



Original Article

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# Current state of neurodevelopmental and psychosocial care practices for paediatric patients with ventricular assist devices: an Advanced Cardiac Therapies Improving Outcomes Network and Cardiac Neurodevelopmental Outcome Collaborative collaborative survey

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## Abstract

**Purpose:** Paediatric patients with heart failure requiring ventricular assist devices are at heightened risk of neurologic injury and psychosocial adjustment challenges, resulting in a need for neurodevelopmental and psychosocial support following device placement. Through a descriptive survey developed in collaboration by the Advanced Cardiac Therapies Improving Outcomes Network and the Cardiac Neurodevelopmental Outcome Collaborative, the present study aimed to characterise current neurodevelopmental and psychosocial care practices for paediatric patients with ventricular assist devices. **Method:** Members of both learning networks developed a 25-item electronic survey assessing neurodevelopmental and psychosocial care practices specific to paediatric ventricular assist device patients. The survey was sent to Advanced Cardiac Therapies Improving Outcomes Network site primary investigators and co-primary investigators via email. **Results:** Of the 63 eligible sites contacted, responses were received from 24 unique North and South American cardiology centres. Access to neurodevelopmental providers, referral practices, and family neurodevelopmental education varied across sites. Inpatient neurodevelopmental care consults were available at many centres, as were inpatient family support services. Over half of heart centres had outpatient neurodevelopmental testing and individual psychotherapy services available to patients with ventricular assist devices, though few centres had outpatient group psychotherapy (12.5%) or parent support groups (16.7%) available. Barriers to inpatient and outpatient neurodevelopmental care included limited access to neurodevelopmental providers and parent/provider focus on the child’s medical status. **Conclusions:** Paediatric patients with ventricular assist devices often have access to neurodevelopmental providers in the inpatient setting, though supports vary by centre. Strengthening family neurodevelopmental education, referral processes, and family-centred psychosocial services may improve current neurodevelopmental/psychosocial care for paediatric ventricular assist device patients.

## Introduction

The use of ventricular assist devices in paediatric populations has increased markedly over the past several decades; now more than 1/3 of children who undergo heart transplant do so from ventricular assist device support.<sup>1–3</sup> With this, waitlist survival has also improved substantially.<sup>4</sup> However, the presence of heart failure requiring ventricular assist device therapy presents substantial medical risks and psychosocial challenges that have the potential to alter children’s developmental trajectory. Specifically, children supported by ventricular assist devices are at high risk for complications such as neurologic injury due to stroke, bleeding, and infection.<sup>3,5</sup>

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Psychosocially, children may experience adjustment issues, anxiety, and depressive symptoms following ventricular assist device implantation, and families endorse high stress and anxiety associated with the demanding care regimen.<sup>6,7</sup> Such findings emphasise the pressing need to better understand the neurodevelopmental and psychosocial sequelae of heart failure requiring ventricular assist device therapy, as well as to identify and implement the requisite supports to help children and families thrive following ventricular assist device placement.

Though research examining neurodevelopment following paediatric ventricular assist device placement is limited, the neurodevelopmental and psychosocial challenges associated with paediatric CHD have been well-documented.<sup>8–10</sup> These include motor delays<sup>11</sup>; difficulties with attention/executive functioning, nonverbal reasoning, and memory<sup>12,13</sup>; academic concerns<sup>12</sup>, and poorer mental/behavioural health.<sup>8,14</sup> Notably, ventricular assist device use can increase risk for developmental disorders in children with CHD.<sup>9,10</sup> Scientific statements and clinical guidelines for individuals with CHD at high risk of developmental concerns stress the importance of early neurodevelopmental evaluation<sup>9,10</sup>; periodic re-evaluations throughout childhood<sup>9,10</sup>; ready access to and utilisation of multidisciplinary neurodevelopmental supports (e.g., speech, occupational, and physical therapies); and availability of mental health services and parent/family supports.<sup>9,10,14–16</sup>

As patients with CHD are only a quarter of those who receive ventricular assist device support<sup>5</sup>, the extent to which these clinical recommendations are applicable to the broader population of paediatric ventricular assist device patients remains unclear. In one study, children receiving ventricular assist devices ( $M_{\text{age}}$  at implant = 14 years, 81.7% cardiomyopathy) endorsed lower overall quality of life compared to both healthy children and children with complex/severe heart disease without ventricular assist devices, with differences present pre-ventricular assist device, 3-months post-ventricular assist device, and 6 months post-ventricular assist device.<sup>17</sup> Specifically, school functioning, as measured by the Pediatric Quality of Life Inventory (PedsQL 4.0)<sup>18</sup>, was lower for the pre-ventricular assist device group versus both comparison groups. Interestingly, the post-ventricular assist device groups rated school functioning on-par with the complex/severe heart disease group (though still lower than healthy children).<sup>17</sup> Among heart transplant recipients, children with pre-morbid cardiomyopathy are at risk for attention and executive functioning difficulties, though they tend to demonstrate less overall cognitive impact than children with pre-morbid CHD.<sup>19</sup> Another study did not find a significant impact of pre-transplant ventricular assist device therapy on post-transplant intellectual functioning, though the study was likely underpowered to detect differences.<sup>20</sup> While longitudinal study is needed to fully characterise neurodevelopmental and psychosocial trajectories of paediatric patients supported by ventricular assist devices, the existing literature points to the urgent and growing need for appropriate clinical infrastructure and resources for this population.

We aimed to enhance neurodevelopmental and psychosocial resources for paediatric patients with ventricular assist device support by forging a collaboration between two learning networks, Advanced Cardiac Therapies Improving Outcomes Network and Cardiac Neurodevelopmental Outcome Collaborative. As collaborative learning networks and data registries, Advanced Cardiac Therapies Improving Outcomes Network seeks to improve outcomes for patients receiving advanced cardiac therapies<sup>21</sup> and Cardiac Neurodevelopmental Outcome Collaborative aims to enhance neurodevelopmental and psychosocial outcomes in paediatric and congenital heart disease.<sup>22</sup> The present collaboration between

Advanced Cardiac Therapies Improving Outcomes Network and Cardiac Neurodevelopmental Outcome Collaborative was initiated by Advanced Cardiac Therapies Improving Outcomes Network's Families in ACTION Committee, which is comprised of patients, parents, and caregivers who advise the network's quality improvement projects. As a first step towards increasing awareness and optimising psychosocial and neurodevelopmental outcomes for children with ventricular assist devices, the Advanced Cardiac Therapies Improving Outcomes Network and Cardiac Neurodevelopmental Outcome Collaborative representatives recommended obtaining a thorough understanding of the current state of neurodevelopmental and psychosocial care practices at paediatric heart centres through an Advanced Cardiac Therapies Improving Outcomes Network-centre survey, which is the objective of the present study.

## Materials and method

### Study design

An electronic survey was sent to active Advanced Cardiac Therapies Improving Outcomes Network Site PIs and Co-PIs in November 2022 via email ( $N = 63$ ). The email briefly described the project and requested one response per site. Email recipients were encouraged to forward the email to the individual(s) at their site best suited to respond to a survey about neurodevelopmental and psychosocial care practices for ventricular assist device patients. One reminder email was sent three weeks after the initial email. The project fell under approved activities with the Advanced Cardiac Therapies Improving Outcomes Network central Institutional Review Board through Cincinnati Children's Hospital.

### Measures

The 25-item survey was developed jointly by representatives from Advanced Cardiac Therapies Improving Outcomes Network and Cardiac Neurodevelopmental Outcome Collaborative using REDCap (<https://www.project-redcap.org/>). Questions were adapted from previous Cardiac Neurodevelopmental Outcome Collaborative site surveys regarding neurodevelopmental practices<sup>23</sup>, edited to focus on the heart failure/ventricular assist device population (Supplemental Material). Additional questions specific to the project goals were written as needed. The survey was reviewed by Advanced Cardiac Therapies Improving Outcomes Network parent/family stakeholders. The survey assessed the following domains: 1) site and respondent demographics, 2) general neurodevelopmental care practices, 3) inpatient neurodevelopmental care practices, 4) outpatient neurodevelopmental care practices, and 5) mental/behavioural health care practices.

### Statistical analyses

Descriptive analyses (frequencies and percentages) and difference testing (Chi-square) were conducted using Statistical Package for the Social Sciences Statistics Version 27.

## Results

Survey responses were received from 24 unique sites, representing 38% of Advanced Cardiac Therapies Improving Outcomes Network sites surveyed. Two sites completed the measure twice; only the first response for each was retained. The responding

paediatric heart centres represented diverse geographical regions: 8.3% ( $n = 2$ ) Northeast United States, 33.3% ( $n = 8$ ) Southeast United States, 29.2% ( $n = 7$ ) Midwest United States, 4.2% ( $n = 1$ ) Southwest United States, 12.5% ( $n = 3$ ) West United States, 8.3% ( $n = 2$ ) Canada, and 4.2% ( $n = 1$ ) South America. Respondents included cardiologists (58.3%), paediatric cardiac intensivists (8.3%), advanced practice providers (e.g., nurse practitioner, physician assistant; 12.5%), psychologists (8.3%), and ventricular assist device coordinators (12.5%). Thirteen sites (54.2%) were Institutional Members of Cardiac Neurodevelopmental Outcome Collaborative. There were no significant differences in Cardiac Neurodevelopmental Outcome Collaborative membership ( $\chi^2(1, n = 63) = 0.050, p > 0.05$ ) or ventricular assist device volume ( $\chi^2(2, n = 45) = 0.298, p > 0.05$ ) between responding and non-responding centres, though ventricular assist device volume data were only available for 45 centres so this result should be interpreted with caution. Among responding sites with available ventricular assist device volume data ( $n = 20$ ), the median volume was 26.50 (IQR 5.75–38.75) from January 2012 to September 2023.

## General practices

### Access to providers

Respondents across sites described various models of collaboration with neurodevelopmental providers (Table 1). While most sites had access to a range of neurodevelopmental providers, few were integrated with the ventricular assist device team exclusively.

### Education

Just over half of respondents reported ventricular assist device teams *always* ( $n = 14, 58.3%$ ) provided patient/family education regarding the risks of neurodevelopmental delays associated with paediatric heart disease. However, this education was not routine for all sites, with 25.0% providing this education *sometimes* ( $n = 6$ ), 12.5% providing it rarely ( $n = 3$ ), and 4.2% providing it *never* ( $n = 1$ ).

### Referral practices

Many respondents reported providing routine neurodevelopmental evaluation and/or therapy referrals for all ( $n = 10, 41.7%$ ) or some ( $n = 3, 12.5%$ ) patients. The remainder of respondents reported that these referrals were not routine from the ventricular assist device programme and were either placed by the primary cardiologist or heart failure team ( $n = 9, 37.5%$ ) or were family-initiated ( $n = 2, 8.3%$ ).

### Differences in neurodevelopmental care

Many respondents ( $n = 12, 50.0%$ ) described no differences between their centre's neurodevelopmental practices for patients with ventricular assist devices compared to CHD patients without ventricular assist devices. However, several respondents ( $n = 4, 16.7%$ ) noted that ventricular assist device patients at their centres were not automatically referred for neurodevelopmental evaluations/services, whereas this was often standard for patients with complex or more severe types of CHD (particularly single ventricle). Other respondents described specialised practices for patients with ventricular assist devices. One respondent mentioned that ventricular assist device patients tend to receive additional psychology/social work evaluations that are not standard for all CHD patients, while another respondent reported their site is

developing additional training curricula for neurodevelopmental therapists to enhance care for patients with devices (extracorporeal membrane oxygenation and ventricular assist device).

## Inpatient neurodevelopmental care practices

### Availability of inpatient neurodevelopmental care

Inpatient neurodevelopmental rounds were available for patients with ventricular assist devices at five sites (20.8%), all of which were Cardiac Neurodevelopmental Outcome Collaborative-affiliated sites. All five sites saw patients ages 0–1 during their inpatient neurodevelopmental rounds, while only three sites (12.5%) saw patients ages 2–18 during these rounds. Neurodevelopmental care consults were available to patients with ventricular assist devices at most sites, including consults to physical therapy ( $n = 22, 91.7%$ ), occupational therapy ( $n = 22, 91.7%$ ), psychology/neuropsychology ( $n = 21, 87.5%$ ), speech and language therapy ( $n = 20, 83.3%$ ), and feeding therapy ( $n = 18, 75.0%$ ). Ten hospitals (41.7%) offered individual neurodevelopmental care plans to patients with ventricular assist devices. Inpatient family support services available to patients with ventricular assist devices and their families included social work ( $n = 23, 95.8%$ ), hospital chaplain ( $n = 19, 79.2%$ ), and hospital-based parent support groups ( $n = 11, 45.8%$ ). Available services are summarised in Figure 1.

### Barriers to inpatient neurodevelopmental care

Respondents described multiple barriers to inpatient neurodevelopmental care (including neurodevelopmental testing, rounds, and consults to specialty services) for patients with ventricular assist devices, including that the medical team is focused on medical status/stability ( $n = 12, 50.0%$ ), the child is too critically ill ( $n = 11, 45.8%$ ), lack of access to neurodevelopmental providers ( $n = 11, 45.8%$ ), the patient/family is focused on medical status or stability ( $n = 5, 20.8%$ ), and billing/insurance issues ( $n = 2, 8.3%$ ). One respondent noted “occasional discomfort by bedside nursing” when implementing neurodevelopmental care.

### Primary successes of inpatient neurodevelopmental care

Despite barriers, respondents described numerous successes of inpatient neurodevelopmental care for patients with ventricular assist devices, including early mobilisation with physical therapy ( $n = 19, 79.2%$ ), parental psychosocial support ( $n = 18, 75.0%$ ), patient psychosocial support and individualised care plans ( $n = 17, 70.8%$ ), non-pharmacologic pain management ( $n = 12, 50.0%$ ), and parental engagement in care ( $n = 10, 41.7%$ ). One respondent also expressed that inpatient neurodevelopmental care has helped patients maintain developmental growth/progress, especially during extended admissions.

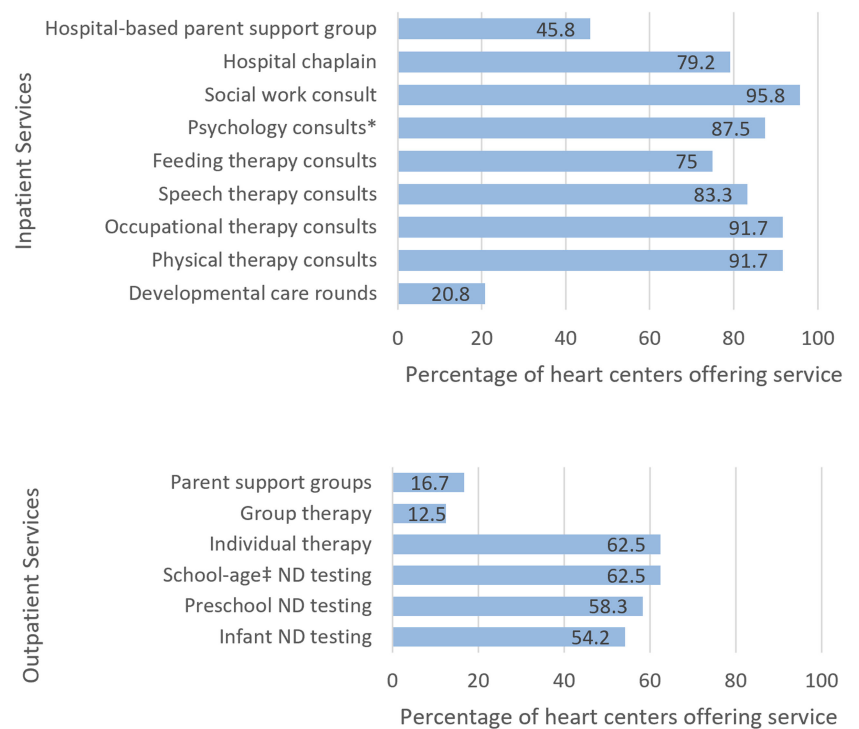
## Outpatient neurodevelopmental care practices

### Availability of outpatient neurodevelopmental care

Over half of heart centres had outpatient neurodevelopmental testing services available to patients with ventricular assist devices: 54.2% ( $n = 13$ ) provided neurodevelopmental testing for infants (ages 0–1); 58.3% ( $n = 14$ ) provided testing for pre-school children (ages 2–5); and 62.5% ( $n = 15$ ) provided testing from school-age through young adulthood (Figure 1). Outpatient individual psychology/therapy was available for ventricular assist device patients at most centres ( $n = 15, 62.5%$ ), though few centres provided

**Table 1.** Ventricular assist device (VAD) teams' collaboration with neurodevelopmental providers

Provider	Full time with VAD team	Full time in Heart Center shared across VAD team and other subspecialties	Available within Heart Center	Available within hospital system (not Heart Center)	Referral required/ not involved
Physical therapy	0 (0%)	11 (45.8%)	7 (29.2%)	6 (25.0%)	0 (0%)
Occupational therapy	0 (0%)	11 (45.8%)	6 (25.0%)	7 (29.2%)	0 (0%)
Speech therapy	0 (0%)	9 (37.5%)	7 (29.2%)	8 (33.3%)	0 (0%)
Developmental paediatrics	0 (0%)	3 (12.5%)	4 (16.7%)	16 (66.7%)	1 (4.2%)
Neurology	0 (0%)	3 (12.5%)	5 (20.8%)	16 (66.7%)	0 (0%)
Psychology	3 (12.5%)	4 (16.7%)	7 (29.2%)	8 (33.3%)	2 (8.3%)
Neuropsychology	0 (0%)	3 (12.5%)	5 (20.8%)	13 (54.2%)	3 (12.5%)
Psychiatry	0 (0%)	3 (12.5%)	5 (20.8%)	15 (62.5%)	0 (0%)
Advanced practice provider	11 (45.8%)	7 (29.2%)	3 (12.5%)	1 (4.2%)	2 (8.3%)
Paediatrician	2 (8.3%)	4 (16.7%)	3 (12.5%)	13 (54.2%)	2 (8.3%)
Social work case management	6 (25.0%)	10 (41.7%)	7 (29.2%)	1 (4.2%)	0 (0%)
Educational specialist	2 (8.3%)	5 (20.8%)	7 (29.2%)	7 (29.2%)	3 (12.5%)
Neonatology	0 (0%)	5 (20.8%)	2 (8.3%)	17 (70.8%)	0 (0%)



**Figure 1.** Available services for patients with ventricular assist devices. ND = neurodevelopmental; \*Psychology consults include neuropsychology; ‡School-age through young adulthood.

outpatient group psychotherapy ( $n = 3$ , 12.5%) or parent support groups ( $n = 4$ , 16.7%). Most centres also provided referrals to outside neurodevelopmental providers as needed ( $n = 17$ , 70.8%).

### Neurodevelopmental evaluation referral practices

Referral practices varied considerably across centres. Most commonly, scheduling of the first outpatient neurodevelopmental evaluation depended upon clinicians recognising the need and making a referral ( $n = 11$ , 45.8%). Other practices included automatically scheduling a patient's first neurodevelopmental evaluation during a cardiology appointment or hospital stay ( $n = 4$ , 16.7%); relying on a family to respond to a letter or autogenerated referral from the neurodevelopmental programme ( $n = 2$ , 8.3%); relying on nurses or scheduling coordinators to reach out to a family to schedule ( $n = 2$ , 8.3%); and scheduling within 6 months of discharge or earlier based on need ( $n = 1$ , 4.2%). Four centres ( $n = 4$ , 16.7%) did not have internal outpatient neurodevelopmental evaluation referral processes in place due to reliance on community providers.

### Barriers to outpatient neurodevelopmental care

Respondents indicated that the primary barriers to outpatient neurodevelopmental care for children with ventricular assist devices were: lack of access to neurodevelopmental providers ( $n = 10$ , 41.7%), the medical team's focus on medical status and stability ( $n = 9$ , 37.5%), patient/family's focus on medical status and stability ( $n = 8$ , 33.3%), lack of insurance coverage for outpatient neurodevelopmental testing ( $n = 5$ , 20.8%), the child was too critically ill ( $n = 4$ , 16.7%), and high demands of at-home ventricular assist device care ( $n = 3$ , 12.5%). Some respondents also noted family's distance from neurodevelopmental care ( $n = 1$ , 4.2%), family's limited interest in comprehensive testing ( $n = 1$ , 4.2%), and scheduling barriers ( $n = 1$ , 4.2%) have impacted receipt of outpatient neurodevelopmental care.

### Mental and behavioural health care practices

#### Diagnostic responsibility

Most respondents indicated that a psychologist was responsible for making mental/behavioural health diagnoses for children supported by ventricular assist devices at their centre ( $n = 17$ , 70.8%). These diagnoses were also made by psychiatrists ( $n = 12$ , 50.0%), social workers ( $n = 6$ , 25.0%), developmental behavioural paediatricians ( $n = 3$ , 12.5%), ventricular assist device and heart failure/transplant team ( $n = 2$ , 8.3%), paediatrician ( $n = 1$ , 4.2%), and cardiac neurodevelopmental programme team ( $n = 1$ , 4.2%). One respondent (4.3%) reported that no one at their centre makes mental/behavioural health diagnoses for patients supported by ventricular assist devices.

#### Available resources for patients and families

Respondents reported on the available resources within their heart centre for patients with ventricular assist devices, parents/caregivers of patients with ventricular assist devices, and young adults with ventricular assist devices transitioning to adult cardiology care, which are described in Table 2. Whereas Table 1 describes various models of multidisciplinary collaboration with ventricular assist device teams, Table 2 summarises available cardiology centre resources in terms of referral/consultative practices to facilitate patient and family access.

### Discussion

As the population of children supported by ventricular assist devices has grown in recent years<sup>1</sup>, efforts to identify best practices to support the neurodevelopmental and psychosocial health of paediatric ventricular assist device patients and their families are vitally important. Our study represents the first multicentre attempt to characterise current neurodevelopmental care practices for children with ventricular assist devices. We found that many centres have established networks of neurodevelopmental providers available to their ventricular assist device patients across both inpatient and outpatient settings, which is consistent with current follow-up guidelines for high-risk CHD.<sup>9,10,15</sup> However, there was considerable variability in how closely ventricular assist device teams collaborated with multidisciplinary providers. A few sites had providers working full-time or exclusively with the ventricular assist device team, whereas most only had access within the larger heart centre or hospital and not within the ventricular assist device team. This is likely due to the low annual patient volume of many ventricular assist device programmes.

While the availability of neurodevelopmental providers at many centres is encouraging, findings illustrate several potential shortcomings in current neurodevelopmental care practices for ventricular assist device patients. Strikingly, over 40% of centres do not always deliver patient/family education regarding the neurodevelopmental risks associated with paediatric heart disease. This mirrors previous findings demonstrating that parents and children with ventricular assist devices often feel under-informed about their child's anticipated ventricular assist device course.<sup>24</sup> Providing families with accurate and timely information empowers parents to proactively monitor their child's neurodevelopment and advocate for assistance should concerns arise.<sup>25</sup> Ventricular assist device programmes are encouraged to evaluate the clinician- and organisational-level barriers associated with educational practices (e.g., clinician unfamiliarity or discomfort with neurodevelopmental education, short appointments, and lack of educational resources) and address them accordingly to improve this aspect of their care. The development of educational resources that can be shared across centres, such as those developed by our current Advanced Cardiac Therapies Improving Outcomes Network-Cardiac Neurodevelopmental Outcome Collaborative collaboration (Supplemental Material, also see [https://myactioneducation.org/courses/wellness/?section\\_id=5658&subtab\\_id=56,584](https://myactioneducation.org/courses/wellness/?section_id=5658&subtab_id=56,584)), may be especially useful.

Our results also highlighted how ventricular assist device patients may "slip through the cracks" during the referral and scheduling process, particularly when automatic referral criteria are based on neonatal surgery or CHD diagnosis. Additionally, approximately 45% of centres rely on clinicians to identify/refer ventricular assist device patients for neurodevelopmental evaluations, and nearly 10% rely on families to reach out to schedule appointments. Such practices may lead to missed opportunities for referrals and low rates of follow-up even when patients are successfully referred given increased scheduling burden on families.<sup>26</sup> When feasible and clinically indicated, ventricular assist device programmes should consider automatic referrals for neurodevelopmental evaluations/services to existing neurodevelopmental follow-up programmes and hospital-initiated scheduling practices, as prior research has shown hospital-initiated scheduling can significantly improve attendance in outpatient cardiac neurodevelopmental follow-up programmes.<sup>26</sup>

Clinicians in our sample recognised numerous benefits of inpatient neurodevelopmental care for both patients and their

**Table 2.** Available resources for patients with ventricular assist devices and their families within the heart centre

Child-Focused resources	Referrals/ consults placed for all	Referrals/ consults placed based on need	Available by request	Not available	No response
Inpatient social work	23 (95.8%)	0 (0%)	0 (0%)	0 (0%)	1 (4.2%)
Inpatient psychology	13 (54.2%)	9 (37.5%)	0 (0%)	1 (4.2%)	1 (4.2%)
Inpatient psychiatry	2 (8.3%)	20 (83.3%)	1 (4.2%)	0 (0%)	1 (4.2%)
Outpatient social work	14 (58.3%)	5 (20.8%)	4 (16.7%)	0 (0%)	1 (4.2%)
Outpatient psychology	8 (33.3%)	11 (45.8%)	4 (16.7%)	0 (0%)	1 (4.2%)
Outpatient psychiatry	0 (0%)	19 (79.2%)	4 (16.7%)	0 (0%)	1 (4.2%)
Support/educational groups	3 (12.5%)	3 (12.5%)	7 (29.2%)	9 (37.5%)	2 (8.3%)
Local counselling referrals*	0 (0%)	11 (45.8%)	7 (29.2%)	5 (20.8%)	1 (4.2%)
<b>Parent-Focused resources</b>					
Inpatient social work	15 (62.5%)	3 (12.5%)	3 (12.5%)	1 (4.2%)	2 (8.3%)
Inpatient psychology	7 (29.2%)	4 (16.7%)	2 (8.3%)	8 (33.3%)	3 (12.5%)
Inpatient psychiatry	2 (8.3%)	6 (25.0%)	3 (12.5%)	10 (41.7%)	3 (12.5%)
Outpatient social work	7 (29.2%)	10 (41.7%)	3 (12.5%)	2 (8.3%)	2 (8.3%)
Outpatient psychology	5 (20.8%)	6 (25.0%)	4 (16.7%)	7 (29.2%)	2 (8.3%)
Outpatient psychiatry	0 (0%)	9 (37.5%)	4 (16.7%)	9 (37.5%)	2 (8.3%)
Support/educational groups	3 (12.5%)	2 (8.3%)	7 (29.2%)	8 (33.3%)	4 (16.7%)
Local counselling referrals*	0 (0%)	9 (37.5%)	8 (33.3%)	4 (16.7%)	3 (12.5%)
<b>Young adult/transition-focused resources</b>					
Neurodevelopmental testing	6 (25.0%)	9 (37.5%)	6 (25.0%)	2 (8.3%)	1 (4.2%)
Inpatient social work	20 (83.3%)	2 (8.3%)	0 (0%)	1 (4.2%)	1 (4.2%)
Inpatient psychology	12 (50.0%)	8 (33.3%)	1 (4.2%)	2 (8.3%)	1 (4.2%)
Inpatient psychiatry	5 (20.8%)	15 (62.5%)	0 (0%)	2 (8.3%)	2 (8.3%)
Outpatient social work	16 (66.7%)	4 (16.7%)	2 (8.3%)	1 (4.2%)	1 (4.2%)
Outpatient psychology	9 (37.5%)	10 (41.7%)	3 (12.5%)	1 (4.2%)	1 (4.2%)
Outpatient psychiatry	2 (8.3%)	16 (66.7%)	3 (12.5%)	2 (8.3%)	1 (4.2%)
Support/educational groups	2 (8.3%)	3 (12.5%)	7 (29.2%)	9 (37.5%)	3 (12.5%)
Local counselling referrals*	0 (0%)	10 (41.7%)	7 (29.2%)	5 (20.8%)	2 (8.3%)
Adult transition programme	10 (41.7%)	4 (16.7%)	0 (0%)	8 (33.3%)	2 (8.3%)

\*Not affiliated with heart centre.

families, underscoring the inherently family-centred nature of neurodevelopmental care.<sup>15,27</sup> Encouragingly, most centres have individual consults to physical, occupational, and speech therapists available to patients with ventricular assist devices, as early and frequent neurodevelopmental consults are critical for young patients with heart disease.<sup>15</sup> Interdisciplinary neurodevelopmental rounds also have been recommended as best practice for hospitalised infants with CHD<sup>15,27</sup>; yet only 20.8% of centres offer neurodevelopmental rounds to their patients with ventricular assist devices. Establishing neurodevelopmental rounds for inpatients with ventricular assist devices may provide an opportunity to individualise neurodevelopmental care, strengthen the partnership between families and neurodevelopmental providers, and proactively address potential concerns before they become clinical problems.<sup>27</sup>

Understandably, illness-related concerns can pose a barrier to some inpatient neurodevelopmental care practices (e.g., physical therapy), emphasising the need for flexibility in delivering neurodevelopmental care in the setting of paediatric heart failure. Many neurodevelopmental care practices can be appropriately and safely delivered even when a child is critically ill. Access to clinicians was another notable barrier endorsed by respondents, consistent with broader staffing challenges faced by U.S. hospitals in recent years.<sup>28</sup> By understanding the ways in which subspecialty services collaborate and overlap with each other, ventricular assist device teams may be able to augment neurodevelopmental care for their patients even if unable to support two separate specialty services. For example, paediatric psychologists and neuropsychologists often are both able to provide neurodevelopmental screenings, while occupational and speech therapists may both support a patient's feeding goals. Additionally, partnerships between neurodevelopmental care providers and social work teams may be another avenue for enhancing neurodevelopmental care for ventricular assist device patients in the setting of staffing challenges, as over 95% of centres in our sample automatically consult inpatient social work for all patients with ventricular assist devices.

Access issues are not restricted to inpatient neurodevelopmental care, as respondents indicated that limited insurance coverage and a dearth of nearby providers are common obstacles to outpatient neurodevelopmental care as well. Such challenges may be addressed, in part, through outpatient social work services, teacher and school education about neurodevelopmental risks, state-based early intervention programmes, and alternative means of service delivery. In recent years, telehealth has emerged as a promising tool to increase access to neurodevelopmental evaluations and therapies, though this can pose difficulties with some aspects of standardised assessment.<sup>29</sup>

Regarding psychosocial care, the American Heart Association recognises the urgent need to embed family-centred mental and behavioural health services into the culture of heart centres as integral components of comprehensive cardiac care.<sup>14</sup> We found that mental and behavioural health providers (e.g., psychology, neuropsychology, psychiatry, and social work) are often available for ventricular assist device patients, but are less available for parents/caregivers despite the considerable stress, anxiety, and caregiving demands associated with parenting a child with heart failure/ventricular assist device.<sup>7</sup> Reliance upon community providers to serve the unique needs of patients with ventricular assist devices and their families likely is not a realistic solution, as nearly 1 in 5 respondents indicated that local psychotherapy referrals simply were not available for ventricular assist device

patients or their parents. Hospital-based psychosocial programme development should remain a priority for heart centres.<sup>14</sup>

### Strengths and limitations

Our study, which represents the inaugural collaboration between the Advanced Cardiac Therapies Improving Outcomes Network and Cardiac Neurodevelopmental Outcome Collaborative learning networks, provided a much-needed overview of current neurodevelopmental and psychosocial care for patients with ventricular assist devices and their families, highlighting several areas for improvement. While the study has many strengths and important clinical implications, results must be interpreted in light of study limitations. First, nearly all respondents represented North American heart centres, limiting generalizability to international sites. Second, the response rate was low, potentially introducing bias, though there were no significant differences in Cardiac Neurodevelopmental Outcome Collaborative membership or ventricular assist device volume between responding and non-responding centres. Third, while respondents were encouraged to solicit information from knowledgeable colleagues when completing the survey, respondents may have had limited awareness or understanding of certain neurodevelopmental services. Finally, neurodevelopmental care encompasses a broad range of services/interventions, not all of which were assessed in this survey (e.g., lactation consults).

### Future directions

More research is needed to characterise neurodevelopmental trajectories and associated risk/protective factors for individuals with ventricular assist devices. Quality improvement efforts should focus on improving patient, family, and clinician education regarding neurodevelopment and psychosocial care of patients with ventricular assist devices. Future research and quality improvement efforts should solicit the perspective of patients/parents, ancillary clinic staff (e.g., nurse coordinators), and school personnel to identify areas of need, potential barriers to services, and strategies to improve neurodevelopmental and psychosocial care for children supported by ventricular assist devices.

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