

CARDIOLOGY
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Neurodevelopmental Outcomes & Parental Engagement

What Does the Evidence Say?

Angela Gooden DNP, APRN, CPNP-PC/AC
Nurse Practitioner, Cardiology
Texas Children's Hospital, Houston, TX



The Good and the Bad...

Good

- Children with congenital heart disease (CHD) are surviving and living longer.

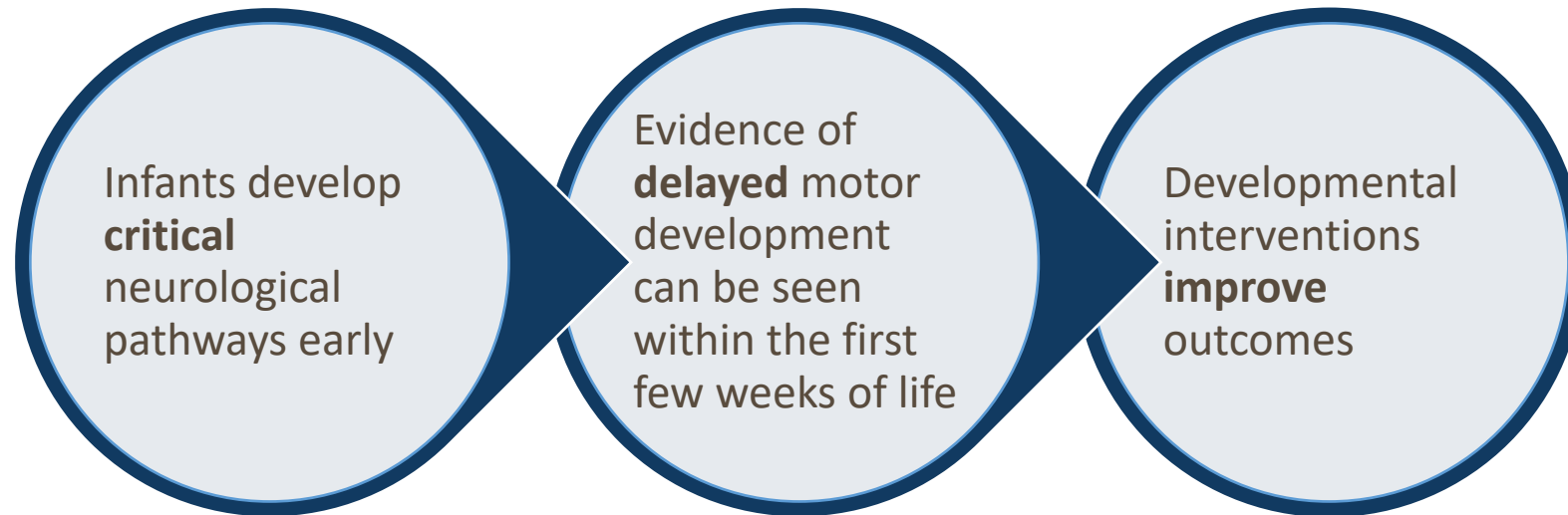
Bad

- Greater risk for developmental delays
- Neurodevelopmental impairments (NDI) similar to those of premature infants
- Increased prevalence and severity with increased complexity

The Challenges

- Abnormal brain development
- Chromosome abnormalities and syndromes
- Perioperative injury
- Physiologic instability
- Activity restrictions
- Nutritional deficits
- Respiratory support, analgesia and sedation
- Prolonged hospital length of stay

The Call to Action



Best Practices



Introduce safe, individualized,
and goal-directed
developmental interventions
early



Engage parents by facilitating,
encouraging, and supporting
family-driven cares and
developmental stimulation

Engagement Strategies

- Champion family presence at the bedside
- Encourage gentle touch, reading, music
- Empower care involvement in feedings, diaper changes, and baths
- Collaborate with the family to develop a daily routine minimizing disruptions
- Involve families in interactive play and therapy sessions

Risks vs. Benefits

Risks

- Potential disruption of supportive catheters and tubes
- Physiologic instability
- Inadequate staff education, resources
- Lack of parental comfort

Benefits

- Reduced physiologic stress and hospital stays
- Decreased parental stress and anxiety
- Improved ND outcomes and care transitions

Texas Children's Heart Center

Developmental Care Rounds

- Multidisciplinary review of medical status, development, and social challenges
- Care coordination and anticipatory support

Books@Heart Initiative

- Developmental Care Team partnership to encourage parents reading to their infants
- Age-appropriate books & reading guidance by speech and language pathology specialists

Take Home Messages

- Developmental delays are tied to the early pre/post-operative experiences of infants with CHD
- Implementation of individualized and multimodal developmental care is imperative to improving ND outcomes
- Engaging parents in developmental care is an important therapeutic addition to the overall plan of care

References

- Andropoulos, D. B., Easley, R. B., Gottlieb, E. A., & Brady, K. (2019). Neurologic Injury in Neonates Undergoing Cardiac Surgery. *Clinics in Perinatology*, 46(4), 657–671. <https://doi.org/10.1016/j.clp.2019.08.003>
- Butler, S. C., Huyler, K., Kaza, A., & Rachwal, C. (2017). Filling a significant gap in the cardiac ICU: implementation of individualised developmental care. *Cardiology in the Young*, 27(9), 1797–1806. <https://doi.org/10.1017/S1047951117001469>
- Harrison, T. M. (2019). Improving neurodevelopment in infants with complex congenital heart disease. *Birth Defects Research*, 111(15), 1128–1140. <https://doi.org/10.1002/bdr2.1517>
- Kaeslin, R., Latal, B., & Mitteregger, E. (2023). A systematic review of early motor interventions for infants with congenital heart disease and open-heart surgery. *Systematic Reviews*, 12(1), 1–149. <https://doi.org/10.1186/s13643-023-02320-3>
- Mazarico de Thomas, E. & Shekerdemian, L. (2020). Cardiac developmental outcomes. In C. M. Mery, P. Bastero, S. R. Hall, & A. G. Cabrera (Eds.), *Texas Children's Hospital handbook of congenital heart disease* (pp. 287–299). Houston, TX: Texas Children's Hospital.
- Tesson, S., Butow, P. N., Marshall, K., Fonagy, P., & Kasparian, N. A. (2022). Parent-child bonding and attachment during pregnancy and early childhood following congenital heart disease diagnosis. *Health Psychology Review*, 16(3), 378–411. <https://doi.org/10.1080/17437199.2021.1927136>