Surrogate uncertainty: who decides

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Funding: This research was funded in whole, or in part, by the Wellcome Trust [203132/Z/16/Z]. The funders had no role in the preparation of this manuscript or the decision to submit for publication. For the purpose of open access, the author has applied a CC BY public copyright licence to any Author Accepted Manuscript version arising from this submission.

Competing Interests: The author has no conflicts of interest.

Contributorship statement: This single-author paper was written and conceived by DW.

In the case that triggered this round-table discussion there are three separate factors that contribute to moral uncertainty.[1] First, the infant, baby T, is extremely premature with suspected brain injury and potentially poor prognosis. Second, the gestational mother is critically unwell herself and her outlook is guarded. Third, as linked commentaries make clear, the legal status of the intended parents (IP) is complex and ambiguous. [2] [3] Any of these factors on their own would be enough to generate ethical complexity and distress in the neonatal intensive care unit. The combination of the three is likely to be highly stressful for all concerned.[4]

Commentaries on the case emphasise the complex legal questions and the potential need to involve the court. One resource that isn't mentioned is the potential value of clinical ethics input in such a case. This is complementary to the need for legal advice. Its aim would be to help think through the specifically ethical, rather than legal questions. There are several things that if I would aim to clarify if chairing a clinical ethics discussion on the case.

First, it may be useful to draw on the concept of the 'zone of parental discretion' (ZPD). [5] This refers to the range of decisions that parents are permitted to make for children.[6] The starting point is that parents should be involved in medical decisions about children – that is why their consent is sought for treatment decisions. However, parental involvement (or 'discretion') is bounded by the need to safeguard the child's interests. Parents are not permitted to make decisions that would be harmful.[7]

Applied to the case, the key question is: Is there sufficient uncertainty about the best interests of the child that it would be ethical either to continue or to discontinue life prolonging treatment. Would one of these options be harmful for T?

If baby T's situation is not in the ZPD - because the baby's prognosis is so poor that treatment must cease, or so good that it must continue, then the question is not what to do, but rather how to enact a particular decision.

Second, if the situation is in the ZPD and the gestational mother is unable to participate in decisions, it is useful to clarify whether decisions need to be made urgently. Can decisions be delayed until the mother regains capacity?

While it can be good to delay decisions to allow all involved to take part - it may be that that would not be in the infant's interests. Continuing treatment is a decision too (it is not possible to not decide). Furthermore, continuing treatment may mean that a window of opportunity to make decisions is lost.[8] Then neither the surrogate mother, nor the IP will have a meaningful opportunity to participate in decision-making.

Third - as with other situations where an adult lacks capacity - it may be possible to know enough about the surrogate mother's views and values to apply to the situation. It would be important to ask those who know her well what her wishes were. Her partner or those close to her could indicate whether she has any relevant religious or other values, or whether she has ever expressed views about continuing intensive care in a setting where a child might have severe long term disability.

Fourth - even if they lack legal status in the decision, it would be ethically important to involve the IP in the decision-making. We might reflect on the ethical reasons for involving parents in decisions about children in the first place. Because of their involvement in the decision to conceive T, their close emotional connection to him, and the presumption that (if he survives) they would care for him long-term, the interests of the IP and T overlap and intertwine in complex ways.[9] Those are the reasons why, when a child's medical treatment is in the ZPD, health professionals would ordinarily defer to the views of biological parents. The ethical reasons that apply to biological parents apply equally to adoptive parents (where a child has been legally adopted), and seem to apply equally to the IP (even if they have not yet acquired this status legally).

That is most easy if it appears that the views and values of all parties line up. For example, it might be that the IP wish for treatment to continue for the baby and there is reason to think that would be the gestational mothers view, or vice versa.

The most difficult situation is where there is either a conflict between the presumed view of the gestational mother and those of the IP. Or where there is no clear evidence about the views of the gestational mother and they might either coincide with the IP or disagree. There is no easy solution to that problem from an ethical perspective. Except that usually, where there is disagreement or significant uncertainty, treatment will continue - and decisions may be revised later if clinical condition deteriorates/more information becomes available

Finally, it is useful to acknowledge that this case will place a greater than usual ethical burden on the clinicians involved. It may be helpful to gain additional clinical opinions. If there is agreement that it would be best for the infant not to continue intensive care, there should then be serious consideration for how that decision could be lawfully made eg through the court appointing one of the IP as having parental responsibility, or through the court reaching a decision in the infant's best interests.

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