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Incorporating the Adaptive Behavior Assessment System Third Edition (ABAS-3) to Follow Cognitive and Developmental Milestones of Patients after ECLS

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Background

- Patients with significant cardiopulmonary insufficiency require extracorporeal life support (ECLS)
- Extracorporeal Life Support Organization (ELSO) is an international non-profit consortium that provides guidelines for healthcare institutions that provide ECLS
- These ECLS patients are at significant risk for neurological injury
- ELSO recommends structured follow-up of ECLS patients, but few programs have long-term follow-up
- At Children's Health, a core ECLS team of clinicians is available 24/7 365. This multidisciplinary team has been in existence for > 30 years and is comprised of respiratory therapists and registered nurses
- In May of 2022, the ECLS team identified an opportunity to better track neurological, social, and physical outcomes of their patients
- Using the ABAS-3 tool, the patients' pre-injury functional level was obtained based on parental feedback
- The inclusion criteria to have the initial assessment completed was >2 months of age.
- Review of the literature yielded no applicable findings for the long term (> 6 months) follow-up process after hospitalization





Newborn patient initiated on ECLS

Inclusion/Exclusion Criteria

- Inclusion criteria were pediatric patients > 2 months up to 20 years old
- Exclusion criteria were >20 years old, or if the family declined the survey
- Surveys were administered by six total staff members with additional training on the administration of the ABAS-3 survey to ensure interrater reliability
- Child's age determined the number of questions administered; which ranged from 170 to 232
- Optimization of survey timing was evaluated, families did best with survey questions administered prior to parents seeing their child
- Survey was administered within the first 3 days of cannulation to allow time for families to accept the new level of care
- Additional considerations included translation into Spanish for Spanish-speaking families, and this was completed by bilingual staff

Literature references and contact information



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Outcomes

- We cared for a total of 66 ECLS patients from May 2022 to **August 2023**
- Out of these, 34 patients met inclusion criteria and completed assessments
- 27 patients did not meet inclusion criteria:
 - 1 family declined
 - 4 passed away with a completed survey on ECLS so could not complete post survey
 - 22 patients not in appropriate age range
- Physicians re-administered the ABAS-3 6 months postdischarge, which enabled tracking of progress with patients' milestones
- Additionally benefits of post-discharge follow up was an opportunity to connect families to needed therapies and evaluations
- In August, 2023 the ABAS-3 intake assessment was established as the new standard of care for all patients receiving ECLS



And NOW: Entering kindergarte n this year!!!

Results/Next steps

- 6 post surveys have been completed
- Out of the remaining patients, 13 have not yet met follow up timing and 13 are deceased.
- Work is in progress to form a specialized clinic for post-ECLS patients

