Mohammed's case

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A recent case in the Supreme Court of NSW examined the legal issues surrounding end-of-life decisions involving children.[1]

Case

In June 2012, Mohammed, then aged 10 weeks, was admitted to hospital with respiratory problems that were thought to be secondary to a viral infection. Mohammed had the mosaic form of trisomy 21 and, soon after his birth, was found to be suffering from a patent ductus arteriosus (PDA).

After admission to hospital in June 2012, Mohammed underwent surgery to repair the PDA and over the ensuing weeks extensive testing was undertaken to identify other underlying conditions. This testing revealed a mitochondrial disorder, pyruvate dehydrogenase deficiency (PDD), which is characterised by elevated serum lactate. The clinical features of PDD include respiratory, cardiac and neurological problems. The neurological problems associated with PDD involve seizures and delayed intellectual and motor development. Mohammed was also thought to be blind and deaf. He was hypotonic and did not respond to touch other than painful stimuli. He required nasogastric feeding because of severe reflux but, despite this, he was losing weight.

By December 2012, the consensus opinion of Mohammed's treating medical team was that his condition would not improve and his disease was fatal. The treating team wanted to provide palliative care for Mohammed and not commence mechanical ventilation should his respiratory condition deteriorate. His parents, however, wanted active medical treatment to be provided, including commencement of mechanical ventilation when required for the management of his respiratory problems.

Medicolegal issues

On 21 December 2012, Mohammed's parents contacted the Supreme Court of NSW seeking an order that the hospital provide mechanical ventilation for Mohammed. An urgent sitting of the Court was held at the hospital later that day. Mohammed's parents, his treating paediatrician and two paediatric intensivists gave evidence.

Mohammed's parents sought an order that the hospital take all necessary steps to place and maintain Mohammed on mechanical ventilation until such time as his parents consented to cessation of mechanical ventilation. The judge considered two questions:

- Was it in the best interests of Mohammed to have treatment by way of mechanical ventilation?
- If it was in the best interests of Mohammed, could and should the Court order that, contrary to the views of the treating doctors, mechanical ventilation be provided?

The treating doctors gave evidence that Mohammed's condition was terminal and it was not possible to alleviate or cure it. It was their opinion that the risks associated with mechanical ventilation, and the pain and distress, significantly outweighed any benefit that Mohammed would obtain from mechanical ventilation. Mohammed's parents argued that Mohammed's various conditions should be viewed separately from the decision as to whether or not to commence mechanical ventilation.

The judge concluded that it was not in Mohammed's best interests to be mechanically ventilated. He reached this conclusion by weighing

up the risks and potential disadvantages for Mohammed if he was mechanically ventilated, against the identifiable benefits of mechanical ventilation. The judge concluded:

> 'If the Court is satisfied that the opinions of the doctors have been reached after careful consideration having regard to the correct and relevant matters and are opinions reached in the proper exercise of their professional judgment as to what is in the best interests of the patient, then I very much doubt that a Court would ever make an order of the kind sought here. That is because it is not the role of the Court to interfere in such a professional relationship and to compel action by an unwilling participant which would have the consequence of placing that individual in the position, in good conscience, of choosing between compliance with a Court order and compliance with their professional obligations.
>
> Here, I am well satisfied that the doctors' opinions as to Mohammed's best interests have been reached conscientiously and in the proper discharge of their professional obligations.'

Discussion

This decision highlights some important general legal principles in relation to end-of-life care:

- At common law, there is no obligation on medical practitioners to provide medical treatment that is 'futile'; that is, where the treatment is of no medical benefit to the patient, or the burdens of the therapy are out of all proportion to any potential benefits. The determination of futility must be appropriately made and, ideally, there should be consensus with the patient and/or their substitute decision maker with respect to the assessment of futility (in some states the consent of the substitute decision maker should be sought before withholding or withdrawing futile treatment). The courts are more likely to intervene if the determination of futility is not in accordance with clinical guidelines and/or hospital policies.

In cases involving children and end-of-life decisions:

- Where the child is unable to understand the nature of the proposed treatment, the child's parent or guardian may lawfully consent to most types of medical treatment. However, parental power to consent to or refuse medical treatment must only be exercised in the child's best interests.
- A Court may override parental consent if the proposed treatment, or refusal of treatment, is not considered to be in the child's best interests. The legal test for best interests includes the physical effects of treatment on the patient, and psychological and social implications.
- The Supreme Court of each state and territory has *parens patriae* powers, which include the power to consent to or refuse treatment in the child's best interests. The history of *parens patriae* is based on powers exercised in the past by the King as the 'parent of the nation' and then later delegated to the courts. In modern times, they are powers exercised on behalf of the community as a whole on the grounds that the community has an interest in the welfare of children and can take control of decisions associated with the welfare of children when it is appropriate to do so.[2] The *parens patriae* jurisdiction can be invoked by any person who has the care of a child, including a medical practitioner, and the applicant can seek a declaration from the Court about what is in the child's best interests.
- Where the treating medical team and the parents or guardian of a child agree that a decision to withhold or withdraw life-sustaining treatment is in a child's best interests, there is no legal obligation to seek the additional approval of a court to withhold treatment.

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References

1. TS & DS v Sydney Children's Hospital Network ('Mohammed's case') [2012] NSWSC 1609.
2. Kerridge I, Lowe M, Stewart C. Ethics and law for the health professions. 4th ed. Sydney: Federation Press; 2013; p 600.

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