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CASE STUDY

To treat or not to treat: A toolkit-based ethics consultation in a newborn

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Abstract

Congenital Diaphragmatic Hernia (CDH) is usually diagnosed prenatally. Despite advances, the prognosis remains poor for severe CDH in many healthcare settings, and many require transition to palliative care. This transition can be an ethical dilemma especially in cases of conflict between stakeholders. A resolution can be accomplished with clinical ethics consultations, but these are rarely available in India. This case report describes how such ethical dilemmas can be resolved by applying paediatric ethics principles in conjunction with Jonsen's four-box model.

Keywords: *Medical ethics, palliative care, Jonsen's four box model, paediatric ethics*

Background

Congenital diaphragmatic hernia (CDH) is a birth defect which causes the abdominal organs to move into the chest and compress the lungs. It occurs in approximately 1 in 3000 births and is associated with lung complications. CDH is diagnosed before birth in 60% of patients, typically on ultrasound, and based on the severity, the mortality of CDH in developing countries varies from 13-60%. Mortality is higher in children with defects on the right side of the diaphragm [1, 2].

Thus, healthcare professionals as well as families are faced with ethical dilemmas about the continuation of pregnancy, neonatal intensive care or surgery [3]. We present a case of severe CDH, which underwent redirection of care after birth, and how the adaptation of a framework such as Jonson's four box model [4] helped resolve an ethical dilemma faced by the treating team. We also apply paediatric ethics principles — the harm principle, the best interest principle and the zone of parental discretion [5, 6, 7, 8].

Case: A 32-year-old lady, 24 weeks pregnant, presented to the antenatal clinic, along with her parents, with an ultrasound report suggestive of right CDH. This was her first pregnancy, and she lived in a village a few hundred kilometres from the city. The paternal family attended the discussion via teleconsultation.

The consensus of the surgery and obstetrics teams was that the baby had less than 50% chances of survival post-surgery, and would require a minimum of 3-4 weeks of post-surgical care in the Neonatal Intensive Care Unit (NICU). The patient was beyond the legal limit for pregnancy termination.

She decided to continue the pregnancy but not to go ahead with surgery after birth. However, there was no consensus regarding resuscitative measures after delivery.

The mother had no further antenatal care follow-up until presentation to casualty at 34 weeks with labour pain. No previous records were available, and she underwent emergency caesarean section. A 2-kg female baby was delivered. The baby did not cry after birth, underwent resuscitation measures, and was shifted to the NICU. The baby required inotropes, mechanical ventilation and additional breathing support including nitrous oxide.

Overnight the baby was managed and stabilised on maximal supports till day 2 of life. Surgical intervention could only happen after stabilisation, and the surgeon agreed with the prenatally estimated outcomes of < 50% survival.

In the family meeting the next day, the maternal grandparents informed the NICU team of their decision of no surgery. Their reasons were:

1. The paternal family was concerned with post-surgery complications causing developmental delays.
2. The short- and long-term costs of prolonged NICU stay, follow up care and repeat surgeries if needed.
3. The possibility of chronic lung disease. A child with lung disease would grow up to be an adult unable to work in the fields, which was important in a farming family.

An urgent palliative care (PC) consult was asked for, and a multidisciplinary meeting was held. This was attended by the maternal grandparents (the mother was consulted later in the postnatal ward), the PC physician, the surgeon, the admitting neonatologist and the NICU fellow who had attended to the baby overnight. The family was offered government schemes and crowdfunding to circumvent financial issues. The NICU team expressed distress at the idea of not proceeding with disease-directed treatment after carrying out resuscitative measures.

Ethical dilemma

This was a conflict between parental refusal and the healthcare team's obligation to act in the best interest of the baby. The ethical dilemma here was: Is it ethically justifiable to withhold definitive surgical care from this newborn, solely based on parental decision, when such care is considered standard and potentially life-saving?

Table 1. Jonsen's Four Box Approach

Medical Indications	Patient Preferences
Beneficence and Nonmaleficence • What is the patient's medical problem? History? Diagnosis? Prognosis? • Is the problem acute? Chronic? Critical? Emergent? Reversible • What are the goals of treatment? • What are the probabilities of success? • What are the plans in case of therapeutic failure? • In sum, how can this patient be benefited by medical and nursing care, and how can harm be avoided?	**Respect for Patient Autonomy** • Is the patient mentally capable and legally competent? Is there evidence of capacity? • If competent, what is the patient stating about preferences of treatment? • Has the patient been informed of benefits and risks, understood this information, and given consent? • If incapacitated, who is the appropriate surrogate? Is the surrogate using appropriate standards for decision making? • Has the patient expressed prior preferences (eg. Advanced directives)? • Is the patient unwilling or unable to cooperate with medical treatment? If so, why? • In sum, is the patient's right to choose being respected to the extent possible in ethics and law?
Quality of Life	**Contextual Features**
Beneficence, nonmaleficence and respect for patient autonomy • What are the prospects, with or without treatment to return to a normal life? • What physical, mental and social deficits is the patient likely to experience if treatment succeeds? • Are there biases that might prejudice the provider's evaluation of the patient's quality of life? • Is the patient's present or future condition such that his or her continued life might be judged as undesirable? • Is there any plan and rationale to forgo treatment? • Are there plans for comfort and palliative care?	**Loyalty and fairness** • Are there family issues that might influence treatment decisions? • Are there provider (physician, nurse) issues that might influence treatment decisions? • Are there financial and economic factors? • Are there religious or cultural factors? • Are there limits on confidentiality? • Are there problems with allocation of resources? • How does the law affect treatment decisions? • Is clinical research or teaching involved? • Is there any conflict of interest on the part of the providers institution?

This dilemma was causing moral distress within the team and required positioning within an ethical framework to help find a way forward. This case study describes an ethical analysis, incorporating paediatric ethical principles along with the four-box model proposed by Jonsen, Siegler and Winslade [4-9].

Resolving ethical dilemmas

Immediately after the multidisciplinary meeting, the palliative and neonatology teams discussed the conflict that they were facing. We adapted the "four boxes" approach in order to clarify the ethical dilemma. Although not originally designed for paediatric use, it is one of the few approaches that comprehensively considers multiple ethical principles. We also incorporated the relevant paediatric ethical principles within the discussion.

The original four-box model can be seen in Table 1 [4]. The description below includes within brackets the relevant biomedical ethical principles as well as specific paediatric ethical principles.

1. *Medical indications (beneficence, nonmaleficence, best interests)*

This case of CDH would be fatal without surgery, but even with surgery there was considerable risk to quality of life. The main concern of the treating team was that surgery was the only chance at meaningful survival and should be offered as per the best interest principle.

2. *Patient and family preferences (autonomy, parental authority, values and preferences)*

Decision making for the baby was done by the mother, with help from the maternal grandparents. They understood the medical condition and prognosis. The paternal family had incomplete information from local doctors, and preconceived notions about survival and residual decline in function, which had to be addressed. Further discussion about values and preferences is presented in the paediatric ethics section below.

3. ***Quality of life (beneficence, nonmaleficence, autonomy, parental values and preferences)***

The family perceived the damage to the baby's lung as a grave problem that would affect the child and the family's future. The treating team felt that since the baby had tolerated resuscitation well, the risk was worth taking, while acknowledging that the clinical course included a real chance of worsening morbidity, increased pain and suffering and long-term complications that would impact quality of life. The team struggled with balancing parental refusal with the child's best interests and beneficence.

4. ***Contextual features (fairness, harm principle, zone of parental discretion)***

The key stakeholders being geographically apart and the language barrier added to the communication challenge. Financial factors were part of the decision making for the family, but the more important aspect was the possibility of long-term sequelae. While there was no conflict regarding allocation of resources, in a busy tertiary centre, emergency cases could occur at any time with a need to divert limited resources elsewhere. The contextual features also include the legal ramifications of discontinuing medical treatment. The Indian Supreme Court has recently prescribed a procedure for withdrawal of support in cases of medical futility, which has been further endorsed in guidelines by the Indian Academy of Pediatrics [10]. Additionally, the treating team had a strong interest in continuing treatment since the hospital is a centre for CDH surgery.

After discussion of all the above aspects, the treating team decided to respect the family's wishes and de-escalate ventilatory and medical supports. Comfort measures were given and the mother spent time with the baby, taking photographs and footprints. The baby passed away peacefully a few hours later.

Discussion

Paediatric ethical principles

Paediatric ethics has since long grappled with the question of "who decides what is best for the child?" Some useful principles here are — the best interest principle, the harm principle and the zone of parental discretion.

The best interest principle (BIP), defined by Buchanan et al has been in use since the 20th century. Its central ethical tenet is beneficence ie prioritising the wellbeing of the child. Its assertion that there is one best answer to a medical problem has come under criticism in complex cases, such as high-risk surgeries or end-of-life scenarios. A full best interest determination includes thinking about the child's place in the family, society, and amidst the practical constraints of its immediate environment [5, 6]. In a family unit with multiple people needing access to limited resources, someone's best interest may have to be sacrificed for that of another. In our case, the child's family found themselves in the difficult situation of balancing the best interests of the family unit with those of the child.

The harm principle (HP) by Diekema (Table 2) has been proposed as an alternative to the BIP. It proposes identifying a range of acceptable options rather than one best interest for the child, and is primarily used for identifying when child protection is warranted by the state. One of its conditions is that interference with the parental decision must offer the child a net benefit, and the intervention denied by the parent must itself not be one that causes significant harm [7]. Applying these conditions yielded the answer of no state intervention, ie, the parents were not unreasonable in deciding not to go in for surgery.

Another framework is that of the "zone of parental discretion" (ZPD) or a "good enough" standard of parenting and medical care, which acknowledges a range of decisions that may be ethically acceptable [8].

The HP and the ZPD both acknowledge the good intentions that parents have while caring for their children, and give a clearer view of when state intervention is warranted and when the act moves out of the zone of appropriate interventions for the child [8,9]. However, there is still a grey zone about what constitutes "significant harm" to the child, which also depends on the parents' values of harm, quality of life, and a good life [8,9].

Jonsen's four-box model

For complex paediatric and neonatal cases, paediatric ethics provides an excellent overarching principle, but a framework is still needed for complex decision making. Application of the four-box model triggered the following discussions amongst the treating team:

1. The family may have made the difficult decision of no surgery keeping in mind the costs they need to face, and the family resources that may be spent in taking care of this child in the years to come, considering their distance from tertiary-level medical care and limited resources.
2. Respect for patient autonomy is more challenging in cases involving children rather than in adults. Parents are the surrogate decision makers, but prima facie, parental authority does not have the same moral force as the respect for individual autonomy does. Along with their responsibility to a child in isolation, parents also consider their responsibility to children that are yet to come, as well as other members of the family.
3. The team reflected that considering only one of the four boxes (medical indications) in such complex cases can lead to distress and moral dilemmas.

Table 2. The Harm Principle for state intervention

Condition No.	Condition	Answer
1	By refusing to consent are the parents placing their child at significant risk of serious harm?	Yes
2	Is the harm imminent, requiring immediate action to prevent it?	Yes
3	Is the intervention that has been refused necessary to prevent the serious harm?	Yes
4	Is the intervention that has been refused of proven efficacy, and therefore, likely to prevent the harm?	It is of proven efficacy but chances of efficacy are < 50% in this case
5	Does the intervention that has been refused by the parents not also place the child at significant risk of serious harm, and do its projected benefits outweigh its projected burdens significantly more favorably than the option chosen by the parents?	The intervention being refused by the parents also puts the child at significant risk such as chronic lung disease, neurodisability and even death
6	Would any other option prevent serious harm to the child in a way that is less intrusive to parental autonomy and more acceptable to the parents?	CDH is a surgical condition and therefore surgery is the only option for managing it. Both situations of going ahead with surgery as well as not doing surgery has a risk of harm to the child
7	Can the state intervention be generalized to all other similar situations?	The state intervention cannot be generalized as surgery outcomes depend on severity of CDH. Parents may have agreed to go ahead with surgery if better outcomes were possible
8	Would most parents agree that the state intervention was reasonable?	Most parents would not agree for state intervention considering India does not have universal healthcare, hence parents have to make this decision based on restricted resources they have for the family and other children to come.

Reframing ethical dilemmas

The question was: Should we continue life sustaining treatment including surgery for this baby? Uncertainty in clinical management can be resolved by referring to clinical practice guidelines and trial-based evidence, after which physicians can apply the benefit/burden ratio and convert it into a medical recommendation/indication for the patient [9]. There is also evidence that clinicians do consider scarcity of resources, financial problems and possibility of disabilities while discussing treatment decisions with families [11].

The question could also be reframed as: What is the family's main concern regarding surgery? This was the possibility of long term sequalae and lack of family support in caring for a sick child. The treating team had no way of ensuring that chronic sequelae would not occur, or that the child would receive long term follow up.

Shared decision making is a well-known approach to problem solving in paediatric palliative care. A discussion of the contextual features as per the four-box model, paediatric ethical frameworks such as BIP, HP and ZPD, and parental values, all contributed to the team's planning for the de-escalation of life sustaining treatment.

There has been criticism of the use of the four principles of biomedical ethics in children, especially regarding parental authority vs the BIP [12]. We believe using these principles in isolation failed to resolve a complex ethical dilemma such as this one, whereas the four-box model (with modifications) helped achieve it. Many so-called "intuitive" approaches used in decision making by neonatologists constitute a mix of paediatric ethical principles and contextual features [11]. The authors call for the development of a paediatric ethical framework that is more appropriate to Indian settings, with an emphasis on distributive justice and relational autonomy.

We would also like to acknowledge the fact that this case would have benefited from a clinical ethics consultation (CEC), which is rarely available in India. Lewin and colleagues recently reported one such retrospective CEC-like approach [13]. CECs, however, require time and resources to put together, and in their absence, an adaptive approach like the one described here may be useful for delineating and resolving ethical dilemmas.

While there are only a few documented case reports on the four-box model in paediatrics [14], our recommendation is that complex cases involving ethical dilemmas would benefit from a multi-disciplinary approach, and the use of adapted clinical ethics-based decision making tools.

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References

1. Coughlin MA, Werner NL, Gajarski R, Gadepalli S, Hirschl R, Barks J, et al. Prenatally diagnosed severe CDH: mortality and morbidity remain high. *J Pediatr Surg.* 2016; 51(7): 1091–1095. https://doi.org/10.1016/j.jpedsurg.2015.10.082
2. Soni R, Soni N, Chakkarapani A, Gupta S, Yajamanyam PK, Ali SKM, et al. The Utility of Serial Echocardiography Parameters in Management of Newborns with Congenital Diaphragmatic Hernia (CDH) and Predictors of Mortality. *Pediatr Cardiol.* 2023 Feb;44(2):354-366. https://doi.org/10.1007/s00246-022-03002-y
3. Leeuwen L, Fitzgerald DA. Congenital diaphragmatic hernia. *J Paediatr Child Health* 2014 Sep; 50(9): 667–673. https://doi.org/10.1111/jpc.12508
4. Jonsen AR, Siegler M, Winslade WJ. eds. *Clinical Ethics: A Practical Approach to Ethical Decisions in Clinical Medicine,* p. 262. 9th ed. New York, NY: McGraw-Hill Education; 2022.
5. Kopelman LM. The best-interests standard as threshold, ideal, and standard of reasonableness. *J Med Philos.* 1997 Jun 1;22(3):271-89. https://doi.org/10.1093/jmp/22.3.271
6. Bester JC. The best interest standard and its rivals: The debate about ethical decision making in pediatrics. In: Nortje N and Jester BC. *Pediatric ethics: Theory and Practice.* Switzerland: Springer Cham; 2022. Pp. 58-67.
7. Diekema D. Parental refusals of medical treatment: the harm principle as threshold for state intervention. *Theor Med Bioeth.* 2004 Jul;25(4):243-64. https://doi.org/10.1007/s11017-004-3146-6
8. Winters JP. When parents refuse: Resolving entrenched disagreements between parents and clinicians in situations of uncertainty and complexity. *Am J Bioeth.* 2018 Aug 3;18(8):20-31. https://doi.org/10.1080/15265161.2018.1485758
9. Opel DJ. A 4-step framework for shared decision-making in pediatrics. *Pediatrics.* 2018 Nov 1;142(Supplement_3):S149-56. https://doi.org/10.1542/peds.2018-0516e
10. Kanwar VS, Bagai P, Borker A, Dinand V, Gursahani R, Kurhade K, et al. Withholding and withdrawal of life-sustaining therapy in terminally ill children with cancer: A position statement by the PHO chapter of the Indian Academy of Pediatrics. *Pediatr Hematol Oncol J.* 2024 Mar 1;9(1):18-23. https://doi.org/10.1016/j.phoj.2024.01.002
11. Miljeteig I, Sayeed SA, Jesani A, Johansson KA, Norheim OF. Impact of ethics and economics on end-of-life decisions in an Indian neonatal unit. *Pediatrics.* 2009 Aug 1;124(2):e322-8. https://doi.org/10.1542/peds.2008-3227
12. Baines P. Medical ethics for children: applying the four principles to paediatrics. *J Med Ethics.* 2008 Mar 1;34(3):141-5. https://doi.org/10.1136/jme.2006.018747
13. Lewin ML, Galagali PM, Hendricks MR, Ravindran GD, Lewin S. Ethics of Managing an Adolescent Living with Disability. *Indian Pediatr.* 2024 Feb;61(2):175-8. https://doi.org/10.1007/s13312-024-3114-3
14. Vargas I, Pavez T. The decision making process in a pediatric patient with Leukemia: ethical issues in Chilean case. *Nurse Care Open Acces J.* 2019;6(2):46-9. https://doi.org/10.15406/ncoaj.2019.06.00182