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# Ethical Decision Making in A Brain-Death Child

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## ABSTRACT

Diagnosing brain death in paediatrics is difficult due to emotional, ethical and legal weightage. This can easily be resolved in a straightforward case following a series of examinations and investigations to confirm that the condition is irreversible. However, in some cases, consideration of religio-cultural, family preferences and other contextual factors have to be carefully considered. This is due to challenges in ethical decision making whether to continue the treatment or to set for discontinuation of active management. There should be an emphasis on appropriate communication, resolution of conflicts and also a focus on supporting the family and health care providers involved in the care of the patient. This is to avoid misunderstanding of information and allowing continuous discussion on the right way forward. Decision-making in a complex situation such as paediatric brain death would require ongoing negotiation based on the best interest and beneficence of the medical actions to avoid ongoing suffering for the patient and his/her family.

**Keywords:** Brain death, Paediatrics, Communication, Challenges, Decision making

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## INTRODUCTION

Most of the paediatric deaths occur in the hospital context. In intensive care settings, children are often managed aggressively with ventilation and active medical intervention. Discussions with the parents of children who have brain death are necessary to decide on withdrawal, continuation, or withholding of medical support. Withdrawal or withholding support accounts for between 28 - 65% of death in paediatric intensive care settings. (1) Brain death is the term coined for an irreversible termination of all brain activities, including the brain stem. To establish this, all reversible causes must be excluded. Unfortunately, the issue of brain death often could be challenging when the patient is often conserved using the ventilatory support without forward planning. Families of an affected child may also be emotionally affected as their child was kept 'alive' by the ventilator despite a futile

brain death situation. Some families may still be hoping for a small chance of recovery even if this chance is so remote. The direction to continue or discontinue treatment should be based on the beneficial outcome, disease prognostication, contextual issues, the child's best interest and the resolution of any ethical dilemma concurrently. (2) We illustrate the challenges in the management of a child with metabolic disease who succumbed and fulfilled the brain death criteria.

## CASE

A 9-year-old boy with a known case of Maple Syrup Urine Disease (MSUD) and global developmental delay presented with a short history of being unwell, lethargy and persistent vomiting. He developed generalized status epilepticus on the ward, requiring intubation for airway protection. His blood investigations revealed markedly elevated serum amino acids with normal brain imaging findings. He was treated for metabolic crisis with encephalopathy and was commenced on high-calorie intravenous drip with the target daily calorie intake of 125-150% of typical energy needs to prevent further metabolic catabolism. However, he later developed multiple complications, including upper gastrointestinal bleeding which required haemodialysis support. Despite aggressive treatment, his condition worsened. His pupils became fixed and dilated. There was an absence of gag reflex with no spontaneous breathing and movement. Parents were counselled regarding withdrawal or continuation of active management. Electroencephalography showed an isoelectric reading related to the absence of brain activity. Two paediatric consultants performed a brain death test, and both agreed on the diagnosis of brain death. Both parents were offered to spend quality time with the patient. They agreed to the withdrawal of ventilatory and inotropic support but not to the escalation of care. The patient was declared dead after 30 minutes post-extubation. Parents were given an appointment at our bereavement clinic.

## DISCUSSION

The criteria for brain death have evolved over time; however, the basic features remain unchanged. The list of preconditions must be fulfilled prior to the diagnosis of brain death. The patient must be in a comatose state with the absence of respiratory effort and the presence of apnoea when the ventilator is withdrawn. The cause of irreversible brain injury should also be fully established. Patient should be free from factors that may have led to the altered consciousness level such as metabolic disturbance, hypothermia, and sedative medications that would have interfered with the breathing, consciousness, and vital signs change for age. Once these preconditions are fulfilled, the diagnosis must be confirmed with clinical examination, performing the apnoeic test with the evidence of absence brain of stem reflexes.

Brain death examination is hands-on and focused on brainstem function examination, performed by two different physicians, who are not involved in the care of the child, separated by an observation period. The criteria are that the patient must exhibit coma, shows absence of brainstem reflexes (table 1) and indicates absence of respiratory effort by formal apnoea testing (3).

Table 1: Brainstem reflex testing

Brainstem reflex	Examination technique	Findings consistent with brain death
Oculocephalic	Rapidly rotate the patient's head to either side and observe for eye movement.	No apparent eye movement within the orbit
Bulbar	Putting Deep pressure on the condyles at the level of the temporomandibular joints and deep pressure at the supraorbital ridge.	No grimacing or facial muscle movement
Oculovestibular	Elevate head of the bed to 30°, irrigate each ear canal in turn with 50 ml of ice water. Observe eye movement.	No eye movement for 1 minute after irrigation of each ear canal
Corneal	Lightly brush the cornea with a sterile cotton swab.	No eye blink in response to corneal stimulation
Cough/gag	Gag: stimulate the deep posterior pharynx with a suction device.  Cough: use endotracheal suctioning to the depth of carina (2 passes with a suction catheter).	No response to either stimulation
Pupillary light	Assess pupillary size and shape in a slightly darkened room, then shine a bright light into each eye and assess the pupils' reaction in each eye.	Pupils dilated, non-reactive to bright light and mid-position within the orbit

## CHALLENGES IN DIAGNOSING BRAIN DEATH

The concept of brain death has been debated for centuries. Three concepts of brain death have been introduced. Higher brain death refers to the concept of the loss of "personhood" or activities that make the patient human, like thinking, feeling, reasoning, and having human interactions (4). This theory has flaws as people who are in a persistent vegetative state and anencephalic babies who are not considered dead even though they have lost their higher-level brain functions. It is reasonable to believe that someone who has lost higher brain function still has the capability to live. The second terminology is related to whole-brain death which refers to the complete loss of brain function, regardless of lung and heart function. Another concept is the concept of no brain death function, where cessation of metabolic function defines death, not the brain activity itself (4).

The evaluation of patients for brain death can be complicated by specific clinical challenges. These conditions include but are not limited to, the presence of spinal reflexes, neuromuscular blockade, therapeutic hypothermia, neonatal cerebral physiology, extracorporeal membrane oxygenation, and variability of drug metabolism. Sometimes, interpretation of clinical signs is clouded by these factors.

The concept of brain death definition is not universally accepted, and some may have religio-cultural aspects that would play a part before final diagnosis could be made.

## **CHALLENGES IN BREAKING NEWS**

Communication regarding redirection of care is considered when short-term inevitable death and the burden of treatment outweigh the benefits. The dilemma of discontinuation of life-sustaining care is challenging as most paediatric patients may not be able to exercise autonomy in decision making, thus requiring parents or legal guardians as proxy decision-makers. As a result, decision makers are vulnerable to emotional burdens. Early and regular discussion should be done to ensure transparency of information, thus avoiding misunderstanding. In the Malaysian context, social inequalities may influence the decision outcome. Effective outcome of discussion includes a multidisciplinary panel discussion, prognosis assessment, building rapport while assessing emotional, social and spiritual aspects of decision makers prior to involving parents in shared decision-making (5). Patient's best interest, family expectations, emotional burden, consequence of decisions and benefits while not prolonging suffering that compromises quality of life need to be discussed.

Some advocated for discontinuation of care as the appropriate next step in the management rather than a non-escalatory approach. Non-escalation of medical care is often decided when the patient's condition deteriorates and possibly develops poor health outcomes. This is similar to withholding any active intervention due to poor prognosis and the experienced primary team determines this. When delivering the devastating diagnosis of brain death, attention should be focused on the language used and understanding of the family background. Most paediatricians would pursue non-active and non-escalatory medical care. It is vital to address this sensitive decision with compassion and provide emotional support to parents while involving them to participate in the care of their child towards end-of-life. Ethical consideration of parental discretion, assistance in decision-making process and consideration of moral distress in individualized approach is essential to achieve holistic well-being of the family (5,6). Health care providers are to support by planning redirection of therapeutic goals with the aim of reducing physical suffering of patients and emotional burden of the families (6).

## **CHALLENGES IN ETHICAL DECISION MAKING**

There is no moral justification for prolonging patients' suffering when it can be reduced or hastening death to end their pain. Previous literature stated 5 circumstances where withdrawal of support may be considered in children. The circumstances are the state of brain death, permanent vegetative state, "no chance", "no purpose" and "unbearable" (7). Despite the framework's comprehensive covers on legal and ethical aspects, it does not give specific advice on each individual case. It is fundamental that quality of life is given consideration during this ethical decision-making. Quality of life interpretation is perhaps different between an adult and a child (8). Measuring quality of life can be vague and full of assumptions. Most of the decisions are based on clinical context, whether the child is likely to suffer, imminent death or poor prognostication. The other contributing factors are related to the perception of a child or parental understanding of the issues discussed. Decision making, especially in paediatric patients must be done cautiously without being judgmental.

At the juncture of non-curative path, often there is dispute when considering the threshold in futility of care, the paradigm of best interest and dignity of an ill child. Communication breakdown at the end of life between the multidisciplinary team and parents can lead to treatment plan ambiguity and resulting personal guilt among health care providers. This could have led to failure in recognizing family expectations and needs. Effective communication overcomes stigma of death and dying issues, becoming a therapeutic route to relieve anxiety. It allows caregivers to face grief while their terminally ill family member is still alive (9). This promotes quality time for the family, resolve guilt, improvise their interaction and deal with separation better (10).

Shared decision -making should be advocated towards comfort care while addressing withholding or withdrawal of life-supportive treatment. Individualized holistic management focusing on the child and family's current needs is vital. Early introduction of palliative care support would achieve better trust, rapport, respect and understanding. If the conflict between the managing team and the family worsens, this should be dealt with by having another senior doctor's opinion to give another review of the patient's clinical status. The clinical progress, continuation of family's involvement in the patient care and psychosocial support should be continued actively. The rights of a child does not imply an obligation, given that many parents cannot assume responsibility in such a difficult scenario. Their decision may cause anguish and, eventually, guilt (11). Health care providers should empathize and avoid placing the burden of the decision on the parents.

Health care providers are also vulnerable to grief when dealing with emotionally exhaustive cases. Debriefing sessions would allow them to reflect and combat moral distress and compassion fatigue while reducing the rate of burnout. This is important to ensure all health care providers practice self-care for the longevity of employment in this area. In the context of the grey zone, prioritizing parental opinions is essential. This is for parents to make decisions since their decisions are relevant to the medical care. There are also cultural contexts, especially when dealing with multi-ethnic and multi-religious wishes of each family. However, the boundary for disregarding parental opinions depends on harm principles. If the child is likely to face harm as a result of parental decision, decision should be made according to the medical responsibility, and to recommend the actions based on the current knowledge and experiences (11).

## CONCLUSION

Managing brain death in children can be challenging. Most of the discussion should be commenced early and the decision to withdraw or withholding care would be dependent on collective and shared understanding between the health care providers and the caregivers, to ensure the best decision-making is made to avoid suffering and poor quality of life.

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