

SPECIAL FEATURE

Life or death decisions in the NICU

N Richards

Department of Philosophy, University of Alabama, Tuscaloosa, AL, USA

When, if ever, should we allow an extremely premature baby to die? The paper explains how that would be answered if we are guided by three reasonable assumptions.

- (1) The value a person's life has is primarily the value it has for that person, rather than a value it has in itself.
- (2) All competent persons have a right to decide for themselves whether their lives are to be prolonged.
- (3) Parents have a right to treat their children as they choose, so long as they neither abuse them nor neglect them.

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When, if ever, should we allow an extremely premature baby to die? Under the laws of Texas, we can do so only if the baby is 'certifiably terminal,' as defined by the state's Advance Directives Act. (Miller *ex rel* Miller v. HCA, INC., 118 S.W. 3rd 761 (Texas 2003)). The court is reporting the reasoning of the Court of Appeals, with which it agrees). Her parents cannot decline treatment for their child because they believe it would be better for her if she were to die, no matter how terrible it would be for her to live.

That is sometimes described as protecting the child's right to life. It can also be understood as taking life itself to have a supreme value of its own, regardless what that life is like for the person who lives it. Either kind of thinking can underlie the use of gestational age and birth weight to determine which newborns can be allowed to die, as well. It does so when the crucial numbers are used to identify newborns who are taken to be too underdeveloped to survive regardless what is performed for them, with all others given the treatments that prolong their lives.

A different ethical position is in play when gestational age and birth weight are used in another way. Here, the crucial numbers

serve to identify newborns who are thought destined *either* to die even if they are treated, *or* if they do survive, to have lives that will be too miserable to make the child endure them. A child in either category can be allowed to die, on this approach. This does permit quality of life to be decisive, although only when that quality is at its worst: only when treating the child would be 'inhumane,' to use the language of the Baby Doe guidelines.¹

I want to offer a third approach, which relies on three assumptions.

- (1) The value a person's life has is primarily the value it has for that person, rather than a value it has in itself.
- (2) All competent persons have a right to decide for themselves whether their lives are to be prolonged.
- (3) Parents have a right to treat their children as they choose, so long as they neither abuse them nor neglect them.

I will not argue for these assumptions, which seem to me as both reasonable and widely held. My aim instead is to explain how we would decide which newborns we sustain and which we allow to die, if these were our assumptions.

1. Where adult patients are concerned, our practice certainly reflects at least one of these assumptions: namely, that the patient has a right to decide whether to prolong his life, if he is competent. That is why there is a right to refuse treatment, even if this means an earlier death. We do not block such decisions on the ground that whatever our patient might think, life is of such value in itself that it must never be allowed to end, except when efforts to prolong it would soon be futile anyway. Rather, the patient has the call, because it is his life. (As we all agree that competent adults have a right to life, it appears that this is a right to make such choices, rather than an obligation to continue to live no matter what life is like).

It might seem inappropriate to extend that to newborns. After all, a newborn is not even capable of choosing for herself: what sense can it make to say she has the same right as an adult to do so? However, the incompetence is only temporary, for most newborns. Given time, they do become capable of deciding for themselves whether their lives should be prolonged. The way to respect this fact is to refrain from foreclosing that future, and to refrain also from taking the choice out of their hands by deciding it for them in advance.

Correspondence: Professor N Richards, Department of Philosophy, University of Alabama, Box 870218, Tuscaloosa, AL 35487, USA.

E-mail: Nrichard@bama.ua.edu

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As an analogy, consider the right to decide whether to have children of one's own. That is not a choice anyone can make while still a newborn, obviously, but most of us do become capable of making it later in life. It properly belongs to the individual, not in that we are the ones who should make it at the moment, but in that it should be held in trust for us to make when we can. That is equally true of the decision whether to prolong one's life or to allow it to end. It too is a choice that a person cannot make in infancy. It too is one that should be reserved for the person he will become, to make in the way of his own choosing (Joel Feinberg speaks of children in a similar way: see Feinberg²) (For criticisms of the use to which Feinberg puts the idea, see Archard³).

That is how it should be if there is going to be such a person, at least. If there *always* would be, then letting a newborn die would always intrude upon that child's right to life, which is a right to make such choices for herself. As we know though, sometimes there will never be a future version of the newborn who will have this ability. Some newborns will remain incapable of making this choice, just as all newborns are in their first days of life. So, if we decide they are to die, this does not take the child's choice for ourselves: there is no sense in which it *is* the child's choice. Choosing that he is to die does not do him the wrong it would, if he had been someone for whom the choice could have been held in trust.

That means our first question about a newborn who is in distress should not concern the quality of life he will have if we prolong his life, but whether he will develop this ability to decide for himself whether to go on living. If he will, then there is a powerful objection to letting him die before he can make such choices for himself. If he will not, that objection falls away. Then the decision whether he is to live should fall to his parents, I suggest, as part of his being their child.

Many choices do belong to parents for that reason, including many that have profound effects on their children: whether the child is to have elective surgeries, where the child is to live, who the child's associates are to be, what education the child is to have beyond whatever minimum the state requires, and so on. Parents have great latitude in such matters, limited only by the requirement that they must neither abuse their children nor neglect them. The same would be true here, for the parent of a child who will never be able to choose for himself whether to go on living. The question of importance in that case is whether dying is so clearly a greater misfortune for the child than living that for his parents to allow him to die would be abuse or neglect on their part.

Both elements of this view need discussion: how we are to decide which newborns will never develop the capacity to make the decision for themselves, and when it would be abusive or neglectful to let such a child die. I will begin with the first of those.

2. As choices are mental acts, making them requires certain cognitive equipment. Some children will never develop what they

need to make the choice of interest to us because of neurological defects. Other children would develop it if they were to live long enough, but their afflictions mean they will die before then. Which children fall into these categories is a question for science, but a rough, partial outline of the answers can be given.

Competence to make a choice includes the ability to understand one's alternatives: someone who cannot even know what her choices are is certainly incompetent to choose among them. To understand the alternatives involves knowing their possible consequences, and how likely those consequences are to occur. That knowledge comes in degrees: one can understand the alternatives very well indeed, only barely, or somewhere between those extremes. To be competent to make a choice does not require that one be perfect in this, of course. Rather, competence is a threshold concept, with the incompetent being those who understand the matters too poorly, or who are too little able to decide on the basis of their knowledge, or both.

It is possible to be incapable of understanding any alternatives at all, and thus of making any choices. It is also possible to be capable of some choices and incapable of others: of choosing between two things to eat, for example, but not of making more complicated choices. The choice of interest to us is a very complicated one as it is between alternative lives: a longer life with treatment and whatever that brings, or a shorter one without the treatment. It would certainly be beyond the person we were just imagining. More generally, our choice would be beyond anyone who was more than mildly retarded, it is fair to say.

Indeed, whether to prolong your life is certainly as complex a decision as the ones that we routinely deny to children until they are at least 15 years old, if not older: whether to continue to live at home, for example, whether to marry, whether to enter a binding contract. Our general view seems to be that until they reach their mid-teens, at least, children are not capable of these choices, or of any choice of great moment. If so, any child who would die before reaching that age could be allowed to die earlier, without offending against her right to make this choice for herself.

Social conventions about children are not exactly scientific, however, and laws governing minors are the products of politics. We can hope to do better at setting the needed lifespan. Still, it seems clear that for a child to become capable of our choice would require years of cognitive development. And there would also be children for whom length of life is not the problem, because they will never be competent to make our choice, no matter how long they live. That would be true of those with brain damage of various kinds, I take it.

Those are speculations, although I hope they are plausible ones. I make them in order to indicate what kinds of prognosis would be of interest to us: which ones would mean the child could be allowed to die without violating her right to make such choices for herself. On the approach being offered, the parents of such a child could allow her to die, as long as this neither abuses her nor

neglects her. The next question is what that permits parents to do, and what it does not.

3. It is clear that no parent can protect a child from all forms of harm, and also that none should try. Children are bound to stub their toes, bruise their knees, catch childhood diseases, and so on, and when they do, it does not follow that their parents have neglected them. This suggests that neglect is a matter of failing to keep one's child not just from risk of harm, but from *substantial* risk of *serious* harm.

What if all your alternatives were like that, though? We will do better to take neglect to be leaving the child at what you know (or, ought to know) is substantial risk of serious harm *when you also know of a safer alternative* (or, ought to know of one). The safer alternative could be one that carried no risk of this same order (yet you left your child greatly in harm's way). Or, the safer alternative could be one that did pose a serious risk of its own, but was still better in this regard than the one you chose. In either case, to turn your back on the better choices would be to fail to do as well as you should at protecting your child from harm. *That* would be to neglect him. Whereas, the bare fact that you exposed him to great risk might only reflect how terrible your predicament was, not a lack of proper concern for the child.

The potential harm in foregoing treatment that is thought necessary to sustain your child's life appears to be that the child will *die* if she is not given the treatment. However, is a person always harmed by dying? Imagine a man who is being tortured to death, and who has no wish to survive as long as he can. Surely it is better for him if he dies sooner, rather than later. The same would be true of a baby whose prospective life would be equally tortured. There are conditions in which 'the child will not live long and will only experience pain and suffering' (Annas says there are two kinds of case in which courts will allow quality of life considerations to permit us to let an incompetent person die, of which this is one);⁴ presumably the writers of the Baby Doe guidelines had at least some such children in mind when they stipulated that some treatment could be forgone because it would be inhumane. If we are right to think that such a baby is not harmed by dying, or if the baby's death is clearly the lesser of two evils, then to let her die cannot be *neglect*, as neglect is failure to protect the child from harm when one should. Indeed, there is a good case for saying that to prolong the life of such a child is to abuse her.

Fortunately, it is rare that the child's life would be this terrible, however. Far more often, we know only that it will have many negative features. Extremely premature babies are vulnerable to respiratory failure, cerebral hemorrhage, renal failure and various defects of the heart. There is misery in store for such a child, both from the medical problems and from the efforts to deal with them. However, to say the child's life must be akin to that of being tortured to death is too strong. Indeed, often we will be uncertain even whether to think of it as a negative life, on balance, or to

think instead that it might be marginally redeemed by positive experiences. If such a child were allowed to die, would that be a case of neglect?

Only if a reasonable person would have known of a better alternative, I suggest. If letting the child die is to be neglect, it must clearly be worse than prolonging her life. The child in question is one whose life we can say will either be negative on balance, or somewhat positive, although only minimally so. We cannot say which it will be. To let such a child die will not be a way of neglecting her, I will argue, because it is not clearly worse for her to die. If not, then we do not have an alternative that we know is a better one to take, or an alternative that we *ought* to know is better. Alternatives of those kinds would be clearly better than the one we chose, but — I will argue — that is not true in this case.

The harm that might be caused if the child is allowed to die is that she will lose what would have turned out to be a minimally positive life. The harm that might be caused if she is kept alive is that she will suffer the miseries of what would have turned out to be a negative one: not dreadful miseries, as in the case parallel to the man being tortured, but something of a lesser order. Neither potential harm to the child is clearly worse than the other. In particular, to lose what would have been only a minimally positive life is not clearly worse than it would be to suffer the miseries in a negative one. Both are very bad things to happen to a person. However, if the risks of each are equal so far as we can tell, then choosing to leave your child at risk of one of them rather than the other is not a way of failing in your duty to protect him from serious harm. What you have is a range of bad alternatives, with nothing that makes any of them clearly better than the others. That means you have latitude to choose among them.

It might be replied that *dying* is different than other harms, and ought always to be given a higher rank than anything else that could happen to a person. Death is the end of life, after all. It means the person has no more possibilities, as far as we know, whereas, after any other harm there is always another day.

To clutch at that in our case would be irrational, however. As far as we can tell, the child we are imagining would have a negative life if we allowed her to live. Losing *that* is the harm we would be saying is not as bad as dying and having no more days at all. However, if the new days she would have in continuing to live would be negative, on balance, then these are not to be *welcomed*, regarded as advantages in being left alive — these are to be regretted. Essentially, in valuing her staying alive so highly, we would have been more optimistic about her future than we had reason to be, betting that really it would be the minimally positive life even though we were not entitled to believe that. We are free to do this where our own lives are concerned, but it would certainly be wrong for the law to require us to make our children suffer in that same hope.

A different argument to the conclusion that dying trumps all other harms would invoke the idea that human life has an inherent value, regardless what that life is like. The claim would be that although condemning someone to a negative life is certainly a bad thing to do, the inherent value of human life makes it a worse harm to end what could well have been a positive one. One problem here is that it will have to be *clear* that life has this supreme inherent value, as only then will we have chosen what we *should have known* was a worse alternative, and only that kind of choice neglects the child. However, surely, whether to be alive at all is something of supreme inherent value is highly disputable, rather than a truth so clear we should all be able to see it. This alone makes the argument fail.

Moreover, if life did have this inherent value, it would be fair to ask why it would not *always* be neglectful to let a baby die. After all, in every such case, we would take something to be more important than preserving human life — even if we were to let the baby die because it would be ‘inhumane’ to keep him alive, to borrow the Baby Doe language. We would have to disapprove of that too, if we thought that preserving human life was clearly more important than serving any other value. We would also have to disapprove of allowing the man to die who is being tortured to death, rather than giving him medical treatments that would keep him alive for more of it, of allowing the life of one’s incompetent, elderly parent to end rather than subjecting her to yet another operation, and even of choosing against surgery or chemotherapy in one’s own case. Those too are cases of taking something else to be more important than preserving human life. If we want to allow them but also to rule out letting the newborn die in a case of the kind we have been considering, we will have to say why preserving human life is worth that much — but not more than that much.

I doubt that can be done, but in any event, it departs from the project of this paper. That project was to say what follows about letting newborns die if we think the primary value that our lives have is their value to us, so that we have a powerful claim to decide not to go on living. If so, I have argued, we ought to regard letting a baby die as a choice that is within the parents’ latitude, if the reasonable belief is that their child will never be able to make such a choice for himself and if their letting him die neither abuses him or neglects him. It does not neglect him, I have argued, if the reasonable belief is that the life the child would have would be a negative one for him, or if we cannot tell whether it would be negative or minimally positive. Uncertainty about that does not change the choice to one the parents may not make, any more than uncertainty about precisely which miseries are in store for the child does so.

Still, what if matters are so uncertain that there is no reasonable belief to have about whether the child will ever develop the capacity we have been discussing? What if that is just too uncertain, as it often must be? What are we to do then?

There seem to be two variables of importance. One is the likelihood that the child will develop the capacity to make the choice. The better our reasons for thinking he will become a capable chooser, the more careful we should be to preserve the choice for him. The second variable is the cost to the child of our doing so. Here, we would turn to the quality of life in store for him. The harder it would be on him to reach what might be competence to make the choice, the less willing we should be to keep him alive long enough to find out whether he does. The cost to some children would be too high to preserve a possibility so remote. For others, the probability that one day they would be able to choose for themselves would be great enough that this same cost would be worth paying, in the hope that we are right.

There is no formula for determining this, any more than there is one for saying how many guilty men we should be willing to allow to go free in order to avoid convicting one innocent one. We should be very careful indeed not to convict the innocent, and very careful indeed not to deprive someone who would have been able to choose for himself of the opportunity to do so. In neither case must we do this at all costs, and in neither case can we be more precise about how careful we ought to be.

Even so, it is clear that it is not only the children who would have died within hours or days or months who would be candidates to be allowed to die, on the approach being developed. Unless empirical research suggests otherwise, so would any child whose condition meant she would live for no more than a half-dozen years, a good many children who would live into their mid-teens, and some children who would live as long or longer but whose mental development would arrest at some earlier stage.

Those are different results than other approaches yield. Their virtue, in my opinion, is that they also reflect the appropriate moral views to take when the life of an extremely premature newborn is in our hands.

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References

- 1 Annas GJ. Extremely preterm birth and parental authority to refuse treatment — the case of Sydney Miller. *N Engl J Med* 2004; **351**(50): 2121.
- 2 Feinberg J. The child’s right to an open future. In: W Aiken and H LaFollette (eds). *Whose Child?* Littlefield & Adams: Totawa, NJ, 1980.
- 3 Archard D. *Children: Rights and Adulthood*. Routledge: London, 1993.
- 4 Annas GJ. *The Rights of Patients*. New York University Press: New York, 2004 p. 289.