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CASE STUDY

Navigating the ethical challenges in the care of a critically ill infant

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Abstract

This case presents the challenges faced in managing a premature infant with multiple unexplained neuromuscular symptoms. The discussion focuses on the ethical dilemmas surrounding the initiation of palliative care in the absence of a clear diagnosis. Key ethical questions include the appropriateness of continuing intensive care when the prognosis is uncertain, and the role of parental autonomy in making informed decisions. This case underscores the importance of ongoing ethical deliberation and sensitive communication in neonatal end-of-life care.

Keywords: *clinical ethics, end-of-life care, palliative care, neonatal intensive care unit*

Case

We present the case of a long-term ventilated neonate patient with an uncertain diagnosis, where the differing opinions of the parents and the healthcare team create an ethical dilemma. Infant A is a baby girl, born prematurely at 31 weeks of gestation, with a birth weight of 1.49kg. Her mother, a 35-year-old mother of three other children, had a low-risk pregnancy. Antenatal screening had revealed no abnormalities.

The patient was intubated at birth for acute difficulty in breathing. Initial examination revealed poor muscle tone and general reflexes with minimal spontaneous movement of the limbs, and arachnodactyly. She had triangular facies, with no facial grimace and widely spaced nipples. Other systemic examinations were unremarkable.

The patient was treated in the neonatal intensive care unit for respiratory distress syndrome and received the required treatment for her lung pathologies. However, several attempts at removal of the ventilator had failed, due to poor breathing effort and apnoea. Her poor sucking-swallowing coordination resulted in episodes of microaspiration (ie inhalation of tiny amounts of foreign matter) despite optimal therapy for gastroesophageal reflux disease.

The ultrasound of her brain and thyroid function tests were normal, other than slight bleeding revealed in the magnetic resonance imaging of the brain, which was deemed non-significant. The chromosomal analysis result was negative for Down syndrome, spinal muscular atrophy, congenital myasthenia gravis, and Prader-Willi Syndrome. An electroencephalogram revealed no evidence of clinical seizures. Screening for inborn errors of metabolism was negative. Her parents did not consent to a muscle biopsy due to concerns regarding the low yield of the investigation.

The patient was still ventilator-dependent at the age of four months without any definitive diagnosis. Her parents visited regularly, and at times, her mother expressed frustration over her inability to form a bond with the patient. They were very hopeful about taking the patient home although she had minimal spontaneous movement, eye-opening and breathing effort. A tracheostomy and home ventilation were an option for this patient, however, the parents were indecisive about this option due to their limited resources. They also refused further diagnostic investigations, particularly those requiring additional costs, anticipating a low likelihood of beneficial results.

At home, the patient had three older siblings and two half-siblings from her father's first marriage. The parents were struggling to balance the management of their household responsibilities with spending time with the infant at the hospital. Her father was the sole breadwinner and received a minimal wage as an electrician. The extended family believed that the underlying cause of the disease was related to supernatural elements, hence the prolonged hospital stays. They were keen for the patient's discharge to seek other alternatives.

The treating team felt they had reached an impasse. Without parental consent for further tests and treatment, their care plan was limited. They tried to assist with alternative funding sources, but those options had also been exhausted.

Ethical considerations

Given the patient's unclear diagnosis and prognosis, the parents' preferences for comfort care and the limited resource allocation, the question arose as to whether it was ethical for the healthcare providers to withhold invasive treatment and initiate palliative care. Another ethical consideration was addressing the perplexing moral dilemmas that parents and healthcare providers face in making these decisions.

The decision to opt for palliative care is a clinical decision that relies on three factors: newborns with diagnostic and prognostic certainty of limited viability, or congenital abnormalities incompatible with prolonged life; and overwhelming illness not responding to life-sustaining treatment [1]. If the diagnosis is unclear but the prognosis is grave, it is argued that palliative care should be the standard of care. This is usually clear in cases of lethal congenital anomalies. However, in this patient, the certainty of improvement with the current treatment remained uncertain. Improvement over time could alter the prognosis at any stage, which remained the hope of both parents and healthcare providers.

Discussion of ethical considerations

Here, we apply Jonsen's four-box model to clinical decision-making [2]. This is an approach to help ethicists in analysing an ethical dilemma, and consists of four categories: medical indications, patient preferences (autonomy), quality of life and contextual features.

Regarding medical indications, as discussed earlier, the patient's condition is critical as she is ventilator-dependent, with unknown reversibility. Despite prolonged stay in the intensive ward, the patient may not yet be in a terminal state. There are still several diagnoses that have not been explored but pursuing them would require substantial resources that the family is unable to provide. Nursing care could be beneficial, as children are resilient and may recover over time. Unfortunately, time is also a resource that both the parents and the healthcare system cannot readily provide.

For the patient's autonomy, the parents are the appropriate surrogates. They are torn between providing the best care for this patient and continuing to support their other children at home. The father, as the sole breadwinner, faces additional pressure as he has responsibilities towards his family from the previous marriage. This situation may jeopardise the patient's best interests; however, allocating unlimited resources at the expense of the family can also be argued as being non-beneficial. Overriding the parents' request and resorting to legal involvement may not be the best option for the patient either. Thus, the mechanisms for resolving the providers' and parental differences were carefully reconsidered and the available ethical frameworks were re-explored [3].

Next, for the quality of life, understanding life-limiting conditions is crucial, as they are defined based on the quantity and quality of life. Life is limited in quantity when there is brainstem death, imminent death or inevitable death. Life is limited in quality when the burden of treatment is worse than the benefits, the burden of the underlying disease is far-reaching and there is a lack of ability to benefit from continued life [4]. In this case, death at that point may have been inevitable due to her inability to breathe independently. Moreover, she did not demonstrate any neurodevelopmental progression indicative of interaction with her surroundings. As healthcare providers, we must advocate for what we believe is best for the patient. It may also be beneficial to respect parental autonomy over the patient's care, although there may be differences in moral beliefs between healthcare providers and parents [4, 5].

The fourth box to consider is contextual features, which include the discussion on limited resource allocation in the current healthcare setting. Balancing the justice of prolonged intensive bed usage with its potential benefit to other patients who have a definite reversible diagnosis is deemed more acceptable. In addition, intensive paediatric beds and ventilators at this district general hospital are limited.

The ethical dilemma surrounding this case was that the parents believed further interventions to be harmful to the child, while the healthcare providers were keen to obtain a definitive diagnosis. Mediation by the ethics committee can be advantageous in this situation [5]. Additionally, counselling and discussions with the family's chosen chaplain or religious advisor may aid in the shared decision-making process.

After lengthy deliberation, the shared decision was to withhold invasive treatment, and the patient passed away shortly thereafter, receiving the comfort care she deserved. Although deeply saddened, the parents accepted the outcome. The involvement of the ethics committee helped minimise the healthcare providers' moral dilemma. The difficult journey was made more bearable through open communication facilitated by the ethics consultation team, who provided support and transparency throughout the decision-making process.

The involvement of the ethics committee played a crucial role in navigating the complex medical and ethical challenges of the case. By offering an objective perspective and facilitating discussions among all parties, the committee helped ensure that the decision was made with careful deliberation and adherence to ethical guidelines. This not only provided clarity for the parents but also helped minimise the moral distress experienced by the healthcare providers, allowing them to fulfill their professional responsibilities with greater confidence and ethical integrity.

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Authors' contribution: AMK and HZA conceptualized the case report, discussion and analysis of the ethical challenges. AMK, NFBN and MAUMN collected the patient's data and wrote the initial draft of the manuscript. HZA reviewed the final manuscript for submission.

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