Re M (Declaration of Death of Child) [2020]: "No Best Interests to Consider"?

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Abstract

When Midrar Namiq was diagnosed brain stem dead at the age of two weeks old, Manchester University NHS Foundation Trust applied for a declaration that it would be lawful to make arrangements for his mechanical ventilation to be switched off. This declaration, which was granted by the High Court, was upheld by the Court of Appeal. Although the child's parents had protested against the withdrawal of ventilatory support on the basis of their religious beliefs, this point was sidelined by the courts. Rather, they viewed their task solely as one to identify whether the child is brain stem dead, hence clinically (and legally) dead, in accordance with the protocol and criteria established by the Academy of Medical Royal Colleges and the Royal College of Paediatrics and Child Health. This frame of reference has led to the conclusion that no consideration of best interests was necessary, as the concept is only relevant for patients who are still alive but who are incompetent on grounds of mental incapacity and/or age. This paper contends that had the parents' religious objections been taken into proper account, best interests is potentially a pertinent consideration in this case. Although the outcome may still be the same, it would be reached through a different legal route.

A. Introduction

The case of Midrar Namiq came before the English Courts in early 2020. Compared to several other cases relating to the withdrawal of mechanical ventilation from infants in recent times,[1] the media coverage of his parents' fight against the medical team's decision to switch off his ventilation was generally low-key. While this may well have been the case because it was eclipsed by more attention-grabbing news like Brexit and the novel coronavirus, it should not escape notice that there is often a sharp contrast in media interest and public sympathy when it comes to parental opposition to the withdrawal of ventilation relating to infants whose brain stems are alive, as opposed to those who are diagnosed as brain stem dead. The former requires the judiciary to engage the best interests test no matter how profoundly brain damaged the child is.[2] This could, nevertheless, lead to a declaration that it would be lawful to withdraw the ventilation where its continuation was deemed to be medically futile.[3] Members of the public have not, of late, been slow to express their discontentment when their assessment of the child's best interests did not align with those of the judiciary and the medical profession.[4] In the meantime, as stated by the courts in Midrar Namiq's case, "there are no best interests to

[1] The most notable of which were Charlie Gard and Alfie Evans.
[2] See e.g. *Great Ormond Street Hospital v Yates, Gard & Gard* [2017] EWHC 972 (Fam); *Alder Hey Children's NHS Foundation Trust v Evans, James & Evans* [2018] EWHC 308 (Fam); and *Kings College Hospital NHS Foundation Trust v Thomas, Haastrup & Haastrup* [2018] EWHC 127 (Fam).
[3] *Ibid.*
[4] N. Triggle, 'Charlie Gard: A Case That Changed Everything?', BBC News, 29 July 2017; J. Thomas, 'Police Confirm Alfie Evans Protest Was Peaceful After Emotional Night Outside Alder Hey Hospital', Liverpool Echo, 13 April 2018.

consider"[5] for brain stem dead patients, as such individuals are considered clinically and legally dead. The test is only necessary for patients who are still alive but are incompetent on grounds of mental incapacity and/or age.[6] The public too, through the noticeable absence of the impassioned reaction which usually accompanies a declaration that it is lawful to withdraw ventilation in a so-called "medical futility" case, seems to have accepted the notion that brain stem death equates the death of the person. Hence as the ventilation is to be removed from one who is already pronounced clinically dead, it does not seem to provoke as much ethico-legal reflections and objections when compared to its removal from patients whose brain stems were still alive no matter how severely brain-damaged they otherwise were.

However, had the parents' religious beliefs been given due recognition, the fact that Midrar was still, as his father highlighted, "showing signs of life"[7] (particularly respiration and heartbeat) albeit with ventilatory support, could give rise to the contention that he was still alive from an Islamic perspective. The matter could then be approached from the angle of "medical futility", warranting a best interests assessment.

B. Midrar Namiq: Dead or Alive?

Midrar Namiq was born at St Mary's Hospital in Manchester on 18 September 2019. His mother's membranes had ruptured on the way to hospital, and the umbilical cord prolapsed. This cut off the oxygen supply to his brain for a significant period. Successfully intubated at birth where a slow heartbeat was detected, he was transferred to the hospital's Neonatal Intensive Care Unit (NICU) and placed on a ventilator. On 1 and 2 October 2019, DNC (death by neurological criteria) tests were carried out and these confirmed that his brain stem was dead. A third DNC test was conducted on 4 November 2019 and this too showed that his brain stem was dead. This was followed by an MRI scan on 5 November 2019 which demonstrated "catastrophic appearances with internal brain liquefaction including brain stem supportive for brain stem test. Complete effacement of intracranial CSF [cerebral spinal fluid] spaces including ventricles and cisterns".[8] Following these findings, the hospital proposed to switch the ventilator off. When his parents protested on the basis of their Islamic religious beliefs, Manchester University NHS Foundation Trust (which runs the hospital) made an application to the High Court on 26 November 2019. It sought for declarations that (a) Midrar did not have the requisite capacity to make decisions concerning his medical treatment; and (b) it was lawful for the hospital to withdraw his mechanical ventilation.

I. Death by Neurological Criteria

The case was heard by Mrs Justice Lieven who framed her task as identifying whether Midrar was dead, according to the DNC tests set out by the Academy of Medical Royal Colleges and the Royal College of Paediatrics and Child Health.[9] Death is defined by these professional bodies as the "irreversible loss of the capacity for consciousness, combined with

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[5] *Manchester University NHS Foundation Trust v Namiq, Ali & Namiq* [2020] EWHC 5 (Fam), *per* Lieven J. at paragraph 32. This was subsequently confirmed by the Court of Appeal - see *Re M (Declaration of Death of Child)* [2020] EWCA Civ 164 at paragraph 96.

[6] *Re M (Declaration of Death of Child), ibid.*, paragraph 24.

[7] Anonymous, 'Life-support Case Doctors "Do Not Need Naming" ', BBC News, 17 February 2020.

[8] *Re M (Declaration of Death of Child),* paragraph 17.

[9] *Manchester University NHS Foundation Trust v Namiq, Ali & Namiq,* paragraph 4.

irreversible loss of the capacity to breathe".[10] Since the irreversible cessation of brain stem function will produce this clinical state, brain stem death is said to be equivalent to the death of the individual.[11] Satisfied that doctors had followed the prescribed protocols and that Midrar had met the relevant criteria for the diagnosis of brain stem death, Mrs Justice Lieven clarified that there were no best interests to consider as Midrar had "irreversibly lost whatever one might define as life".[12] The following declarations were made on 28 January 2020: that (a) Midrar had no capacity to make decisions concerning his medical treatment namely the administration of mechanical ventilation; and (b) it was lawful for the hospital to make arrangements for the ventilation to be withdrawn.

Midrar's parents immediately applied to appeal against the decision to allow the withdrawal of the mechanical ventilation. The application for permission to appeal was heard by Sir Andrew McFarlane, Lord Justice Patten and Lady Justice King in the Court of Appeal. They unanimously agreed that Mrs Justice Lieven was correct in identifying that the issue which called for determination was whether Midrar was dead, in accordance with the DNC tests as set out by the two afore-mentioned professional bodies, and if satisfied that these were met, to declare that it would be lawful for the ventilator to be removed.[13] They also agreed that once it was satisfied on the balance of probabilities that the guidances issued by the Academy of Medical Royal Colleges and the Royal College of Paediatrics and Child Health have been properly applied, it is unnecessary to engage in a best interests analysis.[14] Neither would this exercise be appropriate as "the child is already dead"[15] and "where a person is dead, the question of best interests is, tragically no longer relevant".[16] The Court of Appeal therefore upheld the declaration made by the High Court and refused permission to appeal. It nevertheless suggested and prescribed a clearer form of words to be used by High Court judges in the future. First, that such a declaration should expressly declare that the patient has died at a particular time and date, before granting permission and declaring that it is lawful for mechanical ventilation and other medical interventions to be withdrawn. Second, that the purpose of such a declaration should also be identified as one which is to allow the person who has died "dignity in death".[17]

Within days of the Court of Appeal's judgement, Midrar was disconnected from his ventilator.[18]

II. Death from a Religious Perspective

The parents had voiced their objection to the proposal to withdraw the ventilation on the basis of their religious beliefs, arguing that Midrar was still alive.[19] However, how Islam defines

[10] Academy of Medical Royal Colleges, 'A Code of Practice for the Diagnosis and Confirmation of Death' (2008), p. 11; Royal College of Paediatrics and Child Health, 'The Diagnosis of Death by Neurological Criteria in Infants Less than Two Months Old' (2015), p. 8.
[11] *Ibid.*
[12] *Manchester University NHS Foundation Trust v Namiq, Ali & Namiq*, paragraph 32.
[13] *Re M (Declaration of Death of Child),* paragraph 23.
[14] *Ibid*., paragraph 96.
[15] *Ibid.*
[16] *Ibid*., paragraph 24.
[17] *Ibid*., paragraph 60. This is in line with, and in approval of, the formulation used by Mr Justice Hayden in *Re A (A Child)* [2015] EWHC 443 (Fam).
[18] Anonymous, 'Midrar Ali: Baby's Ventilator Disconnected After Court Ruling', BBC News, 26 February 2020.
[19] In fact, his father, who is a biomedical scientist, went as far as to assert that Midrar was not brain stem dead – see *Manchester University NHS Foundation Trust v Namiq, Ali & Namiq,* paragraph 51. On appeal, the parents also asked the court to take into consideration the wider approach used in jurisdictions which diagnose death by reference to the whole-brain. This issue will be analysed elsewhere.

death was not a matter which received attention in the judgments. Both the High Court and the Court of Appeal were, as highlighted, resolute that their task was to identify whether Midrar was dead in accordance with the protocols and criteria established by the medical profession. It was emphasised that it was not open to them to "contemplate a different test"[20] since brain stem death has been established as the legal definition of death by the House of Lords, the predecessor of the Supreme Court, in the 1993 case of *Airedale NHS Trust v Bland*.[21] This is notwithstanding the fact that, although the religious concept of sanctity of life was mentioned in the judgment,[22] how death is defined from a religious perspective was not an issue that directly came up in the case. The House of Lords was not therefore presented with the opportunity to explore this matter then. In fact, such contestations seemed to have come before the English courts only in the last 5 years. But when they came, this was in quick succession. From *Re A (A Child)*[23] in 2015, to *Oxford University NHS Trust v AB (A Minor), CD & EF*[24] in 2019 and now *Re M (Declaration of Death in Child)* in 2020. All three concerned objections raised by the parents of children whose ventilator and life-sustaining medical treatment were about to be terminated by the medical team upon a diagnosis of brain stem death. Like Midrar's case, in *Re A (A Child)* this was on the basis of the family's Islamic faith, and in *Oxford University NHS Trust v AB (A Minor), CD & EF*, their Christian faith. Just as in Midrar's case, the courts took the view that once brain stem death had occurred, the ventilated child was dead for clinical and legal purposes, and no best interests assessments were necessary.

Had Midrar's parents' religious objection been given sufficient consideration, Islamic scholars and leaders could be invited to testify that some within the religion still do not accept that brain stem death equates the death of a person.[25] Rather, death is demarcated by the departure of the soul,[26] and it is the presence or absence of respiration and heartbeat which signify whether the soul still inhabits or has left the body. Thus as long as a brain stem dead person is still breathing and maintain a heartbeat, even if only through the support of a mechanical ventilator, he is still considered alive.[27] Had this worldview been given recognition in the courts, a best interests analysis would be called for, as Midrar was still breathing and his heart was still beating, hence alive, when and after he was pronounced brain stem dead.

C. Recommendations and Conclusion

Although neurological death has developed firm roots in England and Wales, the idea that brain stem death equates the death of the person is not always shared by religious communities which relate death with the departure of the soul from the body. Not only is the presence or absence of the soul usually associated with the corresponding presence or absence of breathing and heartbeat, there also does not seem to be any indications in religious scriptures that the brain is the exclusive residence of the soul.[28] Thus when the courts came to the conclusion that Midrar

[20] *Re M (Declaration of Death of Child),* paragraph 91.
[21] [1993] AC 789 *per* Lord Keith at 856 and Lord Goff at 863.
[22] *Ibid*., *per* Lord Hoffman at 826.
[23] [2015] EWHC 443 (Fam).
[24] [2019] EWHC 3516 (Fam).
[25] See e.g. A. Bedir & S. Aksoy, 'Brain Death Revisited: It Is Not "Complete Death" According to Islamic Sources' (2011) 37 *Journal of Medical Ethics* 290; M.Y. Rady & J.L. Verheijde, 'A Response to the Legitimacy of Brain Death in Islam' (2016) 55 *Journal of Religion and Health* 1198; H. Chamsi-Pasha & M.A. Albar, 'Do Not Resuscitate, Brain Death, and Organ Transplantation: Islamic Perspective' (2017) 7(2) *Avicenna Journal of Medicine* 35; A.C. Miller, et. al., 'Brain Death and Islam: The Interface of Religion, Culture, History, Law, and Modern Medicine' (2014) 146(4) *Chest* 1092.
[26] Quran, Surah al-Zumar, verse 42.
[27] A. Bedir & S. Aksoy, *op. cit., passim.*
[28] J.L. Verheijde & M. Potts, 'Commentary on the Concept of Brain Death Within the Catholic Bioethical Framework' (2010) 16(3) *Christian Bioethics* 246 at 253.

Namiq had no best interests to consider, the fact that this was derived from the finding that he was already dead on account of having been diagnosed as brain stem dead meant that a different conclusion could be reached on this matter if the courts had recognised the parents' religious viewpoint.

However, even if a best interests assessment had been conducted in this case, it is unlikely that a different outcome would be reached. Apart from the diagnosis of brain stem death, a significant proportion of Midrar's brain had, as observed above, turned to liquid. All these point to a potential finding that the continuation of ventilation would be futile (from a secular medico-legal perspective), following which it would be in Midrar's best interests to have it withdrawn. This, in a sense, demonstrates the limitations of the court as a venue for facilitating faith-based dissensions on neurological death. At most, this legal route could serve as an acknowledgement that the idea that brain stem death equates the death of the person, is not universally accepted. And that there are competing, yet no less viable nor less deeply held, ways of perceiving when life ends. That Midrar's case is the third which have been brought before the courts on this issue in the last 5 years, signifies the depth of its dissenters' conviction. It also signifies that the case may not be the last to make its way to the courtroom.

It is ultimately Parliament which is best placed to safeguard the interests of faith communities on this matter. A fundamental step in this direction would be by facilitating the reasonable accommodation of religious objections to neurological death via legislation. For this, the legislative framework adopted in New Jersey would be instructive. According to its Declaration of Death Act 1991, if a declaration of death by neurological criteria would violate the religious beliefs of the patient, "death shall be declared, and the time of death fixed, solely upon the diagnosis of cardio-respiratory criteria".[29] This is on account of the fact that this traditionally well-accepted method is more sympathetic to faith communities' emphasis on the cessation of breathing and heartbeat when determining death. Further, the Act prohibits any healthcare practitioner or provider or other authorities from denying funding for the continuation of life-support to those patients until such time that their hearts would stop beating naturally, which is usually within days or weeks after neurological death occurred.[30] It is only at that point when the cardiopulmonary criteria for death are met, that the patient would be pronounced legally dead.[31]

If a similar model is implemented in England and Wales, it would obviate the need to go to court for disputes relating to religious objection. In bestowing a religious exemption from brain stem death and placing a corresponding duty on hospitals and medical personnel to allow and facilitate an alternative definition of death, it could spare family members additional pain and distress at a time when they are already struggling emotionally.[32] It would allow them to be reconciled with their impending loss on terms they can accept, without the threat of a unilateral withdrawal of life support looming in the background.[33] This would also lessen friction and angst between them and the medical team at a time when therapeutic alliance should be strong rather than diluted.[34] Such a law also anticipates an endpoint, be this a natural one as described above or when accommodation extends beyond what would be considered

[29] Section 5.
[30] Section 7.
[31] T. Pope, ' Brain Death and the Law: Hard Cases and Legal Challenges' (2018) *Hastings Center Report* S46 at S48.
[32] L.S.M. Johnson, 'The Case for Reasonable Accommodation of Conscientious Objections to Declarations of Brain Death' (2016) *Bioethical Inquiry* 105 at 112.
[33] *Ibid.*, p. 113.
[34] A. Lewis, et. al., 'Prolonging Support After Brain Death: When Families Ask for More' (2016) 24 *Neurocritical Care* 481 at 485.

"reasonable".[35] It could therefore: serve as a practical and compassionate compromise in conflicts relating to brain stem death,[36] and empowers faith communities in a meaningful way.[37]

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[35] M.L. Smith & A.L. Flamm, 'Accommodating Religious Beliefs in the ICU: A Narrative Account of a Disputed Death' (2011) 1(1) *Narrative Enquiry in Bioethics* 55 at 63.
[36] L.S.M. Johnson, op. cit., pp. 113-114.
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