

Ethical Pearls in Fetal and Neonatal Cardiology

Hala Al Alem^{1,2,3,*}

¹King Abdullah Specialized Children Hospital, Riyadh- Kingdom of Saudi Arabia

²King Saud Bin Abdulaziz for Health Science, Riyadh- Kingdom of Saudi Arabia

³King Abdullah International Medical Research Centre, Riyadh- Kingdom of Saudi Arabia

*Correspondence should be addressed to Hala Al Alem, hala.alalem@gmail.com

Received date: September 15, 2024, **Accepted date:** October 14, 2024

Citation: Al Alem H. Ethical Pearls in Fetal and Neonatal Cardiology. J Clin Cardiol. 2024;5(2):85-87.

Copyright: © 2024 Al Alem H, et al. This is an open-access article distributed under the terms of the Creative Commons Attribution License, which permits unrestricted use, distribution, and reproduction in any medium, provided the original author and source are credited.

Opinion

Working in health care institutions- deal with fetal/pediatric congenital heart diseases-build up moral sensitivity at different levels. Patient-family and doctor relationship starts from the moment family decides to seek medical/surgical advice. Parents ask everywhere to choose the best compassionate expert who could help at all levels. Mutual respect and trust are the first ethical values to launch the medical/surgical journey. Health care providers ought to practice integrity-driven ethics to deliver patient – family centered care. Technology and skill advancement will never stop. This fact would put more ethical responsibilities on health care workers. Therefore, teaching and learning how to reach ethical shared decisions are highly important. Do-No-Harm is the cornerstone of any creative innovative test or intervention. Non-maleficence is the giant umbrella over any thoughts, decision, or action [1].

Clinical Ethical consultation initiation would test the proposed diagnostic or therapeutic options against the four principles of medical ethics. Ethics committees are not authority to pursue certain decisions. It is an advisory board that may facilitate unbiased understanding and execution of the shared decision between parents/guardians and treating physician/surgeon [2].

Legal precedence and or ethical precedence may color the decision-making process in many challenging circumstances (complex lesions, conflict, moral distress).

Ethics and law are not the same. Ethics comes above the law. However, one ought to be following his/her land law and to be ethically reasonable at the same time.

In this article, the author will touch on certain issues in the field of fetal and neonatal cardiology.

Ethics and Fetal Cardiology

As early as 11 weeks of gestation, fetal echocardiography in expert hands would diagnose heart diseases. Therefore, the challenge starts early. Uncertainty of the diagnosis remains part of the equation. So, such a situation is full of mixed emotion for both the expectant parents and the treating physicians. Transparent communication is the key. The goal of treating babies with congenital heart disease may start with full cure, or care of symptoms, and/or end with comfort care. This goal of therapy could be determined as early as 11 weeks of gestation. During prenatal period, early diagnosis of complex critical congenital heart disease like hypoplastic left heart syndrome (HLHS) is a good example for clinical and ethical decision -making process as early as 20 weeks.

The goal of therapy needs to be determined as early as the diagnosis is confirmed. Multiple sessions of prenatal counselling to finalize a shared decision is very important. The maternal-fetal medicine service, pediatric cardiologist, genetic counsellor, social worker, clinical psychologist and ethicist are the core expert to run the family meeting. Palliative care service is valuable at this stage and after birth. Question to answer:

Are we aiming for cure, care, or comfort. Cure in this situation would be heart transplantation. Care would be multiple reconstructive surgeries. Comfort would be focusing on quality of life and not to intervene after birth and allow natural death. Any decision could be colored with intense emotions from the involved parties. Previous experience, family dynamics, financial strains, culture and religion may contribute to the decision. All these factors ought to be discussed in a neutral non-biased manner. It is a complex multidimensional process [3,4].

Active listening to the expecting parents is the key to reach ethical shared decision-making options. However, one needs to balance the human rights (pregnant mother) with the fetal viability and welfare options. Other perinatally diagnosed complex congenital heart diseases may be associated with extra-cardiac malformation, genetic syndromes and or poor neurodevelopmental outcome. Again, discussion will involve the following: Abortion if allowed per belief and or law, Centre of excellence managing the mother and the fetus, Fetal intervention in utero if feasible and beneficial, planning management postnatally (medical and or surgical), planning postnatal life-sustaining treatments and or palliative care.

Parental counselling is complex and mandates proper training in advanced communication skills. A compassionate approach and hospital or home-based support is highly recommended.

Ethics and Neonatal Cardiology

Screening programs allowed post-natal diagnosis of congenital heart diseases. It may shock the expecting parents at different levels. Breaking news would be the priority. Furthermore, a multidisciplinary approach to initiate shared decision-making with the parent should be conducted as soon as possible.

Uncertainty is minimized with the proper investigations and review with the expert cardiologist in the field. The type of congenital heart diseases could be simple or complex. Furthermore, it may mandate medical treatment, corrective repair, palliative surgeries, or do nothing (non-operable).

After conducting focused physical examination and certain investigations, neonatologists and pediatricians would confirm the diagnosis of the newborn/neonate with syndromic congenital heart disease or isolated congenital heart disease. This may facilitate the process of ethical and legal decision-making. Mortality and quality of life may be determined by the extra-cardiac anomalies more than the heart lesions.

Non-syndromic, isolated heart lesions are approached mainly on the principle of "Beneficence" and the "Best interest of the future child". Parental autonomy is active but not absolute in this stage. However, shared decision is highly appreciated.

Resource allocation and utilization will be touched in the discussion, once distributive justice as principle is compromised. Thus, futility of any intervention (e.g. mechanical circulatory support/heart transplant) needs to be addressed. The fact that we can perform major aggressive - expensive interventions does not mean it is ethically appropriate. The decision will depend on the context of the case and on benefit/ burden ratio [5].

Ethics and Innovative Technology

Recently we learned genetic testing and its yield in

finalizing prognosis or pursuing personalized gene therapy. Furthermore, artificial intelligence enforces certain diagnosis, prognosis, and therapy. Big data is the merit of the health care. AI is the system to autonomously acquire knowledge extracting patterns. The use of AI tools must always be guided by clinical information and interpretations. However, a safe and precise tool is helping clinicians to manage different diseases including CHD. Ethical challenges around utilizing AI in medicine are under discussion and would need regulation to protect privacy, informed consent, scientific conceptualization laws and regulations [6].

Ethics and End-of-Life Care in Congenital Heart Diseases

At certain stages of managing certain patients with congenital heart diseases, "Goals of Care" must be discussed. Usually this is "End-of-Life Care" phase. Best example is Hypoplastic left heart syndrome with goal of care: NO CODE or Allow Natural Death or Comfort care. Active listening and deep understanding of patients/parent's values, wishes, and preferences is the main cornerstone of this sensitive step.

The process of adding quality to remaining days /weeks/ months of life is more important than sustaining life on life-sustaining technologies. So, palliative care is the top priority at this stage. This could be provided by the treating team with palliative care specialist as possible. Fulfilling the wishes, values, and preferences of the parents is the main responsibility at this stage.

Ethically, reserving dignity may be achieved by withholding aggressive invasive intervention (palliative surgery, mechanical circulatory support, or cardiopulmonary resuscitation) or withdrawing applied invasive interventions example disconnection from ventilator and put the baby in the lap of the care giver. Both actions -with-hold or withdraw therapy - may differ emotionally, but both decisions are ethically correct.

A compassionate approach to such patients- families will include treating any pain or anxiety. Medications like opioid and benzodiazepine are the main therapy at palliative care at end of life. Side effects from these medications may include hemodynamic instability or respiratory depression. In ethics, a doctrine of double effect allows the judicious use of these medications as far as the intention is to alleviate pain and anxiety and not to hasten death.

Lately, execution of these measures at end of life is important to avoid any moral distress or burn out. Training on providing care at end-of-life stage, is highly recommended.

Summary

Antenatal and postnatal diagnosis of congenital heart disease is a challenge for all parties. Involved obstetricians,

neonatologists, cardiologists, and pediatricians are the main medical parties. Appropriate access to care, correct diagnosis, and medical/surgical action plan could be straight forward or complicated.

Non-maleficence, beneficence, relative parental autonomy, and distributive justice are the pillars in ethical analysis and shared decision- making. Occasionally, palliation and end of life care are indicated. So, care providers need to acknowledge that: with-hold therapy and or with-draw therapy are equally ethical. Furthermore, doctrine of double effect is based on intention to Provide COMFORT rather than hasten DEATH.

Finally, dissolving any uncertainty in this highly advancing technology era is the main step in the process of medical decision-making. Furthermore, ethics and genetics, ethics and clinical trials, ethics and utilizing Artificial Intelligent tools are highly appreciated.

References

1. Madrigal VN, Feltman DM, Leuthner SR, Kirsch R, Hamilton R, Dokken D, et al. Bioethics for Neonatal Cardiac Care. Pediatrics. 2022 Nov 1;150(Suppl 2):e2022056415N.

2. Dear PR. Ethics committees and the treatment of congenital heart disease. Heart. 1996;76:463-4.

3. Rychik J. What does palliative care mean in prenatal diagnosis of congenital heart disease? World J Pediatr Congenit Heart Surg. 2013 Jan;4(1):80-4.

4. Kovacevic A, Elsässer M, Fluhr H, Müller A, Starystach S, Bär S, et al. Counseling for fetal heart disease—current standards and best practice. Vol. 10, Translational Pediatrics. Transl Pediatr 2021;10(8):2225-34.

5. Rossano JW, Kaufman BD, Rame JE. Ethical considerations related to the use of mechanical support in congenital heart disease. World J Pediatr Congenit Heart Surg. 2013 Jan;4(1):70-4.

6. Pozza A, Zanella L, Castaldi B, Di Salvo G. How Will Artificial Intelligence Shape the Future of Decision-Making in Congenital Heart Disease? J Clin Med. 2024 May 20;13(10):2996.