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Title

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Permalink

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Journal

Cardiology in the Young, 33(2)

ISSN

1047-9511

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Publication Date

2023-02-01

DOI

10.1017/s1047951122000579

Peer reviewed

Original Article

Cite this article: Kasparian NA, Sadhwani A, Sananes R, Blumenfeld E, Butcher JL, Cassidy AR, Cox SM, Kenowitz J, Miller TA, Sanz JH, Wolfe KR, and Ilardi D (2022). Telehealth services for cardiac neurodevelopmental care during the COVID-19 pandemic: a site survey from the Cardiac Neurodevelopmental Outcome Collaborative. *Cardiology in the Young*, page 1 of 8. doi: [10.1017/S1047951122000579](https://doi.org/10.1017/S1047951122000579)






Received: 20 August 2021
Revised: 25 December 2021
Accepted: 4 February 2022

Keywords:
CHD; COVID-19; pandemic; telehealth; neurodevelopment; disparities

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From the Telehealth Task Force of the Cardiac Neurodevelopmental Outcome Collaborative.

Telehealth services for cardiac neurodevelopmental care during the COVID-19 pandemic: a site survey from the Cardiac Neurodevelopmental Outcome Collaborative

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Abstract

Objective: COVID-19 has markedly impacted the provision of neurodevelopmental care. In response, the Cardiac Neurodevelopmental Outcome Collaborative established a Task Force to assess the telehealth practices of cardiac neurodevelopmental programmes during COVID-19, including adaptation of services, test protocols and interventions, and perceived obstacles, disparities, successes, and training needs. **Study Design:** A 47-item online survey was sent to 42 Cardiac Neurodevelopmental Outcome Collaborative member sites across North America within a 3-week timeframe (22 July to 11 August 2020) to collect cross-sectional data on practices. **Results:** Of the 30 participating sites (71.4% response rate), all were providing at least some clinical services at the time of the survey and 24 sites (80%) reported using telehealth. All but one of these sites were offering new telehealth services in response to COVID-19, with the most striking change being the capacity to offer new intervention services for children and their caregivers. Only a third of sites were able to carry out standardised, performance-based, neurodevelopmental testing with children and adolescents using telehealth, and none had completed comparable testing with infants and toddlers. Barriers associated with language, child ability, and access to technology were identified as contributing to disparities in telehealth access. **Conclusions:** Telehealth has enabled continuation of at least some cardiac neurodevelopmental services during COVID-19, despite the challenges experienced by providers, children, families, and health systems. The Cardiac Neurodevelopmental Outcome Collaborative provides a unique platform for sharing challenges and successes across sites, as we continue to shape an evidence-based, efficient, and consistent approach to the care of individuals with CHD.

Children with complex congenital heart disease (CHD) have known neurological risks and developmental challenges.¹ The Cardiac Neurodevelopmental Outcome Collaborative (CNOC) is a non-profit organisation founded in 2016 (www.cardiacneuro.org) to “optimise neurodevelopmental and psychosocial outcomes for all individuals with CHD across the lifespan through clinical, quality improvement, and research initiatives.”² Cardiac Neurodevelopmental Outcome Collaborative member sites include medical institutions that provide care for children with CHD. Amongst the Cardiac Neurodevelopmental Outcome Collaborative's accomplishments are the establishment of a clinical data registry and publication

of clinical test protocols for neurodevelopmental evaluation in an effort to improve quality of care and research collaborations across member sites and internationally.^{3,4}

Prior to the novel coronavirus disease 2019 (COVID-19) pandemic, multiple centres had identified barriers to recommended neurodevelopmental care for children with CHD resulting in significant health disparities, especially in terms of insurance status, family geographical location (e.g., urban, suburban, or rural), financial resources, and race and ethnicity.^{5,6} More recently, the COVID-19 pandemic and associated restrictions regarding in-person clinical services have markedly impacted the ability to provide timely neurodevelopmental assessment and care in keeping with best practices for this vulnerable patient population.¹ Initiating and integrating telehealth services within neurodevelopmental programmes may offer opportunities to reduce delays and disparities in access to neurodevelopmental evaluation and care, as well as broaden service reach to a larger percentage of the CHD population. Use of telehealth may also mitigate the risks associated with lack of timely access to neurodevelopmental evaluation (e.g., child behavioural, emotional and learning difficulties, academic delays, family psychological stress) and facilitate nimble adaptation to events that limit travel and in-person evaluations including, but not limited to, COVID-19. There is, however, a need to balance the clinical information gained via telehealth against the information lost by not having an in-person neurodevelopmental assessment.

Currently, there is limited understanding of how cardiac neurodevelopmental programmes have responded to the COVID-19 pandemic and the extent to which telehealth may have been adopted into practice. Moreover, there is a striking lack of evidence to guide telehealth-based neurodevelopmental services. To address this knowledge gap, and rapidly respond to questions and concerns about telehealth-based neurodevelopmental care, the Cardiac Neurodevelopmental Outcome Collaborative Steering Committee approved the formation of a Telehealth Task Force in June 2020. The multidisciplinary Task Force included representation from neuropsychology, paediatric psychology, cardiology and patient advocacy, and members were charged with collating available evidence and relevant guidelines and identifying current practices across institutional member sites. The purpose of this survey of Cardiac Neurodevelopmental Outcome Collaborative member sites was to assess the telehealth practices of cardiac neurodevelopmental programmes during the COVID-19 pandemic, including adaptation of clinical services, test protocols and interventions, as well as perceived obstacles, disparities, and successes. A secondary goal was to disseminate findings to the cardiac community, to encourage research and collaboration to ensure timely access to high-quality neurodevelopmental services during COVID-19 and into the future.

Materials and methods

Study design and population

Participants for this cross-sectional survey were recruited via 42 Cardiac Neurodevelopmental Outcome Collaborative member sites across North America within a 3-week timeframe, from 22 July to 11 August 2020. During this period, many states across the United States, as well as many other countries, were experiencing increasing COVID-19 cases and implementing closures and restrictions on in-person clinical services. In addition, many hospitals had implemented policies limiting in-person patient care.

There was also a high level of uncertainty regarding whether children would return to the classroom for in-person schooling in the Fall.

Procedures

An e-mail describing the purpose of the survey was sent to site representatives at all Cardiac Neurodevelopmental Outcome Collaborative member sites, accompanied by a link to an online survey. Each site was invited to nominate a provider from within their cardiac neurodevelopmental programme to complete the survey. A maximum of two e-mail reminders were sent to sites to encourage participation.

Measures

To understand telehealth-related practices during the COVID-19 pandemic, the Cardiac Neurodevelopmental Outcome Collaborative Telehealth Task Force developed a 47-item online survey, delivered via a secure web-based application (REDCap, <https://projectredcap.org>). The survey (see Supplementary Material 1) assessed the seven key areas outlined below.

Pre-Pandemic Clinical Practices (1 item): Types of clinical services routinely provided by each cardiac neurodevelopmental programme prior to COVID-19.

Clinical Practices During COVID-19 (16 items): Service changes in response to COVID-19, use of telehealth, types of patient and caregiver assessments and interventions offered, assessment measures used, patient prioritisation and triage processes, technical aspects of telehealth implementation, and the status of in-person services.

Obstacles (7 items): Frequency of telehealth-related difficulties associated with Current Procedural Terminology coding, billing and insurance reimbursement, patient and provider technology use, staffing or administrative support, access to language interpreting services, and provider confidence delivering telehealth services were assessed on a scale from 1 ("Never") to 5 ("Always").

Licensure, Billing, and Reimbursement (4 items): Out-of-state licensure, billing, and reimbursement by insurance providers and use of grant or donor funds to support telehealth services.

Perceived Disparities in Care (4 items): Each site was asked to identify any disparities in access to or delivery of telehealth services for people of non-English speaking backgrounds; people with limited access to technology; type of health insurance; and children with behavioural, age, or ability-related challenges.

Perceived Success and Patient Satisfaction (8 items): Perceptions of success regarding the use of telehealth to offer caregiver or child interviews, infant and child neurodevelopmental evaluations, test result feedback sessions, and parent- or child-focused interventions were assessed. Respondents also indicated how often families expressed satisfaction or a positive experience with telehealth services using a 5-point rating scale from 1 ("Never") to 5 ("Always").

Provider Training Needs (7 items): Respondents indicated areas their programme could either share and teach successes and lessons learned with other programmes; or could learn from others.

Statistical Analyses

Descriptive statistics, including frequencies, percentages, mean scores, and standard deviations were calculated using Excel for Microsoft 365 (Microsoft Co, Redmond, WA) to explore site

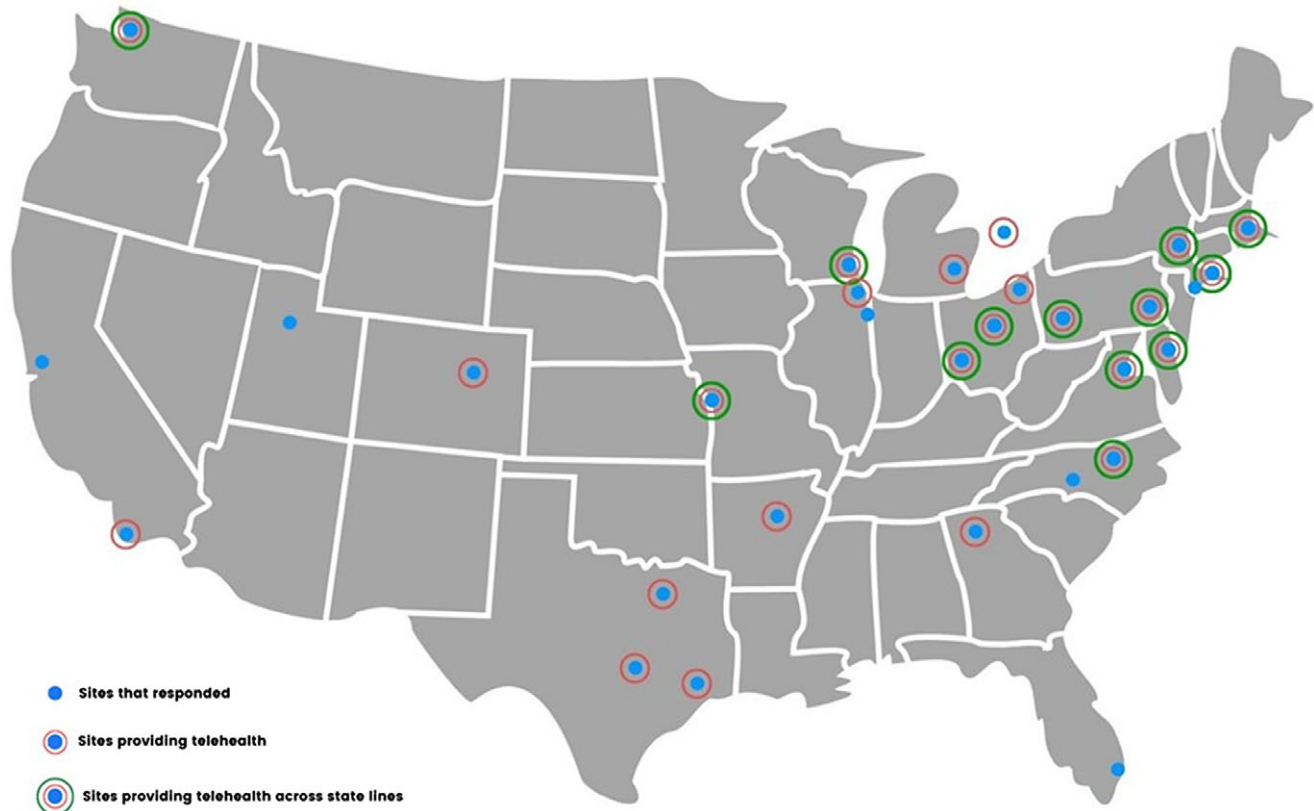


Figure 1. Regional map illustrating telehealth-related characteristics of Cardiac Neurodevelopmental Outcome Collaborative sites who participated in the survey.

characteristics, telehealth practices, and provider views and experiences.

Results

Of the 42 Cardiac Neurodevelopmental Outcome Collaborative sites approached, 30 completed the survey, yielding a response rate of 71.4%. The annual median cardiac surgical volume of responding sites was 426 surgeries (range: 57–1306). Amongst the respondents, 54.5% were psychologists, 27.3% physicians, 15.2% nurses, and 3% developmental specialists. Figure 1 illustrates regional and telehealth-related characteristics of responding sites.

Use of telehealth across cardiac neurodevelopmental programmes

Prior to the COVID-19 pandemic, the 30 participating sites provided a range of in-person clinical services, including neurodevelopmental assessment for infants (90%), pre-school (93%), and school-aged children (90%) with CHD, and interventions for infants or children (50%), caregivers (43%), or caregiver-child dyads (33%; e.g., Parent-Child Interaction Therapy). During COVID-19, at the time of survey completion, all sites were providing at least some clinical services and 80% (24/30) reported using telehealth to provide these services. One site was offering telehealth services exclusively, six had returned to in-person services exclusively, and 23 sites had developed a hybrid model including both telehealth and in-person visits. Change in the use of telehealth for neurodevelopmental care had been initiated in direct response to COVID-19 in all but one of these 24 sites. Twenty-three sites offered telehealth to both new and established

patients, and one site offered telehealth to established patients only. The most frequently used platform for telehealth was Zoom (n = 11), followed by AmWell (n = 4), DoxyMe (n = 3), Vido (n = 3), and Microsoft Teams (n = 2). Of the sites that had returned to in-person services, the date of re-commencement ranged from March (in conjunction with cardiac appointments only) to July 2020, with most sites (21/27) returning to some in-person services in June or July.

Neurodevelopmental evaluation services during COVID-19

Of the sites offering telehealth-based services (n = 24), 22 sites required in-person visits for infant neurodevelopmental evaluation at the time of the survey, one was offering infant assessment via telehealth, and one did not respond (Fig 2). In terms of neurodevelopmental evaluation for children or adolescents with CHD, one site reported providing this service before COVID-19, eight had initiated child or adolescent evaluation via telehealth during the pandemic, and 15 required in-person visits for this service. When implementing telehealth, just over half the sites (n = 13/24) reported transitioning from comprehensive, standardised, performance-based testing to the use of parent rating scales or semi-structured observational methods (Fig 3). Telehealth was used “often” or “always” to prioritise, triage, or determine the need for an in-person visit by 46% of the sites. For all but one site using telehealth, virtual appointments were “sometimes” or “often” followed by an in-person visit to complete the neurodevelopmental evaluation (n = 23). When collecting background and demographic information from caregivers, nine sites used paper-based surveys, four used web-based surveys, and nine used a combination (two sites did not respond).

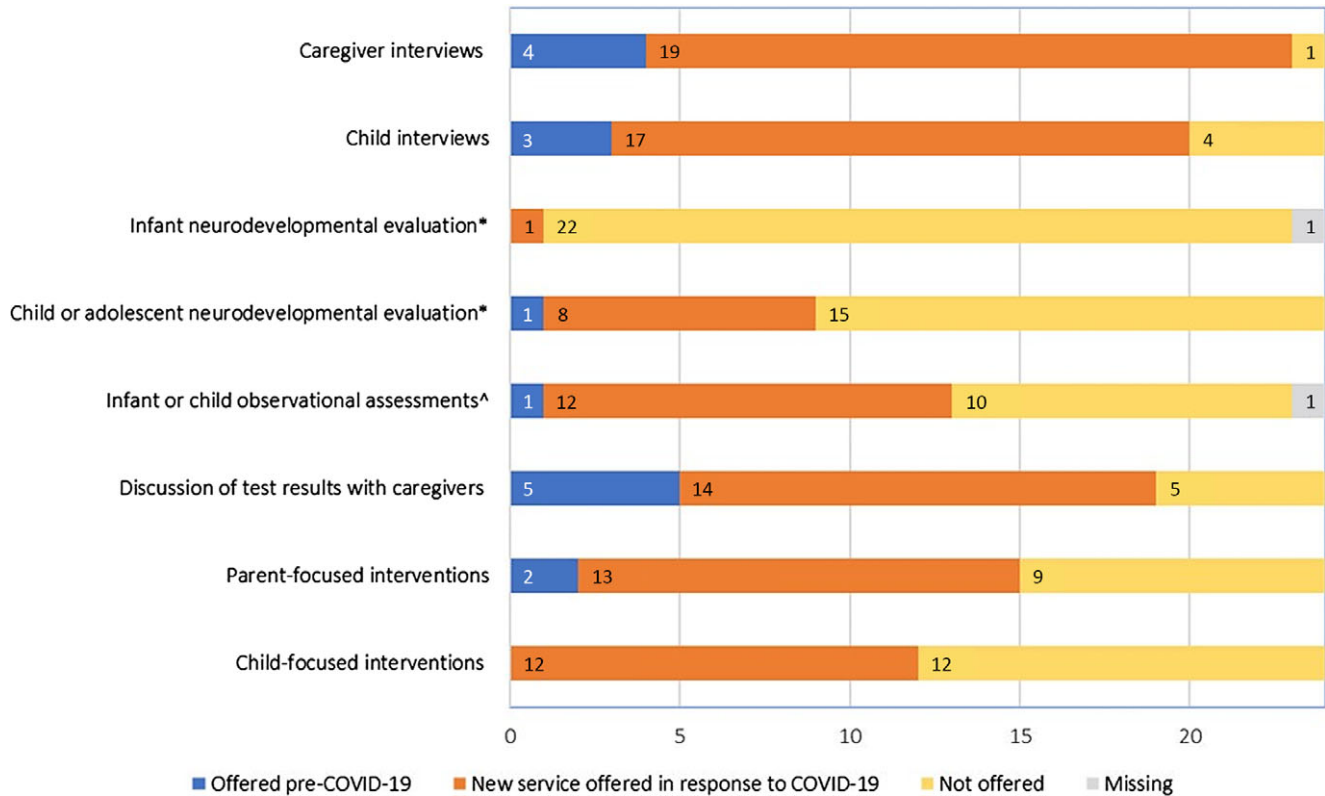


Figure 2. Neurodevelopmental and psychological services provided via telehealth at Cardiac Neurodevelopmental Outcome Collaborative sites ($n = 24$). *indicates evaluation using performance-based tests to at least some extent; ^ indicates semi-structured observational assessment using materials from standardised tests, but not following standardised procedures.

Qualitatively, several sites raised concerns regarding the validity of neurodevelopmental evaluation, given the adjustments to test batteries required to accommodate the telehealth setting. No site, for example, was administering the Bayley Scales of Infant and Toddler Development, Fourth Edition (BSID-4) via telehealth and most sites (67%) “never” used the recommended Cardiac Neurodevelopmental Outcome Collaborative test battery^{3,4} for children and adolescents during telehealth appointments. Alternative measures used for children under age 6 years included the Ages and Stages Questionnaire (ASQ, $n = 7$) and the Developmental Assessment of Young Children, Second Edition (DAYC-2, $n = 3$). Of the sites offering neurodevelopmental assessment for children or adolescents via telehealth, only selected subtests from the Cardiac Neurodevelopmental Outcome Collaborative test battery (assessing domains such as intellectual functioning, academics, memory, executive skills) were administered (Fig 3). Two-thirds of sites (65%) were using parent-proxy rating scales from the Cardiac Neurodevelopmental Outcome Collaborative test battery regularly to assess aspects of child behavioural, socio-emotional, and executive functioning. When administering standardised assessments via telehealth, a few sites implemented a range of strategies to accommodate distance-delivery, including the use of two cameras in the child’s home to increase visibility of the child’s responses during assessments ($n = 1$), mailing test materials (e.g., response booklets) to the home prior to the appointment ($n = 3$), use of an online testing platform ($n = 1$), and requiring number responses for visual items which usually require a pointing response ($n = 1$).

Psychological interventions with children and caregivers

A limited number of sites were offering in-person intervention services for parents ($n = 13$) or children ($n = 15$) prior to COVID-19, and of those sites providing interventions for children, 60% were able to successfully transition to telehealth. At the time of this survey, 15 sites were offering parent-focused interventions via telehealth and 12 were providing child-focused interventions, including 13 sites that were offering intervention services for the first time (Fig 2).

Telehealth implementation

Billing and licensure: At the time of this survey, many payors in the United States expanded billing permissions for telehealth assessment and intervention services in response to the pandemic. Although all surveyed Cardiac Neurodevelopmental Outcome Collaborative sites were able to bill for telehealth services, 46% were unaware of service reimbursement rates. For those with knowledge of reimbursement, rates were the same (34%) or lower (7%) than in-person services or varied based on insurance type (13%). Only two sites reported use of grant or donor funds when families could not pay for telehealth services. Out-of-state psychology licensing requirements were waived in some states; 21% of sites provided out-of-state telehealth services, 29% could “sometimes” offer out-of-state services, 21% could not provide out-of-state services, and 29% were unsure of their capacity to provide out-of-state services (Fig 1).

Table 1. Obstacles encountered by Cardiac Neurodevelopmental Outcome Collaborative sites in the transition to telehealth-based neurodevelopmental and psychosocial services.

Obstacle	Mean rating (SD)	% of Cardiac Neurodevelopmental Outcome Collaborative sites reporting obstacle 'Often' or 'Always'	Obstacle unknown (%)	Obstacle resolved (%)
Patient technology issues	3.00 (0.29)	4%	0	0
Reduced provider confidence delivering neurodevelopmental services via telehealth	2.50 (0.80)	4%	4%	0
Difficulty integrating language interpreting services	2.50 (1.06)	8%	8%	0
Insurance reimbursement	2.40 (1.17)	8%	54%	4%
Provider technology issues	2.35 (0.78)	4%	0	4%
Lack of administrative support or staffing to implement telehealth	2.09 (1.04)	8%	0	4%
CPT coding	1.59 (0.94)	4%	29%	0

Each potential obstacle was rated by the respondent on a Likert scale from 1 ("Never") to 5 ("Always"), or as "Unknown" or "Resolved". CPT: Current Procedural Terminology.

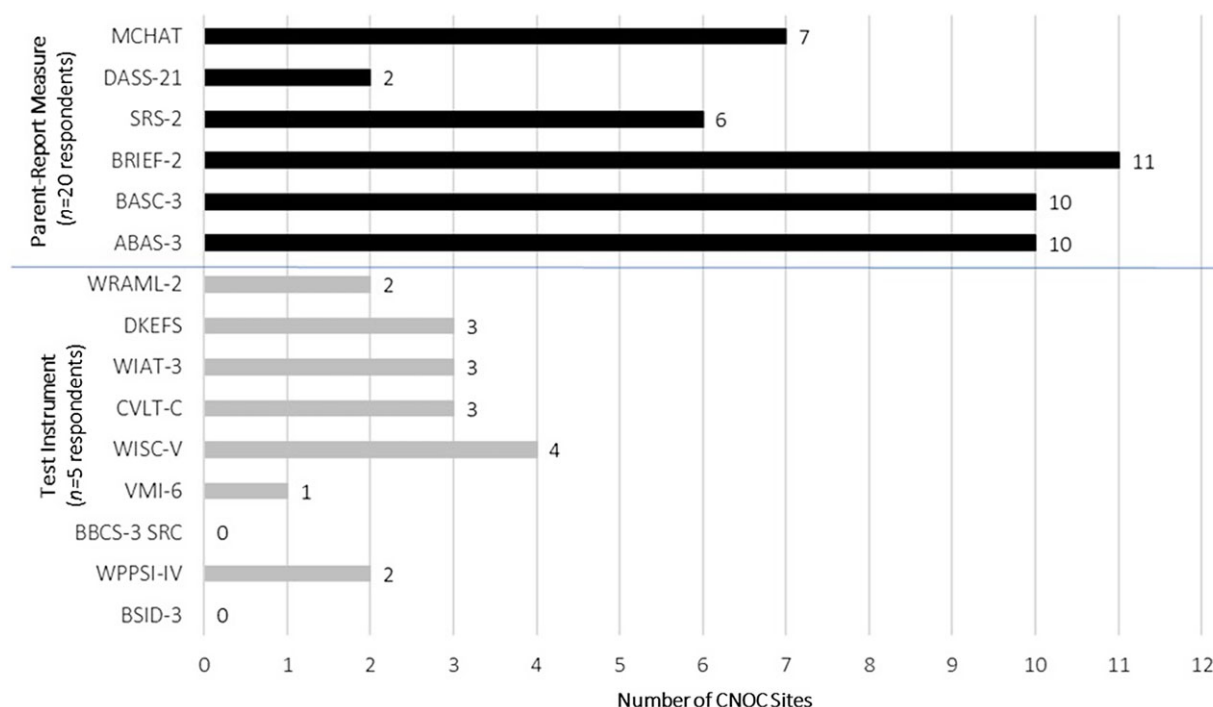


Figure 3. Number of sites administering at least some subtests from the Cardiac Neurodevelopmental Outcome Collaborative recommended test battery (n = 5) and/or parent-report measures (n = 20) via telehealth.

Perceived obstacles and disparities: Across the 24 sites using telehealth for neurodevelopmental and psychosocial care, the most frequently reported obstacles were patient and family difficulties with technology (e.g., poor internet connection), reduced provider confidence delivering neurodevelopmental services via telehealth, and difficulties integrating language interpreting services during telehealth appointments (Table 1). Factors perceived to contribute to disparities in care included limited access to language interpreting services, limited patient access to adequate technology, and children not being able to participate in telehealth due to age, behavioural, or ability-related challenges (Table 2).

Perceived success, patient satisfaction, and provider training needs: Sixty per cent of sites reported that families “often” or

“always” expressed satisfaction with their telehealth experience and the average perceived patient and family satisfaction rating was 3.8 out of 5. Neurodevelopmental care providers also offered spontaneous feedback covering a range of themes related to their subjective experiences with telehealth, including an increased ability to reach at-risk patients, reduced no-show rates, and requests from parents for continued telehealth services after the pandemic due to the convenience afforded. Many respondents expressed an eagerness for opportunities to learn more about and develop or expand skills in telehealth-based neurodevelopmental evaluation and care. A substantial subset of respondents was willing to share information and help train providers at other sites to increase successes and reduce obstacles (see Supplementary Material 2).

Table 2. Disparities in access to, or delivery of, telehealth-based neurodevelopmental and psychosocial services identified by Cardiac Neurodevelopmental Outcome Collaborative sites.

Group	Mean (SD)	% of sites indicating disparity "Unknown"
People with limited access to technology	3.33 (1.06)	8%
Children who cannot participate in telehealth due to age, behaviour, or (dis)ability	3.05 (0.94)	13%
People of non-English speaking backgrounds	2.95 (1.18)	17%
Insurance type	1.56 (0.70)	21%

Response options ranged from 1 ("No disparities identified") to 5 ("Always").

Discussion

We surveyed 30 cardiac neurodevelopmental programmes across North America within a 3-week period during the COVID-19 pandemic (22 July to 11 August 2020) and found that most sites (80%) were providing at least some clinical services via telehealth. All but one of these 24 sites were offering new telehealth services in response to COVID-19, with the most striking change being the capacity to offer new intervention services for children and their caregivers. Only a third of sites were able to carry out standardised, performance-based neurodevelopmental testing with children and adolescents via telehealth, and none had completed comparable testing with infants and toddlers. Moreover, a substantial subset of respondents expressed concerns about the validity and reliability of neurodevelopmental evaluation via telehealth, indicating a need for more data correlating in-person and telehealth evaluation results. In contrast, most sites were administering parent interviews and rating scales and providing feedback on test results using telehealth. While parent interviews and rating scales are a critically important component of neurodevelopmental evaluation for infants, children, and adolescents with CHD, these cannot replace the information gleaned from performance-based neurodevelopmental testing using standardised measures administered by trained professionals.

Concerns regarding various practical challenges associated with telehealth implementation highlight the need for collaborative efforts across congenital heart centres. The wide range of barriers identified in this survey, along with a strong interest in learning more about the use of standardised tests via telehealth, provided the catalyst for the Cardiac Neurodevelopmental Outcome Collaborative Telehealth Task Force to deliver a series of webinars to support its member institutions as they develop and expand telehealth services. These have been well-attended (172 registrations), and additional webinars are planned. Concerns regarding insurance reimbursement rates and the potential inability to serve out-of-state patients are well-founded, given the marked variability in reimbursement laws between states and the durability of limited pandemic-related changes to state laws.⁷⁻⁹ Ongoing advocacy for adequate reimbursement will require understanding of how telehealth challenges may both contribute to disparities in access to care^{10,11} and facilitate access for some children and families who could not otherwise participate in an in-person visit. Telehealth may expand the footprint and breadth of cardiac neurodevelopmental care by bringing expertise to under-served, under-resourced, and remote communities and efficiently directing children and families to the most appropriate services. Recently, the American Academy of Pediatrics (AAP) Section on Telehealth Care, Committee on Practice and Ambulatory Medicine, and Committee on Pediatric Workforce advocated for telehealth as a means of decreasing disparities in access to care by extending

paediatric expertise and best practices to children and adolescents no matter where they are located.¹² This is limited, however, by our capacity to address barriers associated with language, digital literacy, special needs, and access to and payment for technology infrastructure. In addition, the AAP argue for payment for telehealth services at parity with the equivalent services provided in-person by private and public insurers. Such efforts are essential to avoid furthering disparities. Future research is needed to examine the specific ways in which telehealth mitigates or exacerbates disparities in access to and outcomes of neurodevelopmental care for vulnerable populations.

Limited data exist on the use of telehealth for cardiac neurodevelopmental evaluation and care. Most telehealth assessment studies with children thus far have focused on addressing unmet needs in rural or remote communities, such as in Australia, and have used a satellite clinic with additional personnel.^{13,14} While promising, preliminary data on the use of telehealth testing are extremely limited and very few studies have explored telehealth for neuropsychological assessment in the child's home.¹⁵⁻¹⁸ Early motivation for telehealth psychology services was, in large part, associated with attempts to minimise barriers to care imposed by geographical distance. A pre-pandemic survey of parents of children with complex medical conditions identified geographical distance as a major barrier to access to behavioural health services and parents reported a clear preference for telepsychology initiatives over in-person therapy.¹⁹ Evidence supporting the feasibility, acceptability, and efficacy of telehealth-based psychological interventions for children and adolescents predates the pandemic²⁰⁻²³ and indicates that telehealth can be as effective as in-person therapies,^{24,25} with documented improvements in child behavioural and emotional outcomes, parent engagement and mental health outcomes, and family retention and satisfaction with treatment.²⁶⁻²⁹ Benefits of telehealth also include potentially increased generalisability to the natural environment, with greater clinician access to challenges in the family environment resulting in more effective problem-solving or skills implementation.³⁰ Elsewhere, our Task Force has proposed a conceptual model to illustrate how telehealth can be integrated within each stage of cardiac neurodevelopmental care, from intake to evaluation through to follow-up care and intervention, both during and post-pandemic.³¹

Strengths and Limitations

Strengths of this first survey of clinical services in cardiac neurodevelopmental programmes during the COVID-19 pandemic include the relatively high response rate and representation from a diverse group of providers (psychologists, physicians, nurses), sites (various surgical volumes), and locations across North America (Fig 1). The survey captured data on a broad range of

clinical practices applicable across paediatric populations, including caregiver interviews, assessments for children of various ages, family feedback sessions, and child and parent intervention services. The survey findings have already been translated into educational practice, including the launch of a series of webinars hosted by the Cardiac Neurodevelopmental Outcome Collaborative for neurodevelopmental care providers and opportunities for ongoing learning and development between sites. Despite these strengths and the insights provided by the survey, several important limitations must also be considered. First, there are limited data on the validity and reliability of paediatric neurodevelopmental evaluation using telehealth. Any recommendations about current practices should be considered in this context and await empirical support from future studies. Second, the findings described may be specific to the period during which the survey was carried out. The COVID-19 pandemic has served as a catalyst for numerous positive changes in psychology practice, including the issuing of emergency licensure to facilitate out-of-state access to care and the relaxing of restrictions around insurance reimbursement for telehealth services. Many survey respondents did, however, voice concerns about the potential for future contraction of these changes and a high degree of uncertainty about the future of telehealth. Third, respondents predominately represented cardiac neurodevelopmental programmes located in the Northeastern region of the United States. Only four of the participating centres were located in the Western region of the United States and only one programme in Canada participated, limiting the capacity to generalise findings to other countries and health systems. Fourth, while the survey response rate was relatively high (71.4%) and robust in the midst of a pandemic, a notable proportion of Cardiac Neurodevelopmental Outcome Collaborative sites did not take part, potentially due to the rapid changes occurring in the clinical setting limiting time and capacity for survey engagement. It is possible, therefore, that the sample may over-represent sites with greater resources or more established cardiac neurodevelopmental follow-up programmes.

Future directions and recommendations

Across cardiac neurodevelopmental programmes, interest in and questions regarding telehealth are currently ubiquitous and the speed at which practices are adapting outstrips the ability to make scientifically supported recommendations.^{32–35} Collaborative learning, opportunities for research and quality improvement projects, and knowledge dissemination in real-time are critical to ensuring we can rapidly respond to changing circumstances in the future. Research is needed to guide evidence-based recommendations regarding the practical administration of standardised psychological and neurodevelopmental assessments with children via telehealth. Studies are also needed to assess the validity and reliability of neurodevelopmental evaluation in the home via telehealth, including how results compare across settings (i.e., telehealth vs. in-person evaluation). Such studies need to take into consideration the social and psychological effects of the pandemic, changes to the school environment and potential effects on academic and cognitive development, patient and family risk and resilience factors, and variations associated with neurodevelopmental programme characteristics. Collection of data on neurodevelopmental outcomes, and on the validity and reliability of telehealth-based neurodevelopmental services could bolster advocacy efforts to increase insurance authorisation and reimbursement, and expand waivers

for out-of-state licensing requirements for telehealth psychology services. While offering neurodevelopmental services via telehealth could improve access to care and broaden services in resource-limited settings, investigation into the balance between risks and benefits and reimbursement rates of telehealth for families and providers are needed. Mixed methods studies, combining qualitative and quantitative methodologies, should explore patient, family, and provider satisfaction with different approaches to cardiac neurodevelopmental care. In addition, multi-centre longitudinal studies should examine how the implementation of telehealth for neurodevelopmental screening and evaluation influences the total number of patients who access services, the percentage of at-risk individuals reached, the number of referrals for additional services or testing, as well as disparities in care and health outcomes.

Conclusions

The COVID-19 pandemic challenged institutions to rapidly transition to telehealth, and it is clear there is still much to learn to overcome challenges and leverage the progress made. Telehealth has the potential to augment the delivery of neurodevelopmental care for children and young people with CHD and other medical conditions; however, further study is required to broaden the evidence base and strengthen practice. Our survey showed that the implementation of telehealth-based neurodevelopmental services has presented novel challenges for providers and institutions in the areas of clinical practice, technology requirements, patient and family access to care, service reimbursement, and outcomes measurement. Despite these challenges, we found that most cardiac neurodevelopmental programmes we surveyed had pivoted to delivering at least some neurodevelopmental services via telehealth in response to COVID-19 and many of these sites expressed a strong interest in receiving additional training and resources or sharing their successes with others. We envisage that the Cardiac Neurodevelopmental Outcome Collaborative will play a role in guiding providers and institutions as they plan and adapt to new telehealth-based neurodevelopmental services. This coordinated effort across institutions will allow for an evidence-based, efficient, and consistent approach to the care of individuals with CHD and other medical conditions.

Supplementary material. To view supplementary material for this article, please visit <https://doi.org/10.1017/S1047951122000579>

Acknowledgements. We gratefully acknowledge our colleagues and fellow providers from across North America, for their thoughtful responses to the survey, as well as the research assistance provided by Meghan Ford, Jennifer Hembree, Nicola Porter, Diya Sanghavi, and Jessica Cowin. We also thank the Cardiac Neurodevelopmental Outcome Collaborative Publications Committee, for insightful feedback on an earlier version of this manuscript.

Financial support. Nadine Kasparian is the recipient of a National Heart Foundation of Australia Future Leader Fellowship (101229) and support from the Heart Institute Research Core at Cincinnati Children's Hospital.

Conflicts of interest. The authors have no potential, perceived, or real conflicts of interest to declare. The first draft of the manuscript was written by Nadine Kasparian, Dawn Ilardi, Anjali Sadhwani and Renee Sananes, and all authors contributed to manuscript review and revision. No honorarium, grant, or other form of payment was given to any author to produce this manuscript.

References

- Marino BS, Lipkin PH, Newburger JW, et al. Neurodevelopmental outcomes in children with congenital heart disease: evaluation and management. A scientific statement from the American Heart Association. *Circulation* 2012; 126: 1143–1172.
- Marino BS, Sood E, Cassidy AR, et al. The origins and development of the cardiac neurodevelopment outcome collaborative: creating innovative clinical, quality improvement, and research opportunities. *Cardiol Young* 2020; 30: 1597–1602.
- Ware J, Butcher JL, Latal B, et al. Neurodevelopmental evaluation strategies for children with congenital heart disease aged birth through 5 years: recommendations from the cardiac neurodevelopmental outcome collaborative. *Cardiol Young* 2020; 30: 1609–1622.
- Ilardi D, Sanz JH, Cassidy AR, et al. Neurodevelopmental evaluation for school-age children with congenital heart disease: recommendations from the cardiac neurodevelopmental outcome collaborative. *Cardiol Young* 2020; 30: 1623–1636.
- Locco EC, Yu S, Donohue J, et al. Prevalence and risk factors associated with non-attendance in neurodevelopmental follow-up clinic among infants with CHD. *Cardiol Young* 2018; 28: 554–560.
- Glotzbach KL, Ward JJ, Marietta J, et al. The benefits and bias in neurodevelopmental evaluation for children with congenital heart disease. *Pediatr Cardiol* 2020; 41: 327–333.
- Federation of State Medical Boards. U.S. States and Territories Modifying Licensure Requirements for Physicians in Response to COVID-19, 2021. Retrieved April 1, 2021, from <https://www.fsmb.org/siteassets/advocacy/pdf/state-emergency-declarations-licensure-requirements-covid-19.pdf>
- Federation of State Medical Boards. U.S. States and Territories Modifying Requirements for Telehealth in Response to COVID-19, 2021. Retrieved April 1, 2021, from <https://www.fsmb.org/siteassets/advocacy/pdf/states-waiving-licensure-requirements-for-telehealth-in-response-to-covid-19.pdf>
- Center for Connected Health Policy. Retrieved April 1, 2021, from <https://www.cchpca.org/covid-19-related-state-actions>
- Hirko KA, Kerver JM, Ford S, et al. Telehealth in response to the COVID-19 pandemic: implications for rural health disparities. *J Am Med Inform Assoc* 2020; 27: 1816–1818.
- Chunara R, Zhao Y, Chen J, et al. Telemedicine and healthcare disparities: a cohort study in a large healthcare system in New York City during COVID-19. *J Am Med Inform Assoc* 2021; 28: 33–41.
- Curfman AL, Hackell JM, Herendeen NE, et al. Telehealth: improving access to and quality of pediatric health care. *Pediatrics* 2021; 148: e2021053129.
- Hodge MA, Sutherland R, Jeng K, et al. Agreement between telehealth and face-to-face assessment of intellectual ability in children with specific learning disorder. *J Telemed Telecare* 2019; 25: 431–437.
- Hodge MA, Sutherland R, Jeng K, et al. Literacy assessment via telepractice is comparable to face-to-face assessment in children with reading difficulties living in rural Australia. *Telemed J E Health* 2019; 25: 279–287.
- Harder L, Hernandez A, Hague C, et al. Home-based pediatric teleneuropsychology: a validation study. *Arch Clin Neuropsychol* 2020; 35: 1266–1275.
- Ransom DM, Butt SM, DiVirgilio EK, et al. Pediatric teleneuropsychology: feasibility and recommendations. *Arch Clin Neuropsychol* 2020; 35: 1204–1214.
- Salinas CM, Bordes Edgar V, Berrios Siervo G, Bender HA. Transforming pediatric neuropsychology through video-based teleneuropsychology: an innovative private practice model pre-COVID-19. *Arch Clin Neuropsychol* 2020; 35: 1189–1195.
- Peterson RK, Ludwig NN, Jashar DT. A case series illustrating the implementation of a novel tele-neuropsychology service model during COVID-19 for children with complex medical and neurodevelopmental conditions: a companion to Pritchard et al., 2020. *Clin Neuropsychol* 2021; 35: 99–114.
- Williams TS, McDonald KP, Roberts SD, et al. In their own words: developing the Parent Experiences Questionnaire (PEQ) following neonatal brain injury using participatory design. *Brain Inj* 2018; 32: 1386–1396.
- Wade SL, Oberjohn K, Burkhardt A, Greenberg I. Feasibility and preliminary efficacy of a web-based parenting skills program for young children with traumatic brain injury. *J Head Trauma Rehabil* 2009; 24: 239–247.
- Wade SL, Gies LM, Fisher AP, et al. Telepsychotherapy with children and families: lessons gleaned from two decades of translational research. *J Psychother Integr* 2020; 30: 332–347.
- Wade SL, Cassidy AE, Shultz EL, et al. Randomized clinical trial of online parent training for behavior problems after early brain injury. *J Am Acad Child Adolesc Psychiatry* 2017; 56: 930–939.
- Comer JS, Furr JM, Miguel EM, et al. Remotely delivering real-time parent training to the home: an initial randomized trial of internet-delivered parent-child interaction therapy (I-PCIT). *J Consult Clin Psychol* 2017; 85: 909–917.
- Gloff NE, LeNoue SR, Novins DK, Myers K. Telemental health for children and adolescents. *Int Rev Psychiatry* 2015; 27: 513–524.
- Osenbach JE, O'Brien KM, Mishkind M, Smolenski DK. Synchronous telehealth technologies in psychotherapy for depression: a meta-analysis. *Depress Anxiety* 2013; 30: 1058–1067.
- Thongseiratch T, Leijten P, Melendez-Torres GJ. Online parent programs for children's behavioral problems: a meta-analytic review. *Eur Child Adolesc Psychiatry* 2020; 29: 1555–1568.
- Ingersoll B, Berger NJ. Parent engagement with a telehealth-based parent-mediated intervention program for children with autism spectrum disorders: predictors of program use and parent outcomes. *J Med Internet Res* 2015; 17: e227.
- Ingersoll B, Shannon K, Berger N, Pickard K, Holtz B. Self-directed telehealth parent-mediated intervention for children with autism spectrum disorder: examination of the potential reach and utilization in community settings. *J Med Internet Res* 2017; 19: e248.
- Jenkins-Guarnieri MA, Pruitt LD, Luxton DD, Johnson K. Patient perceptions of telemental health: systematic review of direct comparisons to in-person psychotherapeutic treatments. *Telemed J E Health* 2015; 21: 652–660.
- Antonini TN, Raj SP, Oberjohn KS, Wade SL. An online positive parenting skills programme for paediatric traumatic brain injury: feasibility and parental satisfaction. *J Telemed Telecare* 2012; 18: 333–338.
- Cox SM, Butcher JL, Sadhwani A, et al. Integrating telehealth into neurodevelopmental assessment: a model from the Cardiac Neurodevelopmental Outcome Collaborative. *J Pediatr Psychol* 2022, jsac003. DOI [10.1093/jpepsy/jsac003](https://doi.org/10.1093/jpepsy/jsac003).
- Taddei M, Bulgheroni S. Facing the real time challenges of the COVID-19 emergency for child neuropsychology service in Milan. *Res Dev Disabil* 2020; 107: 103786.
- Loman M, Vogt E, Miller L, et al. How to “operate a pediatric neuropsychology practice during the COVID-19 pandemic: real tips from one practice’s experience. *Child Neuropsychol* 2021; 27: 251–279.
- Hewitt KC, Rodgin S, Loring DW, Pritchard AE, Jacobson LA. Transitioning to telehealth neuropsychology service: considerations across adult and pediatric care settings. *Clin Neuropsychol* 2020; 34: 7–8.
- Koterba CH, Baum KT, Hamner T, et al. COVID-19 issues related to pediatric neuropsychology and inpatient rehabilitation: challenges to usual care and solutions during the pandemic. *Clin Neuropsychol* 2020; 34: 1380–1394.