<sup>5</sup> In a case such as Bella's, parents and medical teams would often decide to withdraw active treatment or continue treatment only after much deliberation. Many doctors who might acquiesce to parents' request for continuing active treatment before the results of her MRI would have deep misgivings about continuing to sustain her life in the context of this new discovery. On the other hand, where intellectual disability is not present (or predicted), even when the child's prognosis is very grim, or includes substantial physical disabilities, there

The following case is fictitious (the medical and ethical issues, however, are real and not uncommon).

Bella is born prematurely at a gestational age of 28 weeks (12 weeks premature). She is reasonably healthy at birth, is taken to the neonatal intensive care unit and makes good initial progress. At 1 week of age, however, she develops a life-threatening intestinal infection (necrotising enterocolitis). She is resuscitated and transferred to a surgical unit for an urgent laparotomy. At operation almost all of her intestine is found to be necrotic. Her parents are immediately counselled that her long-term outlook is grim, but they wish everything possible to be done. Bella recovers from the surgery and the infection of her bowel, but is left with insufficient intestine to ever be able to feed normally. She will require nutrition via a surgically inserted intravenous catheter for the remainder of her life. She is expected to have recurrent infections in those catheters, to spend large parts of her infancy and childhood in hospital and is likely to die in childhood. Bella subsequently undergoes magnetic resonance imaging of her brain, which shows that she has suffered diffuse white matter injury from her period of being seriously unwell. It is expected

**Abbreviation:** PVS, persistent vegetative state

Throughout this paper, I will be referring to "severe" and "profound" intellectual disability. I am using this terminology consistent with traditional classification of intellectual disability, albeit fairly informally. For example, the International Classification of Diseases, 10th revision, classifies severe intellectual disability as having an intelligence quotient of 20–34, and profound disability as having an intelligence quotient of <20. People with severe disability usually have impairment of motor skills, difficulty in ambulation and limited communication ability. Most of them require close supervision and care throughout life. Those with profound disability are able to achieve even rudimentary self-care tasks only with extensive training, and require total supervision and care.<sup>5</sup>

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is often a reluctance to countenance anything less than maximal treatment. For example, in some units at least, palliative care is not usually offered as an option to parents of infants with the severe congenital heart problem “hypoplastic left heart” or parents of extremely premature infants (say 24 weeks gestation), unless severe brain damage is evident.

There has been relatively little discussion in the medical or bioethics literature, as available, on the validity of assigning such importance to cognitive disability in decisions on life-sustaining treatment. Campbell and Duff were among the first neonatologists to write about withdrawal of life-sustaining treatment in newborn infants. They believed that the most important medical criterion for decisions was “the degree of abnormality, disease or damage to the central nervous system”.<sup>6</sup> In the 1980s, Weir<sup>7</sup> delineated a group of conditions where he thought that treatment was not in the best interests of the child. He noted that virtually all of these conditions involve serious neurological deficits, whereas most of the conditions that he thought merited treatment do not involve cognitive impairment.<sup>7</sup> In a more recent survey on withdrawal of neonatal treatment in the UK, McHaffie and Fowle<sup>8</sup> found that mental disabilities were more influential than physical disabilities in treatment decisions.

When decisions are made to withhold or withdraw life-sustaining treatment, the justification for these decisions is often that it is not in the interests or best interests of the child to continue to prolong life. This is the line of thinking recommended by professional bodies,<sup>9–13</sup> is supported by a large number of writers in the ethics literature<sup>7 14–17</sup> and accords with the terminology used by the courts in such cases.<sup>18–20</sup> The link between intellectual disability and the interests of the child, however, is not immediately obvious, and some would refute such a connection. In particular, it may be claimed that the use of intellectual disability to justify withholding life-sustaining treatment is discriminatory or is based on a false assessment of the quality of life of those with such disabilities. I will return to these objections a little later, but first it would be worthwhile taking a step back to ask what “interests” are and what “best interests” mean.

## WHAT ARE “INTERESTS” AND “BEST INTERESTS”?

For adults, decisions are made on the basis of autonomous choice or (in cases where they are not competent, but their wishes are known) by what is known as “substituted judgement”. In contrast, for those never competent, such as newborn infants, decisions have to be made by a proxy. This is usually a parent, although sometimes the courts, by using their *parens patriae* jurisdiction, will serve as decision makers. In either case, the standard often appealed to in making decisions is that of the best interests of the child. This is a beneficence standard, and reflects an attempt to weigh up different competing interests, or to adjudicate which course of action will lead to the best balance of net benefits and burdens for the child. The judicial interpretation of best interests in neonates and in other incompetent patients has been criticised as uncertain<sup>20</sup> or as an empty formula that is applied uncritically without sufficient analysis.<sup>21</sup> In clinical use, there has been criticism that appeals to best interests may actually reflect other considerations resource, for example, limitations, parental interests or the interests of other siblings (Beauchamp,<sup>14</sup> p 171).<sup>22</sup> <sup>ii</sup> More fundamental objections have been raised on the appropriateness of using best interests in treatment decisions, on the grounds that the standard is unrealistic, unknowable or overly individualistic

<sup>ii</sup>Brody<sup>23</sup> makes a further objection to “best interests”—that it yields the wrong answer in children who are profoundly disabled (p 38). This paper can be seen as providing a reply to this objection, by emphasising the effect of severe intellectual disability on the benefits of life.

(Beauchamp,<sup>14</sup> p 171).<sup>23–25</sup> For a response to these criticisms see Kopelman.<sup>26</sup> Nevertheless, as already mentioned, the notion of the best interests of the child forms part of most professional guidelines. If we are to use the interests of the child as a guide to treatment decisions in severely impaired newborns, we need to be clear what the standard means (in theory and in practice). To take this further, we need to clarify what we mean by interests.

In philosophical discourse, to have an interest in X is to have a stake in it—that is, to stand to gain or to lose, depending on the nature or conditions of that something.<sup>27</sup> This sense of interest is different from that used in everyday language, when we talk about taking an interest in something or being interested in it.<sup>28 29</sup> Rather, we have an interest in something when we may be benefited or harmed by it. The subsidiary question of what can benefit or harm someone, or what is good for them raises further fundamental questions about prudential value. Is it necessary to be conscious of something for it to be in (or against) our interests (subjective model of value)? Or alternatively, are there some things that are good for us regardless of whether or not we can perceive them (objective model)? (Veatch<sup>25</sup>, p 7).<sup>30</sup> Such things may include health, autonomy, deep personal relationships, accomplishment and enjoyments.<sup>31</sup> Different models of prudential value may yield starkly different results on the best interests of an individual.<sup>31</sup> This is particularly the case for newborn infants, whose consciousness of themselves and of the world is limited in comparison to competent adults. For example, philosophers such as Peter Singer and Michael Tooley have argued, using a subjective model of value, that as newborns lack the capacity to conceive of themselves as individuals continuing over time, they cannot be said to have an interest in life-sustaining treatment.<sup>32 33</sup> <sup>iii</sup> Furthermore, it becomes important to know how to give weight to the future interests of individuals, particularly when they may or may not exist to experience them, and, again, such questions have provoked considerable debate.

I am going to sidestep these questions a little, by outlining two features of the way in which the notion of best interests is applied in practice. Firstly, regardless of how we account for interests arising in the future, it is possible for future interests to count against life-sustaining treatment (Brody,<sup>23</sup> p 38 and Kuhse,<sup>28</sup> pp 140–46). Thus, if an individual were predicted to have a life of intense unremitting suffering, without a possibility of cure or respite, it would be reasonable to think that their future interests would count against prolonging their life. This would be the case even if they were presently unconscious and had no current preferences or desires that were being frustrated. Secondly, I think that there is an assumption in the minds of parents and doctors that a future of overall benefit is in the interests of the newborn infant. This may not make sense in a purely subjective model of interests (as the newborn is not able to perceive or prefer that future, it can be neither in, nor contrary to, their interests). Nevertheless, I believe that if best interests are to have any meaning in treatment decisions for neonates, it can only be by holding that a future of value is in their interests.<sup>iv</sup> In practice then, the key task for parents and treating teams is to imagine what the future life of that newborn infant will be like, and the key question is whether the life in prospect will be of sufficient quality (or “value” or “net benefit”) for that individual, to justify continuing to sustain it.

I accept that the above account is brief and outlines several assumptions that I do not have room to justify in depth here.

<sup>iii</sup>Tooley uses the language of “rights” rather than interests.

<sup>iv</sup>This argument has obvious similarities to Don Marquis’s argument on the wrongness of killing fetuses.<sup>34</sup>

But, I think that it provides the basis for what follows—which is an attempt to understand how the prediction that a child will have severe intellectual disability may affect the child’s interest in life-sustaining treatment.

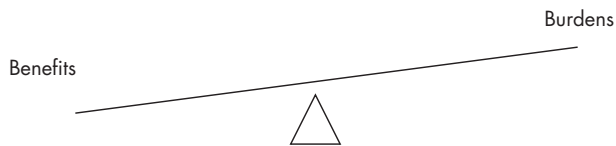
**HOW DOES PREDICTED SEVERE INTELLECTUAL DISABILITY AFFECT THE INTERESTS OF THE CHILD?**

It may be helpful in what follows to use a simple schematic diagram to illustrate the possible ways in which intellectual disability may affect the best interests of a child. If I am right in assuming that the key question is to examine the future for that child, our task is to appraise the benefits and burdens of the child’s future life. This can be construed as a kind of weighing-up or balancing process (fig 1).

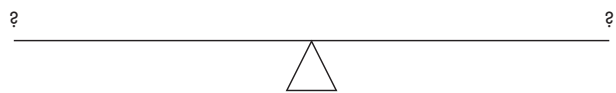
There are three possible ways in which the interests of an infant can be adversely affected by the prediction that they will be severely intellectually disabled. Firstly, it is possible that the disability is so severe that all concept of interests becomes meaningless (fig 2). Secondly, intellectual disability may substantially increase the burdens of life (by causing suffering; fig 3). Finally, severe intellectual disability may diminish the benefits of life that will be enjoyed (fig 4). I will deal with each of these in turn.

**Abolition of interests**

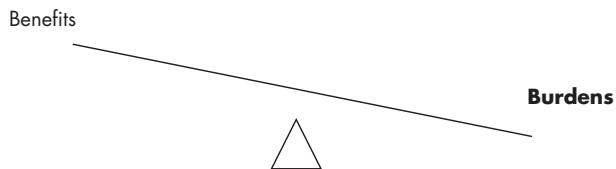
Intellectual disability includes a spectrum of degrees of impairment of thinking, communication and awareness. At the most severe end of the spectrum, however, are some rare conditions that seem to preclude even rudimentary consciousness. Infants with anencephaly are born with their



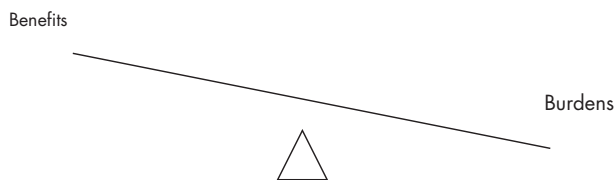
**Figure 1** Assessing the best interests of an infant. What is the balance of benefits and burdens in the infant’s future life?



**Figure 2** The best interests of a child with anencephaly. The interests of the child seem to lose meaning.



**Figure 3** An increase in the burdens faced. Does intellectual disability per se cause suffering?



**Figure 4** The other side of the balance. Does intellectual disability decrease the benefits of life?

skull and spine open to the air, their brain having almost completely failed to develop.<sup>35</sup> Infants born with the similarly named, but unrelated, hydranencephaly have a cerebrum largely filled with fluid.<sup>36</sup> Infants with anencephaly or hydranencephaly often die in utero or shortly after birth, but, occasionally, can be sustained alive for months or even years.<sup>36 37</sup> These infants lack the anatomical substrate for sensory processing, cognition and motor coordination. They do not seem to have any capacity for sensory awareness.

Conditions as severe as these have been argued to be inconsistent with any concept of interests.<sup>38–41</sup> Even conservative writers have struggled to make sense of infants with anencephaly being benefited from anything.<sup>42</sup> Of course, if an objective model of the good is appealed to, the infant can still be said to have an interest in the goods of life. Yet, to say that health, deep personal relationships or even nurturing can be good for an infant with anencephaly seems difficult to accept.<sup>v</sup>

Such conditions provide a fundamental challenge to the notion that biological human life is intrinsically valuable. Foot<sup>43</sup> sees life as good in itself (rather than instrumentally), but she too seems compelled to admit that the connection between life and good may be broken when “consciousness has sunk to a very low level, as in extreme senility or severe brain damage”. At such a level, an individual can no longer be said to have an interest in anything, even in life. Whether there is a threshold below which life loses intrinsic value, or whether it is more plausible to think of the instrumental value of life being diminished by progressively more limiting disabilities, is a question that I will return to later.

In some ways, these infants are similar to adults in a persistent vegetative state (PVS). Judicial decisions in PVS have referred to these individuals as having no interests.<sup>18</sup> Drawing on such a premise, the courts and some writers have argued that life-sustaining medical treatment is not in the patients’ best interests. Fenwick<sup>18</sup> has questioned the logic of applying best interests considerations to individuals with no interests. The apparent justification of decisions to withdraw treatment in patients with PVS has sometimes relied on an inversion of the best interests standard, with adjudication of treatments that are “not in a patient’s best interests”.<sup>vi</sup> The objections to this manoeuvre are, however, twofold. Firstly, if a patient has no interests, then application of a test for best interests is redundant, if not meaningless. Secondly, to say that treatment is not in a patient’s best interests in this context is not to say that it is against the patient’s best interests to continue treating, nor that the cessation of treatment is in the patient’s best interest. Justification for decisions on treatment must lie elsewhere. If we return to an infant with anencephaly, such justification may lie in the wishes of the infant’s family or in the cost to the state of continuing treatment without benefit.

**Increase in burdens**

Sometimes when writers talk about treatment decisions in newborn infants, they use the examples of infantile Tay Sachs disease or Lesch–Nyhan syndrome. Tay Sachs disease is a disorder causing progressive neurological deterioration after 6 months of age, with severe epilepsy, cognitive decline and death in the second year.<sup>44</sup> Lesch–Nyhan syndrome is an inherited disorder of amino acid metabolism that leads to severe physical and intellectual disability, with spastic

<sup>v</sup>This intuition is perhaps a reason to reject purely objective models of value.

<sup>vi</sup>This has the apparent object of avoiding making a controversial judgement—that is, that a patient is “better off dead”. Fenwick<sup>18</sup> goes further in suggesting that at times best interests are also appealed to in an attempt to avoid making explicit “quality of life” judgements.

tetraparesis as well as repeated self-mutilation.<sup>45</sup> These conditions are often referred to as paradigm conditions that cause the child so much suffering (ie, increase the future burdens) that life-sustaining treatment would be contrary to best interests (Kuhse,<sup>28</sup> pp 140–4 and Weir,<sup>7</sup> pp 116–24, 235–7).<sup>46–47</sup> Does severe intellectual disability cause an individual to suffer per se? Unhappiness, as measured by the incidence of clinical depression, seems to be more common in people with cognitive impairment.<sup>48</sup> This may be partly ascribed to awareness of their difference from others, the limitations imposed on them by their disability and the consciousness of being treated differently (or even discriminated against). But there is a paradox. It is conceivable that the more severe an individual's cognitive disability, the less severe is the degree of unhappiness or preference-frustration that is caused. Beyond a certain point, people lose insight into their own disability, and hence lose the distress associated with awareness of their own limitations. At the other end of the age spectrum, in people with progressive senility, a phase of distress is associated with awareness of cognitive decline, followed at a certain point by a sort of blissful ignorance. The paradox here lies in an intuition that the more severe an infant's predicted cognitive impairment, the more important its role in questions on providing life-sustaining treatment. Yet, the degree to which infants may be made to suffer by their cognitive disability (on its own) may be inversely proportional to the severity of the disability. Harm from negative subjective experiences alone cannot substantiate a claim that ongoing treatment is against the best interests of the child who has severe cognitive impairment (Arras,<sup>38</sup> pp 30–1).

On the other hand, many people with severe intellectual disability also have major physical disabilities or illnesses. They may have painful contractures, muscle spasms, dislocated joints or unstable epilepsy. Furthermore, there is a sense in which intellectual disability may impair an individual's ability to bear suffering. This is because the ability to rationalise or understand the cause of physical suffering, its necessity and its finitude, and to anticipate its relief is what makes it possible to endure. Intellectually normal children or adults may take psychological refuge from their discomfort, whereas for people with severe intellectual disability, even a routine trip to the dentist or to the doctor can be a terrifying ordeal.<sup>vii</sup>

It may be interesting to imagine a child with Lesch–Nyhan syndrome who was predicted to have normal intellect. Some may well be less inclined to withdraw life-sustaining treatment for this child compared with a child with Lesch–Nyhan syndrome and severe intellectual disability. It is, however, not clear that this is justifiable on the basis of suffering. On the basis of what we have just discussed, the child with intellectual disability may suffer less than one with normal intellect, although it is difficult to know whether the lack of existential suffering would be outweighed by the lack of ability to understand and withstand distress from physical illness. If we are to make sense of this, I think that we must look instead at the other side of the equation—the benefits side—and ask whether intellectual disability affects the benefits that can be gained from life.

### Reduced benefits

Before we talk further about the benefits or value of life of an individual with an intellectual disability, it is worthwhile distinguishing two ways of looking at the value of life. Sometimes the lives of different people are compared, perhaps to decide which of them should be saved with an organ transplant. This sort of valuation is controversial, and to many offensive, because it conflicts with notions of

equality of opportunity. (Buchanan and Brock<sup>39</sup> (p 74) refer to this as social worth or interpersonal value.) But, a different way of looking at the value of a life is to assess the value of the life to the individual who is experiencing it or who will experience it. This sort of intrapersonal valuation (Buchanan and Brock<sup>39</sup> (p 74)), by contrast, does not imply any sort of comparison with others. When we are making decisions on life-sustaining treatment for a newborn on the basis of the infant's best interests, it is this intrapersonal sort of value that we must assess.

Does intellectual disability affect the benefits that an individual will accrue from life? One critical difficulty in answering this is that the very nature of severe intellectual disability prevents us from accessing the experience of those who have severe disability. The level of disability that we are referring to makes communication difficult, if not impossible. To assess the quality of life of individuals who have severe impairment, we are forced to imagine what life would be like from their perspective. This sort of exercise may, however, implicitly bias our assessment.<sup>49</sup>

One who has never known the pleasures of mental operation, ambulation and social interaction surely does not suffer from their loss as much as one who has. While one who has known these capacities may prefer death to a life without them, we have no assurance that the handicapped person, with no point of comparison would agree.<sup>50</sup>

To imagine life as experienced by people with severe cognitive impairment is particularly difficult, as the fear of the loss of our own mental capacities is widespread and deep rooted. We must imagine what it would be like to lack most of our powers of reflection and reason (and imagination!), but also imagine never having had them and ignore our underlying aversion to being in such a state. Whether this is even possible is a moot question. Some have wondered whether doctors and philosophers may have a further bias in their assessment of the quality of life of people with intellectual disability, because their profession and scientific model is dependent on intellectual competence<sup>viii, 51</sup>. Robertson<sup>50</sup> takes this scepticism (of our ability to judge the internal experience of people with severe disability) to its logical extreme by imagining a “profoundly retarded, nonambulatory, blind, deaf infant who will spend his few years in the back-ward cribs of a state institution”. Even in this case, Robertson suggests that we cannot conclude that life is not worth living. Arras sees Robertson's example as implying two possibilities—that the best interest standard mandates treatment even in the worst cases (provided that the child is not in pain) or, alternatively, that in such extreme cases the concept of best interests has been stretched beyond its capabilities (Arras,<sup>38</sup> pp 30–1). He follows the second course and suggests that an additional principle is needed to provide a limit to the best interests standard. But I think that it is worth considering Robertson's suggestions a little further.

Our capacity to know or even imagine what the internal experience of life is like for those who are most severely affected is extremely limited. This difficulty leads Robertson to reject any assessment of the future quality of life of infants with disability. This may be reasonable if there was literally no other way to assess the intrapersonal value of an individual's life. In fact, Robertson's approach seems to assume a mental-state model of value. This regards the

<sup>vii</sup>I am grateful to a reviewer for highlighting this point.

<sup>viii</sup>Boddington and Podpacdec<sup>51</sup> criticism is aimed at philosophers, but it applies equally to doctors.

absence of pain in particular as the only relevant moral consideration (Arras,<sup>38</sup> pp 30–1). On the contrary, I would suggest that, in cases where an individual's subjective experiences are inaccessible, we are forced to look at their ability to benefit from things that are often believed to be objectively valuable in human life. These may include knowledge, communication, the development of deep reciprocal relationships, or the achievement of goals or ambitions (Veatch<sup>25</sup>, p 7).<sup>30</sup> The specific contents of this list and the order in which they are listed vary with different writers. I think, however, that many of them are considerably limited or prevented by severe intellectual disability. Why should this be the case? It is at least partly because reason is a key distinguishing characteristic of humans. When we try to define what things are good in human life, it is not surprising if the goods that we agree on are dependent on cognitive capacity and limited by cognitive disability.

Is this a fair comparison however? I have already suggested that our focus is not on comparing the life of an individual with disability with one without disability. Should there be different goods for someone with severely limited capacities? For example, a dog may have a good life even though it attained few, if any, of the objective goods of a human life. Should the goods of life for a human with the cognitive capacity of, say, a dog be those that we think of in relation to the life of a dog? McMahan<sup>52</sup> asks a similar question. This state would be unfortunate for the human with disability, but not for a dog (it may be a relatively fortunate state for a dog). Is this distinction non-arbitrarily justifiable? McMahan rejects species membership as a plausible solution, but does not find a conclusive answer to the problem. Perhaps the conclusion will be the same. If an individual with severe cognitive impairment had a different set of objective goods, they would seem to be lesser goods than those that apply to normal human life. While the individual would have an interest in attaining them the ability of those goods to outweigh suffering would, I believe, be reduced.

The above analysis provides reasons for thinking that the degree to which the interests of an individual will be reduced is proportional to the severity of their intellectual impairment (unlike the harm attributable). Accordingly, the value of life for that individual is reduced in proportion to the severity with which he or she is affected. In the most profound types of cognitive disability, there do not seem to be any benefits in life for the individual. This accords with a suggestion that I made earlier, that the ascription of “no interests” to those who have anencephaly or hydranencephaly is at the far end of a continuum of progressive reduction in the instrumental value of life. I think that this makes more sense than invoking a threshold below which interests are lost. For example, various writers have suggested that either the capacity to develop relationships<sup>53</sup> or the capacity to engage in minimal social interaction<sup>54</sup> is the critical capacity for ascription of interests.<sup>ix</sup> But, each of these represents a limited vision of the good of human life. These are but a few of the many goods of life that are diminished by severe and especially profound intellectual impairment.

Does this mean that severe intellectual disability provides grounds for thinking that life-sustaining treatment is not in the best interests of the child? If we return to our schematic diagram (figure 4), it becomes apparent that this is only the case where there are significant burdens on the other side of the equation. Where infants are not predicted to suffer, the fact that they have severe intellectual disability does not

<sup>ix</sup>For similar suggestions, see Arras<sup>38</sup> (p 32). A related claim is that life without the capacity for certain goods is “meaningless”.<sup>55</sup>

<sup>ix</sup>It is thus a form of discrimination (in the uncontroversial sense)—but not “unjust” to do so.

provide on its own justification for withdrawal of active treatment, although it provides less of a counterweight. Its importance is such that less suffering may be required for us to think that the balance of benefits and burdens is skewed against prolonging life.

## CONCLUSIONS

We can now explain how the news that Bella will have severe intellectual disability may affect a “best interests” assessment of decisions on treatment. Although Bella will almost certainly have severe cognitive impairment, she will have some degree of consciousness and be able to experience both pleasure and distress. Accordingly (regardless of how we may view her interests at this moment, or which model of value we use), if she lives, she will have interests. The effect of her disability on her interests is not of the sort that might take place if she were permanently unconscious or had anencephaly. Secondly, although Bella might be predicted to have considerable suffering in her future life (related to complications of short gut and parenteral nutrition), her intellectual disability will not directly contribute to her suffering, although it may make the aforementioned complications harder to bear. Accordingly, her disability probably does not substantially add to the burdens that she will face.

If intellectual disability is to affect Bella's interests, it must be by means of the third possibility outlined above—that is, that it reduces the benefits available to her in her future life, and correspondingly provides less of a counterweight to the expected suffering. To think about this question in slightly different terms: Bella's parents may ask themselves whether it is worth putting Bella through the misery and certain suffering of further surgery and the attendant complications. The things that make it worthwhile in their eyes would depend on the specific things in life that her parents value. These may include having some ability to develop as an individual, being able to communicate, develop relationships and interact with her parents and siblings. The absence or diminishment of such benefits may well make them think that it would not be in her best interests to prolong her life.

In this paper, I have attempted to explore the question of predicted severe intellectual disability and how it may affect the interests of an infant in the provision of life-sustaining treatment. For treatment decisions we can make sense of the best interests of a neonate only by assuming that the neonate has an interest in a future life of net value. This necessitates some sort of appraisal of the balance of burdens and benefits in the infant's future life. Intellectual disability *per se* does not provide grounds for withdrawal of intensive care from newborn infants. Its effect on interests is not straightforward. It may abolish interests (but only in the most profound cases); it does not directly increase the burdens faced by the child (but may do so indirectly); and it may reduce the benefits of life for the child. I have suggested that this last factor (of reducing the benefits of life) is the most important, and is proportional to the severity of intellectual disability. Physical disability may also be important in so far as it is likely to cause substantial physical suffering for the infant, or to preclude the infant from accessing those things which are objectively valuable in human life.

I have also dealt with two important objections to intellectual disability playing a significant role in treatment decisions in newborn infants. This does not necessarily rely on a false assessment of the quality of life of individuals with intellectual disability. The benefits of life may be reduced in those with severe and profound disability. Furthermore, this analysis provides reasons why it would not be unjustly discriminatory to rely on such factors. Ethically relevant reasons exist for considering severe intellectual disability to be important in thinking about the interests of a child.<sup>ix</sup>

Weighing up the future benefits and burdens in a child's life is an extremely difficult task. How should different goods of life be weighed? How much suffering is enough to outweigh them? I have argued in this paper that severe intellectual disability can affect the balance. I have, however, been deliberately vague on the exact nature of this effect, as it seems that clear cut-offs are impossible to define. There will be many instances where the uncertainties of prediction mean that the balance is genuinely unclear. In such cases, the interests of the parents or of other siblings or of society may be relevant and may help sway decisions. The best interests of the child is a laudable standard to appeal to; however, it may provide little practical guidance to decision making. Accordingly, we may be tempted to ask whether it should be held up as the only way to make such decisions.

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## REFERENCES

- Duff RS, Campbell AG. Moral and ethical dilemmas in the special-care nursery. *N Engl J Med* 1973;**289**:890–4.
- Caniano DA, Hazebroek FW, DenBesten KE, et al. End-of-life decisions for surgical neonates: experience in The Netherlands and United States. *J Pediatr Surg* 1995;**30**:1420–4.
- Singh J, Lantos J, Meadow W. End-of-life after birth: death and dying in a neonatal intensive care unit. *Pediatrics* 2004;**114**:1620–6.
- de Leeuw R, de Beaufort AJ, de Kleine MJ, et al. Foregoing intensive care treatment in newborn infants with extremely poor prognoses. A study in four neonatal intensive care units in The Netherlands. *J Pediatr* 1996;**129**:661–6.
- King B, Hodapp R, Dykens E. Mental retardation. In: Sadock B, Sadock V, eds. *Kaplan & Sadock's comprehensive textbook of psychiatry*. 7th edn. Philadelphia: Lippincott, Williams and Wilkins, 2000.
- Campbell AG, Duff RS. Author's response to Richard Sherlock's commentary. *J Med Ethics* 1979;**5**:141–2.
- Weir R. *Selective non-treatment of handicapped newborns: moral dilemmas in neonatal medicine*. Oxford: Oxford University Press, 1984:237–8.
- McHaffie HE, Fowlie PW. *Life, death and decisions: doctors and nurses reflect on neonatal practice*. Hale: Hochland and Hochland, 1996:96.
- Royal College of Paediatrics and Child Health. *Withholding and withdrawing life-saving treatment in children: a framework for practice*. London: Royal College of Paediatrics and Child Health, 1997.
- American Academy of Pediatrics Committee on Fetus and Newborn. The initiation or withdrawal of treatment for high-risk newborns. *Pediatrics* 1995;**96**:362–3.
- American Academy of Pediatrics Committee on Bioethics. Guidelines on foregoing life-sustaining medical treatment. *Pediatrics* 1994;**93**:532–6.
- British Medical Association. *Withholding and withdrawing life-prolonging medical treatment: guidance for decision making*. London: BMJ Books, 2001.
- General Medical Council. *Withholding and withdrawing life-prolonging treatments: good practice in decision-making*. London: General Medical Council, 2002.
- Beauchamp TL, Childress JF. *Principles of Biomedical Ethics*, 3rd edn. Oxford: Oxford University Press, 1989:162.
- Spence K. The best interest principle as a standard for decision making in the care of neonates. *J Adv Nurs* 2000;**31**:1286–92.
- Kluge E-HW. Severely disabled newborns. In: Kuhse H, Singer P, eds. *Bioethics: an anthology*. Malden, MA: Blackwell, 1999:246.
- The Commission. *Deciding to forego life-sustaining treatment: a report on the ethical, medical and legal issues in treatment decisions*, President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research. Washington: The Commission, 1983:217–23.
- Fenwick AJ. Applying best interests to persistent vegetative state—a principled distortion? *J Med Ethics* 1998;**24**:86–92.
- Gostin L. A moment in human development: legal protection, ethical standards and social policy on the selective non-treatment of handicapped neonates. *Am J Law Med* 1985;**11**:31–78.
- Shewchuk TR. The uncertain 'best interests' of neonates: decision making in the neonatal intensive care unit. *Med Law* 1995;**14**:331–58.
- Donnelly M. Decision-making for mentally incompetent people: the empty formula of best interests? *Med Law* 2001;**20**:405–16.
- Bailey S. In whose interests? The best interests principle under ethical scrutiny. *Aust Crit Care* 2001;**14**:161–4.
- Brody H, Bartholome WG. In the best interests of. *Hastings Cent Rep* 1988;**18**:37–40.
- Engelhardt HT. Taking the family seriously: beyond best interests. In: Kopelman LM, Moskop JC, eds. *Children and health care: moral and social issues*. Boston: Kluwer Academic, 1989:231–7.
- Veatch RM. Abandoning informed consent. *Hastings Cent Rep* 1995;**25**:5–12.
- Kopelman LM. The best-interests standard as threshold, ideal, and standard of reasonableness. *J Med Philos* 1997;**22**:271–89.
- Feinberg J. *The moral limits of the criminal law: harm to others*. Oxford: Oxford University Press, 1984:33–4.
- Kuhse H. Interests. *J Med Ethics* 1985;**11**:146–9.
- Regan T. McCloskey on why animals cannot have rights. *Philos Q* 1976;**26**:251–7.
- Parfit D. *Reasons and persons*. Oxford: Oxford University Press, 1984:493–502.
- DeGrazia D. Value theory and the best interests standard. *Bioethics* 1995;**9**:50–61.
- Kuhse H, Singer P. *Should the baby live? The problem of handicapped infants*. Oxford: Oxford University Press, 1985:132.
- Tooley M. Abortion and infanticide. *Philos Public Aff* 1972;**2**:37–65.
- Marquis D. Why abortion is immoral. *J Philos* 1989;**86**:183–202.
- Jones KL. *Smith's recognizable patterns of human malformation*, 5th edn. Philadelphia: WB Saunders Company, 1997:608–9.
- McAbee GN, Chan A, Erde EL. Prolonged survival with hydranencephaly: report of two patients and literature review. *Pediatr Neurol* 2000;**23**:80–4.
- McAbee G, Sherman J, Canas J, et al. Prolonged survival of two anencephalic infants. *Am J Perinatol* 1993;**10**:175–7.
- Arras JD. Toward an ethic of ambiguity. *Hastings Cent Rep* 1984;**14**:31–2.
- Buchanan A, Brock DW. Deciding for others. *Milbank Q* 1986;**64**:75–9.
- Fleischman AR. The right to die vs death in the best interests of the infant. *J Perinatol* 1989;**9**:86–7.
- Keyserlingk EW. Non-treatment in the best interests of the child: a case commentary of Couture-Jacquet v. Montreal Children's Hospital. *McGill Law J*, 1986–7, **32**:428.
- Fast N. Counseling families who have a child with a severe congenital anomaly. *Pediatrics* 1981;**67**:321–4.
- Foot P. Euthanasia. *Philos Public Aff* 1977;**6**:95.
- Fernandes Filho JA, Shapiro BE. Tay-Sachs disease. *Arch Neurol* 2004;**61**:1466–8.
- Harris J. Disorders of purine and pyrimidine metabolism. In: Behrman R, Kliegman R, Jenson H, eds. *Nelson textbook of paediatrics*. 16th edn. Philadelphia: WB Saunders, 2000:423–30.
- Steinbock B, McClamrock R. When is birth unfair to the child? *Hastings Cent Rep* 1994;**24**:15–21.
- Engelhardt HT. Ethical issues in aiding the death of young children. In: Kohl M, ed. *Beneficent euthanasia*. Buffalo: Prometheus Books, 1975:180–92.
- McBrien J. Assessment and diagnosis of depression in people with intellectual disability. *J Intellect Disab Res* 2003;**47**:1–13.
- Freeman J. *Medical wisdom and ethics in the treatment of severely defective newborns*. Fountain Valley, CA: Eden Press, 1978 (quoted in Kuhse, op cit p 63); Weir, op cit, pp 182–3).
- Robertson JA. Involuntary euthanasia of defective newborns: a legal analysis. *Stanford Law Rev*, 1974–5, **27**:213–70.
- Boddington P, Podpadek T. Measuring quality of life in theory and in practice. In: Kuhse H, Singer P, eds. *Bioethics: an anthology*. Oxford: Blackwell, 1999:277.
- McMahan J. *The ethics of killing: problems at the margins of life*. New York: Oxford University Press, 2002:325.
- McCormick RA. To save or let die. The dilemma of modern medicine. *JAMA* 1974;**229**:172–6.
- Engelhardt H. Medicine and the concept of a person. In: Beauchamp TL, Perlin S, eds. *Ethical issues in death and dying*. New Jersey: Prentice-Hall, 1978:271–84.
- Kohl M. Voluntary death and meaningless existence. In: Kohl M, ed. *Infanticide and the value of life*. New York: Prometheus Books, 1978:210.