The baby MB case: medical decision making in the context of uncertain infant suffering

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The recent MB case involved a dispute between an infant's parents and his medical team about the appropriateness of continued life support. The dispute reflected uncertainty about two key factors that inform medical decision making for seriously ill infants: both the amount of pain MB experiences and the extent of his cognitive capacities are uncertain. Uncertainty of this order makes decision making in accordance with the best-interests principle very problematic. This article addresses two of the problems that cases such as that of MB pose for those charged with making medical decisions for infants. First, the question of the moral significance of the interest in avoiding pain is considered. It is claimed that this interest can be outweighed by higher-order interests such as those related to autonomy but that where such higher-order interests do not exist, the interest in avoiding pain should be prioritised. Second, the question of how to proceed in cases in which the level of pain or the extent of an infant's higher-order interests cannot be decisively established is considered. It is suggested that when genuine uncertainty over the interests of an infant exists, parental views about treatment should prevail.

The English family courts recently adjudicated on another case involving conflict between parents and a medical team over the provision of life-prolonging medical treatment for an infant. At the time of the ruling, MB was an 18-month-old boy with type I spinal muscular atrophy. His life expectancy was very short (perhaps another year), he was almost completely paralysed (he could move his eyes and had slight movement in his eyebrows, the corners of his mouth, thumb, toes and feet) and he required constant ventilation. MB's parents wanted a tracheotomy to be performed to facilitate long-term ventilation and allow for some independence from the hospital ward, but the National Health Service Trust in question considered this to be against MB's best interests. Moreover, they advocated withdrawal of the current level of respiratory support (ventilation via endotracheal tube), in favour of furnishing ''such treatment by way of pain relief and sedation and nursing care as may be appropriate to ensure M experiences the least distress and pain and retains the greatest dignity'' as his life ends.[1 2]

Two major sources of uncertainty about the facts of this case contributed to the conflict between the parents and the medical team. First, the extent of MB's cognitive function was uncertain. His eyes could follow objects moved in front of his face, and his parents say that he exhibited awareness of his surroundings and was able to respond to them. They took this to indicate that MB was capable of experiencing things, interacting with others, and deriving pleasure from these experiences. But MB's consultants claimed that it was impossible to assess his cognitive function due to the extent of paralysis: MB may not have had the experiences his parents attributed to him.

Second, there was uncertainty about the extent of MB's physical suffering. Many of the procedures MB requires daily, such as deep suction, are known to be uncomfortable and distressing, but because MB is unable to communicate, it is unclear how great his distress is. In the face of this uncertainty, MB's parents prefer life at the expense of possible suffering, while his doctors favour an end to suffering at the cost of reduced quantity of life.

The established legal principle for proxy decision making for children is that of ''best interests'': decisions should be made with exclusive reference to the child's interests and should serve those interests in the best possible way. But in cases such as this, in which the facts required to reach informed and reliable accounts of an infant's best interests cannot be decisively established, identifying which course of action satisfies the best-interests principle is highly problematic.

In order to reach an assessment of best interests in a specific case, the facts must be known and an account of their effect upon the infant's interests is required. This paper comments upon two specific issues that arise in cases like that of MB, in which there is dispute both about the facts and about their significance with respect to the child's interests.

First, the significance of the interest in avoiding pain is discussed, and it is argued that, given the limited nature of infants' interests, avoiding pain is important but may be trumped by autonomy-based interests, where they exist.[i] For those infants without autonomy-based interests, however, the interest in avoiding pain is paramount to the child's best interests.

Second, the claims of parents in conditions of uncertainty are considered. It is argued that, where it is impossible to establish whether an infant is in pain or possessed of autonomy-based interests, parental views should be decisive in a way that the best-interests principle does not normally allow for.

This discussion operates under several constraints. First, it will be assumed that the correct principle to apply to medical decision making for infants is that of best interests. This principle means that the child's interests, rather than those of, say, the parents, guide decisions. This suggests that infants have high moral status (or that they are persons), as moral status means that your interests are worthy of serious consideration. (For further reading regarding moral status, see box). Although this is contentious, I will accept that infants do have high moral status for the purposes of this discussion.

Second, I acknowledge that resource constraints are of central importance to the resolution of cases such as that of MB, but, because of space constraints, they will not be fully dealt with here. Instead, the focus will be on the determination of the interests of infants and the role that parental interests might play with respect to them.

[i] I refer to the interest in avoiding pain for its own sake: a ''secondary'' interest may be derivable from other interests. For instance, if autonomy is impaired by high levels of pain, an autonomy-related interest in avoiding pain may develop.

Further reading

For further discussion of moral status, see:

- Harman E. The potentiality problem. *Philos Stud* 2003;**114**:173–98.
- Lipke R.Why persons are the ground of rights (and utility isn't). *J Value Inq* 1984;**18**:207–17.
- Singer P. *Practical ethics*. Cambridge: Cambridge University Press, 1993.
- Singer P. *Rethinking life and death*. Oxford: Oxford University Press, 1995.
- Tooley, M. Abortion and infanticide. *Philos Public Aff* 1972;**2**:37–65.
- Warren MA. *Moral status: obligations to persons and other living things*. Oxford: Oxford University Press, 2000.

For further discussion of effects of self-direction on the value of life, see, for instance Lipke, *op cit.*, and:

- Kant I. *Groundwork of the metaphysic of morals*. Paton HJ, tr. New York: Harper, 1964.
- Kant I. *Critique of practical reason*. Beck LW, tr. New York: Garland, 1976.
- Mill JS. *On liberty*. London: Watts, 1929.

For interesting guidance regarding uncertainty surrounding the child's interests, see:

- Royal College of Paediatrics and Child Health. *Withholding and withdrawing life-sustaining treatment for children: a framework for practice*. 2nd edn. London: RCPCH, 2004.

Third, the focus here is on decision making for babies and infants—children in the first year to 18 months of life. However, many of these points will also apply to older children with interests that are similarly difficult to identify.

MEDICAL DECISION MAKING AND INTERESTS IN AVOIDING PAIN

In order to determine how central considerations relating to pain should be to medical decisions for infants, it is useful to note how these considerations feature in decisions for adults. There is, of course, no universally accepted method of ranking interests, but surrogate medical decisions do tend to reflect certain widely shared views about the relative contribution of various interests to quality of life, and one of these concerns pain.

Although most of us consider that pain is against our interests, we are willing to accept some pain—for ourselves and when making medical decisions for others—in order to survive or to maintain certain key functions. Although there are exceptional cases in which levels of pain are so high that death would seem preferable, generally we think that a certain amount of pain can be offset by benefits such as increased quantity of life or retention of cognitive function.

Why does pain seem preferable to death or the loss of certain key functions? A full answer requires an account of what we think makes life valuable. Although accounts of this type vary enormously, one element common to many may explain our willingness to accept pain in order to protect key functions, and to survive. That element is autonomy.

The belief that the ability to act in a self-directed manner increases the value of life is widespread, and decision making reflects this. (For further reading, see box.) Interests that have a direct impact upon our capacity for autonomy are generally protected at the expense of interests whose impact is less direct. For instance, retaining a certain level of cognitive function directly affects autonomy: acting in a self-directed manner requires a host of cognitive skills and abilities, and therefore we take measures to protect cognitive function in our decision making. Pain, on the other hand, does not generally have such a direct impact upon autonomy: although severe pain may hinder autonomous action (and it may be expected that decision makers would exhibit an increased concern about pain when it reaches these levels), it does not generally pose the direct threat to autonomy that loss of cognitive function presents. Thus, a (moderately) painful treatment that preserves cognitive function is likely to be looked upon favourably by decision makers.

Considerations of autonomy may explain why we protect interests such as that in retaining cognitive function at the cost of pain when making medical decisions for adults. What about the interest in survival? Here again autonomy may feature. We think that while life holds the prospect of autonomy and all the goods that it entails, it is worth living, even at the cost of pain. This preference for interests such as those relating to autonomy is evident in theory as well as practice. Experiential interests, such as that in avoiding pain, are often distinguished from ''higher-order interests'', among which autonomy-based interests figure. The distinction between higher-order and lower-order interests owes a lot to Mill (see box). Autonomy-based interests are not alone in this category, and other higher-order interests (for instance, that in forming relationships with others) may conflict with experiential interests in similar ways. This discussion focuses upon autonomy-based interests, however.

Higher-order interests are often accorded priority over experiential interests, because of the perceived relationship between higher-order interests and the moral status of persons. Many regard the capacity for autonomy, for instance, as the source of the special moral significance associated with personhood, and the right to life is often linked to this capacity. Experiential interests are important, in so far as their fulfilment makes a life go better, but autonomy-based interests do more than make a life go better: they also make it more valuable, to its subject and in a more general sense.

To sum up, we can explain why a certain level of treatment-related pain is accepted in medical decision making for adults by reference to autonomy. If the widely accepted priority placed upon autonomy is correct, we have reasons to prioritise autonomy-based interests when we make medical decisions for adults. But should we apply the same ranking to infants?

INFANTS AND THE INTEREST IN AVOIDING PAIN

At first sight, the interests that compete with pain avoidance do not appear to apply to infants. Infants are not autonomous, and are largely unable to appreciate the non-experiential values open to persons. This may suggest that autonomy-related interests do not apply to infants, and that medical decisions for them should be made purely on the basis of those interests that they do have, which are likely to be largely experiential. If this is the case, treatments that advance autonomy at the cost of causing, or preventing the alleviation of, pain and suffering ought not to be provided to infants.

Despite the fact that infants do not exhibit the qualities associated with autonomy, there is a sense in which autonomy-related and other ''higher-order'' interests might apply to them. Most infants have the potential to develop into autonomous persons, should certain conditions be secured, and if they have interests in realising this potential, as many believe they do, they also have interests in securing the conditions of their future autonomy.

If a life characterised by the capacity for autonomy is preferable to a life without this capacity (perhaps because of the range of goods that autonomy renders

accessible, or because of the intrinsic value of autonomy itself), then it is reasonable to hold that an infant has an interest in developing this capacity, which should be taken into account in medical decision making.

Of course, decisions cannot always advance all of a subject's interests equally, and an infant's interest in securing the conditions of her future autonomy may compete with her interest in avoiding pain. These cases call for some method of weighing the current interest in avoiding pain against the future-regarding interest in safeguarding the capacity for autonomy. In some cases, the amount of pain and the extent of the compromise wrought with autonomy are such that weighing these interests against each other is easy; in others, they are very finely balanced.

Avoiding pain is clearly in the interests of all infants, simply because experiencing pain is unpleasant—it makes life worse. This interest may be particularly acute in the case of infants, because they are unable to rationalise the experience of pain in terms of treatment-related benefits. There is controversy about the effectiveness of current practices with respect to pain relief in babies, and this is in part a function of the difficulty of assessing pain levels in those with a limited capacity to communicate.[3–6] Our understanding of pain mechanisms in infants, particularly premature neonates, is far from complete, and there is a strong case for further research into infant pain and its treatment. But we do not have the luxury of awaiting the results of such research before making decisions for infants such as MB: we must act under conditions of uncertainty about the extent to which pain-related interests are at play in a given case, but we can formulate general principles about how much influence these interests should have on decision making, once they are established.

Obviously, where it is possible to relieve an infant's pain without compromising other significant interests, this should be done. If pain relief comes at the expense of interests that make a greater contribution to wellbeing, however, those more fundamental interests warrant priority. But what interests are more fundamental to the child's wellbeing than pain avoidance? Interests that relate to autonomy are likely to fall into this category. If it is true that autonomy makes a life more valuable, then infants will have a strong interest in securing the means by which to realise their potential for autonomy, and thus live more valuable lives. Securing this interest may justify painful treatments during infancy.

But as pain differs in degree, so do the autonomy gains that medical treatments can secure. A very small gain in autonomy could not justify prolonged and acute pain, although a more substantial gain in autonomy could. Autonomy-based interests will not trump pain-related interests in all cases: each case must be considered individually, in the light of the general principle that autonomy-related interests can outweigh interests in avoiding pain when these interests apply to a similar magnitude.

But autonomy-based interests do not apply to all infants equally: some simply do not have the capacity to develop into autonomous persons, no matter how much treatment they receive. Can painful treatments be justified for infants in this category?

PAIN AND INFANTS WHO LACK AUTONOMY-BASED INTERESTS

An infant's life prospects may preclude autonomy-based interests for one of several reasons: her life expectancy may be too short to allow this, or her cognitive function and potential may be so compromised that she has no potential for autonomy, regardless of her life expectancy. Infants in these categories do not possess autonomy-related interests that compete with their experiential interests. Given this, experiential interests such as that in avoiding pain should assume a more central position in decisions for infants in this category.

We should operate a strong presumption against imposing painful treatments or leaving pain untreated in infants who retain experiential interests but lack autonomy-based interests. Infants with Tay–Sachs disease or Lesch–Nyhan syndrome fall into this category, as will newborns with normal cognitive function but incontrovertibly short life expectancies. This presumption would mean that some lives that could have been extended through the application of painful treatments will not be, on the grounds that such an extension would not be in the infant's best interests, given her life prospects and the pain involved in prolonging that life.[ii]

It is important to note that very few infants lack autonomy-based interests entirely. Most infants with compromised cognitive status nevertheless retain some potential to develop the capacities associated with autonomy. Autonomy is not an all-or-nothing affair, and autonomy-based interests will apply to most infants with compromised cognitive status (to varying extents). Furthermore, in many cases it will be difficult to accurately assess an infant's autonomy-related potential in the first few years of life, even if a diagnosis associated with reduced capacity has been established. Where it is uncertain whether an infant has autonomy-based interests, we should err on the side of over-estimation, given the value we place on autonomy. This does not mean that all infants with any potential for autonomy whatsoever should be given painful life-extending treatment, as small gains in autonomy can be outweighed by large amounts of pain, whatever an infant's potential. But it does mean that the presumption against painful life-extending treatment that I am arguing for will apply only to the most severely compromised infants.

So, in summary, autonomy-related interests warrant priority over pain-related interests when making decisions for infants, but this priority is not absolute: a small gain in autonomy cannot justify severe, prolonged pain. In each case, autonomy and pain-related interests must be balanced against each other in the light of the general principle that autonomy-related interests outweigh interests in avoiding pain when these interests apply to a similar magnitude. For the small group of infants who do not possess autonomy-based interests, interests in avoiding pain should prevail, and decisions for them will conform to the best-interests principle where they minimise pain and suffering, even at the expense of prolonged survival.

PARENTS AND TREATMENT DECISIONS UNDER CONDITIONS OF UNCERTAINTY

Cases such as that of MB demonstrate that the guidance laid out above is of limited use when we cannot accurately determine the extent of an infant's pain or autonomy-based interests. In cases of acknowledged uncertainty about the facts, decisions must nevertheless be made, but the prevailing uncertainty about the child's interests suggests that it is appropriate to place less emphasis on them and to consider other factors to reach a decision (for further reading, see box). The interests of parents are obvious candidates here.

Parental interests might be factored into decisions in several ways: I will focus on the interest in making decisions for one's child. Although this interest may conflict with parents' other interests

[ii] Here I argue that the best-interests principle requires us to forgo painful treatments for infants who lack autonomy-based interests. But if high moral status is a function of autonomy (this is highly debatable), infants who lack autonomy-based interests also lack high moral status. If this is the case, one might question the application of the best-interests principle to these infants, as this standard presupposes the high moral status of the subject. I cannot explore the implications of this line of argument here.

(sometimes the decisions parents make will turn out to be against their overall interests), the problems with identifying the ''true'' content of other people's substantive interests makes this interest a good candidate for advancement. There are a number of reasons to think that parental interests should be accorded greater independent weight when we cannot reach a reliable conclusion about an infant's interests.

The first reason relates to the strength of parental claims for consideration. In general, parents are major stakeholders in decisions for infants. Decisions and their outcomes have a significant, often life-changing, impact upon parents. They rejoice when their child flourishes and grieve when her welfare deteriorates. Although this interest is less direct than the interest that the infant herself has in the decisions made on her behalf, its intensely personal and emotional nature, and its capacity to affect parents' lives in profound and enduring ways, gives us cause to take it seriously. When we are unable to identify how to serve the child's best interests, the parental interest in deciding is a strong contender for understudy.

The second reason relates to the malleable nature of many interests held during infancy. Uncertainty about interests is a feature of many decisions for infants, not just those involving pain and autonomy. Some of this uncertainty is not attributable to our ignorance alone, but also reflects the fact that infants' interests are not entirely established: the treatment they receive can shape the interests that they develop. This is clearer in some non-medical contexts: raising a child in a given religious tradition can promote interests that they may not otherwise have had, for instance. But parents are in a position to affect their infants' interests in the context of health, too. A nurturing parent who spends a lot of time comforting an ill baby may reduce the net effect that her pain has on her wellbeing, for instance, or an infant's potential for autonomy may be improved through certain interactions. We know that parents have a big impact on their children, and we can in some cases serve the child's interests by serving those of the parent. If parents are committed to their infants' survival, this may manifest itself both in the decision they reach and in their treatment of their child and may affect the child's interests significantly.

These reasons give support for the inclusion of parental interests in decisions made for infants, where genuine and irresolvable uncertainty about the infant's interests exists. But what does inclusion of parental interests in the decision making process mean in practice? I suggest that in cases such as that of MB, in which it is impossible to gauge an infant's interests, parental views about treatment should prevail. If parents believe that treatment is in the child's interests, and genuine uncertainty about the child's interests means that they could be right, the child should receive treatment. If the parents are opposed to treatment, it should be withheld. This does not mean that parents should dominate decision making for their children altogether: wherever the child's interests can be established, decisions for that child should, in accordance with the best-interests principle, be made exclusively with reference to those interests, regardless of parental views.

This approach faces several possible objections. The first relates to resources. The treatment that children such as MB require is enormously expensive, and specialist paediatric and neonatal services are extremely stretched. Allowing parents to determine whether treatment is applied could mean that, as in the case of MB, treatment that doctors would choose to forgo is given, and this will cost. Of course, it is possible that parents will choose to forgo treatment that doctors would persist with, but perhaps that is the less common scenario. My arguments could lead to a situation in which care of debatable benefit is given to children, and in a public health system in which such specialist resources are scarce, this could be a problem.

There is no doubt that issues about the use of resources in paediatric medicine are underconsidered, and we must be realistic about what we can achieve with the resources that we have. Resource considerations tell against the best-interests principle, which requires that we make decisions with exclusive reference to the child's interests. But the law currently requires that we apply the best-interests principle, and this discussion suggests an approach to decision making within the current legal parameters. It is important to remember that parental views would determine action only when their child's interests are genuinely uncertain and that those children nevertheless have interests which we are obliged to serve. It would be unfair if we operated a policy against the provision of care to such children merely because we are unable to determine what their interests require.

A second objection to privileging parental views in cases of genuine uncertainty obtains when the two parents disagree. In such cases, the involvement of the courts is almost inevitable, but I suggest that, if it is possible to identify one parent as the primary carer, their views should prevail. This reflects the reasons for extending priority to parents in cases of genuine uncertainty: the interests of the primary care giver are likely to be affected most by the decision, and they are in a better position to influence the interests that the child develops through their care.

Decisions about painful, life-extending medical care for infants are always difficult, but never more so than when profound uncertainty about the child's interests exists. In such cases, we must use a method by which to reach a decision that does not lose sight of our obligation to serve the child's interests. The depth of parental interest in such decisions, along with their ability to shape the interests their child develops, suggests that abiding by parental views in such cases may present the best solution.

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