Informed non-dissent for brain death testing in children: ethical and legal perspectives

Dominic Wilkinson [1,2,3,4] Christopher Miller,[5] Stephen W Turner [6]

A 14-year-old girl, Hana, is admitted to the paediatric intensive care unit following a sudden collapse at home. She is found to have sustained a severe haemorrhagic stroke. Despite emergency neurosurgical intervention, she deteriorates over several days. Her family have been struggling to accept the possibility that she would not recover. Hana remains unresponsive, has fixed dilated pupils and has developed diabetes insipidus. The clinical team suspect that she is brain dead.

Should the family's consent be sought for brain death testing? (This case is fictitious.)

In mid-2022, the high profile case of Archie Battersbee raised a number of ethical and legal questions about the medical care of children suspected to be brain dead, particularly in the setting of family disagreement.[1 2] Ultimately in Archie's case, formal brain death testing was not possible (because he did not meet the preconditions). However, there was a long delay before this was able to be assessed. That was in part because his parents refused consent for brain death testing to be carried out.

Here, our aim is not to examine the Battersbee case in detail, nor to explore wider questions about the nature or diagnosis of brain death. We focus first on the specific ethical question relating to consent for the diagnosis of brain death raised in Archie's case and highlighted in the fictional case of Hana above. We identify ethical arguments in favour of one approach—informed non-dissent. We then explore legal aspects of this question and approach.

[1]Oxford Uehiro Centre for Practical Ethics, University of Oxford, Oxford, UK
[2]Centre for Biomedical Ethics, National University of Singapore Yong Loo Lin School of Medicine, Singapore
[3]Newborn Care, John Radcliffe Hospital, Oxford, UK
[4]Murdoch Children's Research Institute, Melbourne, Victoria, Australia
[5]Fourteen Chambers, London, UK
[6]Women and Children Division, NHS Grampian, Aberdeen, UK

Correspondence to Dr Dominic Wilkinson, Oxford Uehiro Centre for Practical Ethics, Oxford OX1 1PT, UK; dominic.wilkinson@philosophy.ox.ac.uk

ETHICAL VIEW

Some ethicists and clinicians argue that consent should be sought for brain death testing.[3 4] Parents are central to medical decisions for children. It would be standard to involve them in decisions about treatment for a child. Furthermore, testing for brain death is extremely important. It is, quite literally, a life and death decision, since the results are that the patient has either died, or remains alive.

But there are several powerful countervailing arguments. The first is that for critically ill children, parents' permission is not sought for every procedure or examination, particularly diagnostic tests. It would not be practical to do so; moreover, parents are presumed to agree to these when the child was admitted to intensive care. In neonatal and paediatric intensive care, parents are regularly updated and informed, wherever possible, of what is planned for the child and why. Explicit consent is sought if the child is going to have surgery or an invasive procedure, start on an experimental treatment or be involved in research. But brain death testing is none of these.

A second reason to think that doctors might not need to seek consent is that this decision is not an *option* for parents to ethically choose. Parents have an important role in medical treatment decisions for children, but their rights have limits.[5] In particular, they are not ethically or legally permitted to insist that treatment continue in a child who is already dead. But if the attending clinical team required permission from Hana's parents for brain death testing, this would give the parents a de facto right to continue interventions (at least temporarily) in a child who has, in fact, died. If, as suspected, Hana has in fact died, continued medical interventions cannot be in her interests, and indeed are ethically suspect since ordinarily, they may only be performed on live patients.

PROPOSAL: INFORMED NON-DISSENT

One potential solution would be to adopt an 'informed non-dissent' approach for brain death testing in children.[6] This is a model that has been developed in a related context for potentially futile or medically inappropriate interventions at the end of life in critically ill children and adults.[7] In such a setting, some families are emotionally unable to agree to limitations on treatment (even if they recognise that this may be in their child's best interest).[8] An informed non-dissent approach involves informing caregivers about the patient's clinical condition and a proposed plan for further care (for example, that cardiopulmonary resuscitation would not be provided in the event of a cardiac arrest). The family's explicit agreement is not sought, either verbally or in writing. However, the family are given the opportunity to ask questions and to express concerns or opposing views. If the family do not disagree, the medical team is able to proceed with the plan they have described.

One arguable benefit of 'informed non-dissent' is that this potentially avoids or reduces the burden on families. It can be a valuable compromise option that allows medical teams to make plans in the best interests of the patient, but avoids some of the ethical challenges of unilateral decision-making.[9]

LEGAL VIEW

Would this approach be lawful? In some jurisdictions, doctors may carry out brain death testing autonomously (ie, without the need to seek consent) as part of the routine function of their work.[10 11] There is currently no domestic law in England and Wales which explicitly authorises such an approach. This means that the legal framework must be understood from wider principles set out in relevant case decisions from the senior Courts of Precedent. Brain death testing is not an emergency, is not life-saving, but has profound (indeed fundamental) ramifications for the patient, involves doctors touching the patient and involves some invasive procedures. In Hana's case, until clinical suspicions of death have been confirmed, then she may be alive. It follows that currently, it may be unlawful for doctors in England and Wales to carry out brain death testing autonomously.[12]

If this is correct, then it also follows that if a parent/carer (once notified of the intent to carry out brain death testing) objects explicitly to the testing, then the only way that brain death testing lawfully can be carried out is following the court having granted permission to do so.[13]

What, then, if Hana's parents (having properly been informed of both the proposed procedures and the consequences

that follow the outcome of testing) do not object to testing being carried out?

This situation is, perhaps, best explored under the law relating to implied consent. There is no requirement in England and Wales for consent to medical procedures to be in any particular format.[14] Where consent is required, that may be express oral or express written consent or implied consent. For legal purposes, acquiescence, that is, acceptance without protest, is different from consent.[15] Implied consent (ie, a set of facts, going beyond mere acquiescence by the patient/carer, but falling short of explicit consent) from which a decision to consent is reasonably inferred by those treating is, in this jurisdiction, a valid form of consent.

Consent to testing is implied routinely in a variety of different ways in different clinical settings. Necessarily the 'critical mass' of facts required to reach the threshold at which consent will be implied will vary depending on the type of testing being considered and also the clinical setting. The criteria set by the Academy of Royal Medical Colleges are the definition of death in the UK in both law and medicine.[16] It is obvious that establishing whether or not the patient is alive is a core responsibility of any medical team. Given the need to determine whether Hana is alive, the threshold of implied consent is, we would argue, relatively low, despite the clinical situation being grave. Providing that a parent is properly informed and does not object to the testing, then we would argue that consent can properly be implied by their informed non-dissent.

For reasons explored above, there are also sound ethical reasons why explicit consent should not be essential before brain death testing is undertaken. The House of Lords has emphasised the importance of the law and ethics of medical practice moving together.[17] This provides another powerful reason why the law should be interpreted in a way which permits the use of informed non-dissent to be the routine approach adopted to consent to brain death testing in this jurisdiction. In practice, as with all important issues relating to consent, the clinical record should be completed to confirm the explanation given, the parental response and the medical decision to treat informed non-dissent as implied consent to brain death testing.

CONCLUSIONS

Fortunately, the number of cases of children who develop catastrophic brain injury is relatively small. However, the care of these children and their families can be medically, emotionally and ethically fraught.

For patients like Hana, who are suspected to be brain dead, it is crucial that formal testing is able to proceed to confirm or refute clinical suspicion. In this paper, we have argued that an informed non-dissent model may be an ethical and lawful framework for communicating this to families. If parents were to object to testing, this should lead to a short pause (perhaps for a few days) to allow sensitive exploration of the reasons for the family's concerns. These might arise from misunderstandings or misgivings that can be addressed, issues of trust, guilt or anger relating to the child's illness, or more profound cultural differences in their concept of death. Where parental objection persists, an urgent court order should potentially be sought (as occurs, for example, in cases of parental refusal of blood transfusion).

Informed non-dissent will not make a difference in all cases where death is suspected. In some cases, parents will object to testing, and an application to the court will be necessary. In others, parents would readily and rapidly agree to testing if asked. However, in some cases (and Hana's might be in this category), informed non-dissent may facilitate timely clarification of the child's clinical and legal status and avoid significant delays to the diagnosis of death.

X Dominic Wilkinson @NeonatalEthics

Contributors DW conceived of this article and wrote the first draft. CM contributed the legal analysis. CM and SWT edited and revised the paper.

Funding This research was funded, in part, by the Wellcome Trust (203132/Z/16/Z).

Disclaimer The views expressed in this paper are the authors' own.

Competing interests DW, CM and SWT are members of the Ethics and Law Advisory Group of the Royal College of Paediatrics and Child Health (RCPCH). DW is a member of a working group on Diagnosis of Death by Neurological Criteria for the RCPCH.

Provenance and peer review Not commissioned; externally peer reviewed.

To cite Wilkinson D, Miller C, Turner SW. *Arch Dis Child* 2024;**109**:359–360.
Published Online First 17 February 2024

Arch Dis Child 2024;**109**:359–360.
doi:10.1136/archdischild-2023-325635

ORCID iDs
Dominic Wilkinson http://orcid.org/0000-0003-3958-8633
Stephen W Turner http://orcid.org/0000-0001-8393-5060

REFERENCES

1 Lewis A. An Overview of Ethical Issues Raised by Medicolegal Challenges to Death by Neurologic Criteria in the United Kingdom and a Comparison to Management of These Challenges in the USA. *Am J Bioeth* 2024;24:79–96.
2 Wilkinson DJ. Resolving conflict about treatment for seriously ill children. *BMJ* 2022;378:2000.
3 Muramoto O. Is informed consent required for the diagnosis of brain death regardless of consent for organ donation? *J Med Ethics* 2020;47:medethics-2020-106240.
4 Lee BM, Trowbridge A, McEvoy M, *et al*. Can a Parent Refuse the Brain Death Examination? *Pediatrics* 2020;145:e20192340.
5 McDougall R, Delany C, Gillam L, eds. *When doctors and parents disagree: ethics paediatrics and the zone of parental discretion*. Sydney: Federation Press, 2016.
6 Truog RD, Morrison W, Kirschen M. What Should We Do When Families Refuse Testing for Brain Death? *AMA J Ethics* 2020;22:E986–994.
7 Kon AA. Informed nondissent rather than informed assent. *Chest* 2008;133:320–1;
8 Kon AA. Informed non-dissent: a better option than slow codes when families cannot bear to say "let her die." *Am J Bioeth* 2011;11:22–3.
9 Real de Asúa D, Lee K, Koch P, *et al*. We don't need unilateral DNRs: taking informed non-dissent one step further. *J Med Ethics* 2019;45:314–7.
10 State of Virginia, USA; Lawson v VCU medical centre No CL16-2358 (13th Circuit Va. 2016.
11 Shemie SD, Wilson LC, Hornby L, *et al*. A brain-based definition of death and criteria for its determination after arrest of circulation or neurologic function in Canada: A 2023 clinical practice guideline. *Can J Anaesth* 2023;70:483–557.
12 Sidaway v Bethlem Royal Hospital Governors [1985] 1 All ER 643.
13 Glass v UK [2004] 1 FCR 553.
14 Taylor v Shropshire Health Authority [1998] Lloyd's Rep Med 395.
15 St George'S Healthcare NHS Trust v S [1998] 3 All ER 673.
16 Re M (declaration of death of child) [2020] EWCA Civ 164.
17 Airedale NHS Trust v Bland [1993] 1 All ER 821.