Supplemental Material

**Neurodevelopmental Care Practices in Pediatric VAD**

**ACTION Clinician Survey**

**Instructions:** Please provide one response per ACTION center. If respondent is unfamiliar with neurodevelopmental care practices, it is recommended that information be gathered from others before completing/submitting survey to best represent this important aspect of care at your center.

General Questions

1. Site name [free response]
2. Is your site an Institutional Member of CNOC (Cardiac Neurodevelopmental Outcome Collaborative)?
   1. Yes
   2. No
   3. Don’t know
3. Please provide your first and last name [free response]
4. Please indicate your specialty:
   1. Cardiologist
   2. Surgeon
   3. VAD Coordinator
   4. Advanced Practice Provider (NP, PA)
   5. Psychologist
   6. Psychiatrist
   7. Other: [free response]
5. In regard to supporting neurodevelopment, the VAD team accesses individuals with the following expertise: For each professional, select level of involvement: a) Full time with VAD team, b) Full time in heart center shared across VAD team and other subspecialties, c) Available within the heart center, d) Available within the hospital system, but not heart center, e) Referral required (outside hospital system)
   1. Physical Therapy
   2. Occupational Therapy
   3. Speech Therapy
   4. Developmental Pediatrics
   5. Neurology
   6. Psychology
   7. Neuropsychology
   8. Psychiatry
   9. Advanced Practice Provider (NP or PA)
   10. Pediatrician
   11. Social Work Case Management
   12. Educational Specialist
   13. Neonatologist
   14. Other (free response)
6. How often does your VAD care team provide education to patients/families about the child’s risk for neurodevelopmental delays and differences given risks associated with pediatric heart disease?
   1. Always
   2. Sometimes
   3. Rarely
   4. Never
   5. Unsure
7. How many patients with VAD are routinely referred for neurodevelopmental evaluations and/or therapies?
   1. None routinely from the VAD program, dependent on referral from primary cardiologist or HF/Transplant team
   2. None routinely from the VAD program, dependent on interest from or concern raised by family which then leads to referral
   3. Some, routinely from VAD program
   4. All, routinely from VAD program

If some or all patients with VAD are routinely referred for neurodevelopment services or evaluations, what is the criteria for routine referral? [choose all that apply]

1. All individuals meeting AHA CHD high risk criteria
2. Infants with single ventricle heart disease
3. Individuals with a history of neonatal surgery
4. Individuals with recognized needs who are referred by clinicians
5. Infants with VAD placement
6. VAD placement (any age)
7. ECMO history
8. Stroke
9. Pre-heart transplant (e.g., evaluation/listing)
10. Post-heart transplant
11. Neurodevelopmental and/or psychosocial problems
12. Other [fill in the blank]
13. At your center, how do neurodevelopmental practices for patients with VAD differ from neurodevelopmental practices for patients with CHD not supported by VAD?
    1. [free response]

Inpatient Neurodevelopmental Care Practices

1. Which of the following inpatient neurodevelopment services are available to pediatric patients with VAD support at your center? Choose all that apply.
   1. Inpatient neurodevelopmental care rounds (age 0-1)
   2. Inpatient neurodevelopmental care rounds (ages 2-5)
   3. Inpatient neurodevelopmental care rounds (ages 6-18)
   4. Inpatient consults for neurodevelopmental care providers. Choose all that apply:
      1. Speech Therapy
      2. Physical Therapy
      3. Occupational Therapy
      4. Feeding Therapy
      5. Psychology/Neuropsychology
      6. Other [free response]
   5. Individualized developmental care plans
   6. Family Support Services
      1. Social Worker
      2. Chaplain
      3. Parent Support Groups (Inpatient/Hospital based)
      4. Other [free response]
2. Which of the following professionals provide inpatient ND care for patients with VAD/heart failure at your center? For each professional, select the level of involvement: a) Consulted for all patients; b) Consulted depending on patient need; c) Not involved in inpatient ND care
   1. Physical Therapy
   2. Occupational Therapy
   3. Speech Therapy
   4. Developmental/Behavioral Pediatrics
   5. Neurology
   6. Psychology
   7. Psychiatry
   8. Neuropsychology
   9. Advanced Practice Provider (NP or PA)
   10. Bedside Nurse
   11. Social Work
   12. Educational Specialist
   13. Neonatologist
   14. Child Life Specialist
3. How are neurodevelopmental rounds formatted at your institution?
   1. Bedside rounds on select patients at any given time
   2. Bedside rounds on all eligible patients
   3. ‘Table rounds’ with review of current patients and needs
   4. We do not have neurodevelopmental rounds
   5. Other (free text)

*If respondents select a, b, c, or e for question 11, then ask the following question:* Which of the following professionals participate in inpatient neurodevelopmental rounds for patients with VAD/heart failure? For each professional, select the level of involvement: a) Participate in neurodevelopmental rounds (ICU); b) Participate in neurodevelopmental rounds (non-ICU); c) Not involved in inpatient neurodevelopmental rounds

1. Physical Therapy
2. Occupational Therapy
3. Speech Therapy
4. Developmental/Behavioral Pediatrics
5. Neurology
6. Psychology
7. Psychiatry
8. Neuropsychology
9. Advanced Practice Provider (NP or PA)
10. Bedside Nurse
11. Social Work
12. Educational Specialist
13. Neonatologist
14. Child Life Specialist
15. How frequently do inpatient neurodevelopmental rounds occur in your cardiac or intensive care units that care for patients with VAD?
    1. Daily
    2. 2-3x/week
    3. Weekly
    4. Less than once per week
    5. We do not have neurodevelopmental rounds
16. Which patients are seen during inpatient neurodevelopmental rounds?
    1. Infants under 12 months
    2. Patients with specific diagnoses
       1. Please describe: [free response]
    3. Extended admission
    4. Other criteria
       1. Please describe: [free response]
17. What are the primary barriers to **inpatient** neurodevelopmental care (including, but not limited to, neurodevelopmental testing, neurodevelopmental rounds, and consults to specialty services) for children with VAD? Choose all that apply.
    1. Child is too critically ill.
    2. Patient/family is focused on medical status/stability.
    3. Medical team is focused on medical status/stability.
    4. Lack of access to developmental care clinicians
    5. Billing/insurance issues
    6. Other [free response]
18. What are the primary successes of inpatient neurodevelopmental care for children with VAD? Choose all that apply
    1. Non-pharmacologic pain management
    2. Parental psychosocial support
    3. Parental engagement in cares
    4. Early mobilization and physical therapy
    5. Patient psychosocial support and individualized care plans
    6. Other

Outpatient Neurodevelopmental Care Practices

1. Which of the following outpatient neurodevelopmental services are available to pediatric patients with VAD support who receive care at your center? Choose all that apply.
   1. Neurodevelopmental testing
      1. Age 0-1
      2. Age 2-5
      3. Age 6 to young adult
   2. Individual therapy
   3. Group therapy
   4. Parent support groups
   5. Referrals to outside providers as needed
   6. Not sure
   7. Other [free response]
2. How is the first outpatient neurodevelopmental evaluation for patients with VAD created/scheduled at your center?
   1. Dependent on clinician recognizing need and making a referral
   2. Dependent on nurse or scheduling coordinator reaching out to the family
   3. Dependent on family responding to letter or auto-generated referral from neurodevelopment program
   4. Scheduled automatically during another cardiology appointment or hospital stay
   5. Elevated score on neurodevelopmental screening in cardiology clinic (for example, ASQ-3 or other developmental screener)
   6. We do not have internal outpatient ND evaluation referral process in place at our center; we rely on community providers.
   7. Other [free response]
3. Who typically makes referrals for outpatient neurodevelopmental evaluation for patients with VAD at your center?
   1. Pediatrician
   2. Cardiologist
   3. VAD Coordinator
   4. Psychologist
   5. Other [fill in the blank]
   6. Not applicable; referrals for ND evaluations are not routine for patients with VAD
4. Where are pediatric patients with VAD seen for neurodevelopmental evaluation follow-up?
   1. Existing cardiac neurodevelopmental program
   2. Separate neurodevelopmental/neuropsychology program
   3. Both/It depends
      1. Please describe: [free response]
   4. Other [free response]
5. Describe the location of your outpatient neurodevelopment evaluation program/clinic for patients with VAD.
   1. Co-located with outpatient cardiology clinic
   2. Same campus, but not co-located with outpatient cardiology clinic
   3. Different campus from outpatient cardiology clinic
   4. Other [free response]
6. What are the primary barriers to **outpatient** neurodevelopmental care for children with VAD? (Neurodevelopmental care includes neurodevelopmental evaluation, OT, PT, ST, feeding therapy, psychological/neuropsychology services, and family support services.) Choose all that apply.
   1. Child is too critically ill.
   2. At-home VAD care is demanding.
   3. Patient/family is focused on medical status/stability.
   4. Medical team is focused on medical status/stability.
   5. Lack of access to developmental care clinicians
   6. Lack of insurance coverage for outpatient neurodevelopment testing
   7. Other [free response]

Mental/Behavioral Health

1. Who is responsible for making mental and behavioral health diagnoses for children with VAD who are cared for at your center?
   1. Developmental Pediatrician
   2. Psychologist
   3. Psychiatrist
   4. Social Worker
   5. No one
   6. Other (fill in the blank)
2. What mental health resources are available at your center for **children** with VAD? For each response, please how parents can access resources: a) Referral/consults placed for all parents; b) referrals/consults placed based on need; c) available at parents’ request
   1. Inpatient social work
   2. Inpatient psychology
   3. Inpatient psychiatry
   4. Outpatient social work
   5. Outpatient psychology
   6. Outpatient psychiatry
   7. Patient support/educational groups
   8. Local counseling referrals (not affiliated with heart center)
   9. Other [fill in the blank]
3. What mental health resources are available at your center for **parents** of children with VAD? For each response, please how parents can access resources: a) Referral/consults placed for all parents; b) referrals/consults placed based on need; c) available at parents’ request
   1. Inpatient social work
   2. Inpatient psychology
   3. Inpatient psychiatry
   4. Outpatient social work
   5. Outpatient psychology
   6. Outpatient psychiatry
   7. Parent support/educational groups
   8. Local counseling referrals (not affiliated with heart center)
   9. Other [fill in the blank]
4. What neurodevelopmental and mental/behavioral health resources are available at your center for **young adults with VAD who are transitioning to adult care**? For each response, please how patients can access resources: a) Referral/consults placed for all patients; b) referrals/consults placed based on need; c) available at patients’ request
   1. Neurodevelopmental testing
   2. Inpatient social work
   3. Inpatient psychology
   4. Inpatient psychiatry
   5. Outpatient social work
   6. Outpatient psychology
   7. Outpatient psychiatry
   8. Patient support/educational groups
   9. Local counseling referrals (not affiliated with heart center)
   10. Adult Transition Program
   11. Other [fill in the blank]