The Inherent Complexities of Pediatric Cardiac Surgery: A Health Literacy Perspective

ABSTRACT

Pediatric cardiac surgery involves navigating profound perplexities for caregivers, from understanding intricate pathophysiology to managing long-term care. So, explore these challenges through a health literacy lens, arguing that low health literacy exacerbates inherent difficulties, jeopardizing informed consent and postoperative outcomes. It is concluded that integrating health literacy sensitive communication is not ancillary but fundamental to achieving equitable, high-quality, and family-centered care.

Paper Type: letter to the Editor

Keywords: Health Literacy, Cardiac Surgery, Pediatric, Patient Education.

Mahmood Hosseinzadeh Maleki
Department of Cardiac Surgery, Imam Reza Hospital, Mashhad University of Medical Sciences, Mashhad, Iran.

Mohammad Reza Naghibi Sistani
Pediatric and Congenital Cardiology Division, Department of Pediatric, Faculty of Medicine, Mashhad University of Medical Sciences, Mashhad, Iran.

Ghazaleh Khademian
Department of Anesthesiology, Razavi Hospital, Imam Reza International University, Mashhad, Iran.

Mohsen Yaghubi
* Department of Extra-Corporeal Circulation (ECC), Razavi Hospital, Imam Reza International University, Mashhad, Iran.
(Corresponding Author): n.m.yaghubi@gmail.com

Received: 14 August 2025
Accepted: 01 November 2025
Doi: 10.22038/jhl.2025.91176.1855

Citation: Hosseinzadeh Maleki M, Naghibi Sistani MR, Khademian G, Yaghubi M. The Inherent Complexities of Pediatric Cardiac Surgery: A Health Literacy Perspective. *Journal of Health Literacy*. *Spring* 2026; 11(2): 09-11.

Dear Editor

In this context, health literacy is not merely about understanding information but about having the capacity to navigate a lifelong, dynamic, and technically complex medical journey. The inherent features of the disease and its treatment directly create and exacerbate health literacy demands (1).

First, the specific challenge is that parents of pediatric patients must understand their child's heart defect and the complexity of the medical condition. At the same time, each defect has unique implications for surgery, recovery, and long-term outcomes. This matter is considered a literacy barrier because the Parents are required to learn a new, highly specialized vocabulary and complex spatial relationships under extreme stress (2).

On the other hand, postoperative recovery from cardiac surgery in pediatrics is known to be non-linear and unpredictable. Major concepts, such as "cardiac output", "balance between pulmonary and systemic blood flow", and "managing filling pressures", reveal physiologic pediatric stability that is invisible to parents. They must be relying on interpreting monitor variables and subtle signs (such as pallor, energy level, and feeding vigor) to understand their child's health status. Therefore, parents require critical health literacy to become adept observers and decision-makers in a high-stakes environment (3). Even with high ability of parents' critical health literacy, the unpredictable trajectory and the constant fear of complications significantly heighten parental stress, which in turn impairs their ability to process information and participate in decision-making.

Furthermore, for the most complex heart defects, surgery is palliative, not curative. In this lifelong management situation, the parents must understand the goals and consequences of a multi-stage surgical pathway, and they need to grasp that each stage addresses different physiological challenges and that the "final" physiology comes with its own set of lifelong risks and necessary surveillance (4). Therefore, this requires functional, interactive, and critical health literacy simultaneously.

Last but not least, the High-Stakes Discharge and the transition from the 24/7 monitored ICU to the home is one of the most anxiety-provoking times due to the shift of responsibility to parents. They are often sent home to manage life-sustaining therapies, including administering complex medication regimens, providing specialized nutrition, and monitoring for subtle signs of severe complications. It demands a level of proficiency typically expected of trained healthcare professionals. A misunderstanding or error in medication dosing, or a missed warning sign, can have immediate, life-threatening consequences (5).

Therefore, it seems that the inherent medical complexity of pediatric cardiac surgery creates a health literacy demand orders of magnitude higher than in most other healthcare scenarios. In addition, it is apparent that health policies regarding health literacy in pediatric patients after cardiac surgery require significant reform; now is the time for action!

Acknowledgment: Not applicable.

Availability of data and materials: Not applicable.

Conflicts of interest: All authors declare that they have no conflict of interest.

Consent for publication: Not applicable.

Ethics approval and consent to participate: Not applicable.

Funding: None.

Authors' Contribution: M. H. M.: Contributed to the conception and design of the study, critical revision, and approval of the manuscript's final version; M. R. N. S. and G.K.: Contributed to acquiring data, drafting the manuscript, and approving the final version. M. Y.: Contributed to the conception and design of the study, data interpretation, drafting of the manuscript, critical revision, and approval of the final version.

Declaration of AI Use: All authors declare that they have not used any AI tools or technologies to prepare this manuscript.

References

1. Lai WW, Vervoort D, Bradley D, Cabrera AG, Culbertson C, Floh A, et al. Pediatric and Congenital Cardiac Services: An Innovative and Empowering Approach to Global Training and Equitable Care. J Am Heart Assoc. 2025; 14(8):e040003.
2. Sprong MCA, Zwagerman IR, Soeters L, Slieker MG, Takken T, van den Hoogen A, et al. Prioritizing family-centered developmental care: insights from parents of children with critical congenital heart disease: a qualitative study. Eur J Pediatr. 2024; 183(9):3863–76. https://doi.org/10.1007/s00431-024-05600-9 PMid: 38888645 PMCid: PMC11322194.
3. Kruszecka-Krówka A, Cepuch G, Micek A. Stress Coping Strategies in Parents of Newborns and Infants with Congenital Cyanotic Heart Disease with Regard to Stress Levels and Negative Emotions. Children (Basel). 2024; 11(5). https://doi.org/10.3390/children11050508 PMid: 38790503 PMCid: PMC11120106.
4. Ghasemi Shayan R, Fatollahzadeh Dizaji M, Sajjadian F. Surgical and postoperative management of congenital heart disease: a systematic review of observational studies. Langenbecks Arch Surg. 2025; 410(1):113. https://doi.org/10.1007/s00423-025-03673-0 PMid: 40164780 PMCid: PMC11958500
5. Gaskin KL, Barron D, Wray J. Parents' Journeys of Mastery and Knowledge Construction After Their Infant's First Stage of Surgery for Complex Congenital Heart Disease. Compr Child Adolesc Nurs. 2024; 47(1):68–81. https://doi.org/10.1080/24694193.2023.2293993 PMid: 38090784.