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Paediatric cardiologist adherence to American Heart Association neurodevelopmental recommendations for CHD patients

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Original Article

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Abstract

A 2012 American Heart Association statement concluded that children with CHD are at an increased risk for neurodevelopmental delays. Routine surveillance and evaluation throughout childhood are recommended. To assess paediatric cardiologist compliance with American Heart Association guidelines and developmental referral practices, a survey was distributed to paediatric cardiologists nationwide (n = 129). The majority of participants (69%) stated they were somewhat familiar or not familiar with the American Heart Association statement and were concerned about patients not being properly referred to specialists for developmental evaluation. Forty paediatric cardiologists (31%) indicated that their institution did not have a neurodevelopmental cardiology programme. Of these, 25% indicated they generally did not refer CHD patients for neurodevelopmental evaluation, 45% performed surveillance and referred if warranted, and 30% generally referred all patients for surveillance. Lastly, 43% of paediatric cardiologists did not feel responsible for developmental surveillance, and 11% did not feel responsible for referrals. To ensure all children with CHD are appropriately screened and referred, paediatricians and cardiologists must work together to address differing impressions of accountability for surveillance and screening of children with CHD.

CHD has a prevalence of 4–12 per 1000 live births, with more than 30% requiring palliative or corrective surgery in early life.[1] Children with CHD are at an increased risk for neurodevelopmental morbidity.[2] Developmental issues in this population are characterised by impairments in cognition as well as social, motor, and communication skills. As a result, children with CHD are more likely to perform poorly in school and in the workforce, which may limit their quality of life. For these reasons, many children with CHD benefit from therapy and school services, including tutoring, special education, physical therapy, speech therapy, and occupational therapy.[3]

In recent decades, there has been a growing awareness and recognition of the abnormal neurodevelopmental outcomes in children with repaired CHD, especially as more infants with CHD are surviving to adolescence and adulthood than ever before.[4] In 2012, the American Heart Association released a statement titled "Neurodevelopmental Outcomes in Children with Congenital Heart Disease: Evaluation and Management."[5] According to these recommendations, children with CHD should receive routine neurodevelopmental screening. If the patient is identified as low-risk, general developmental surveillance and screening should be continued. However, if high-risk criteria are met, formal neurodevelopmental evaluation is recommended. In addition, all high-risk CHD patients and low-risk patients who do not pass routine screening should be referred for early intervention programmes, such as physical therapy or childhood special education. Table 1 summarises the specific recommendations the American Heart Association made in these guidelines.

According to the United States Department of Health and Human Services (2010), children with developmental delays require continuous holistic care through shared partnership and management among the primary care provider and subspecialists, including paediatric cardiologists.[6] As a cohesive medical team, implementation and coordination of an individualised care plan with specification of each professional's role are necessary to ensure that the special needs of these children are being met. Despite these existing guidelines, however, children with CHD may not be referred for neurodevelopmental evaluation and/or early intervention in a timely and efficient manner for a variety of reasons. Ambiguity among medical care providers may exist regarding primary responsibility for developmental surveillance and appropriate

Table 1. 2012 American Heart Association guidelines, "Neurodevelopmental Outcomes in Children with Congenital Heart Disease: Evaluation and Management," with recommendations.[5]

2012 American Heart Association Recommendations

1. The medical home model of care may be effective and beneficial in the management of patients with chronic conditions such as CHD
2. Existing AAP guidelines for surveillance, screening, evaluation, and intervention should be adhered to, with the following additions for patients with CHD:
   a. The following groups should be considered at high risk for DD
      i. Neonates or infants requiring open heart surgery (cyanotic and acyanotic types).
      ii. Children with other cyanotic heart lesions not requiring open heart surgery in the neonatal or infant period.
      iii. Children with any combination of CHD and other comorbidities.
      iv. Other conditions determined at the discretion of the medical home providers.
   b. Risk stratification of patients with CHD into low and high-risk categories for DD at every medical home visit can be useful and beneficial.
   c. Behavioral screening of patients with CHD undergoing developmental screening based on age (9, 18, 30, 48 months) or concerns detected in surveillance (early childhood through adolescence) can be useful and beneficial.
3. For patients with CHD stratified as being at high risk for DD, the following strategies can be useful and beneficial:
   a. Referral to formal developmental and medical evaluation can be useful and beneficial.
   b. Referral to early intervention services or early childhood special education services before confirmation of a specific developmental diagnosis can be useful and beneficial.
   c. Periodic reevaluations for DDs and developmental delays at 12 to 24 months, 3 to 5 years, and 11 to 12 years of age can be useful and beneficial.
   d. Referral of young adults for higher education and/or vocational counselling can be useful and beneficial.

referral of CHD patients. For example, paediatric cardiologists may expect primary care clinicians to manage developmental surveillance and referral. Unfamiliarity with these American Heart Association recommendations by either paediatric cardiologists or primary care physicians in the United States may result in CHD patients not receiving services that they would be entitled to and benefit from. The objective of this study was to gauge the familiarity and adherence of paediatric cardiologists to American Heart Association guidelines relating to CHD. Specifically, developmental referral and surveillance practices, as well as sense of responsibility for these actions, were explored.

Materials and methods

Paediatric cardiologists across the United States were recruited via e-mail to participate in an anonymous, voluntary, online survey. E-mail addresses of paediatric cardiologists were obtained from Medical Marketing Services, Inc., a company that provides a direct mail marketing service to deliver messages to healthcare professionals. The e-mail explained the general nature of the survey, mentioned the estimated time commitment (5 minutes), and provided the link to the anonymous questionnaire, as well as contact information to the authors of the study for any questions or concerns. Participants were directed to the questionnaire on SurveyMonkey, an online survey website. Participants did not receive an incentive for completing the survey. This study was approved by the Northwell Health Institutional Review Board (IRB Number 15-281).

Cohort identification

To be eligible to complete the survey, participants had to be board certified or eligible in paediatric cardiology. This included physicians with advanced fellowship training in paediatric cardiology, which includes subspeciality training such as cardiac intensive care, interventional cardiology, and advanced imaging. Current paediatric cardiology fellows who were not board eligible were excluded from the survey. Fellows who were board certified in paediatric cardiology and were currently completing further training were included. This was enforced by addressing e-mails to eligible physicians only. In addition, participants could not be retired from practice.

Measures

The anonymous survey had four parts:

Part 1: Participants were asked about their practice setting (Urban, Suburban, Rural), the number of years they had been in practice (<5 years, 5–15 years, 16–30 years, >30 years), their weekly teaching responsibilities (None, 1–3 hours, 4–6 hours, 7–12 hours, >12 hours), and the number of outpatients appointments per week (None, 1–10 patients, 11–30 patients, 31–50 patients, >50 patients).

Part 2: Each respondent was asked whether their practice had a neurodevelopmental follow-up clinic for CHD patients at high risk for developmental disorders or delays, and those who answered "Yes" were asked about the ages their clinics serve as well as the director(s)'s specialty (Developmental & Behavioral Paediatrician, Child Neurologist, Child Psychologist, Primary Care Physician, Paediatric Cardiologist). To assess the referral practices of those who did not have an affiliated neurodevelopmental follow-up clinic, those who expressed that their practice did not have a neurodevelopmental clinic were asked whether they 1) do not refer or surveil their patients, 2) perform surveillance and refer their patients when warranted, or 3) refer all patients for surveillance. Participants who indicated that they perform initial surveillance or refer for surveillance were asked to whom they refer if they suspect the patient to be developmentally delayed. Participants who indicated that they neither surveil nor refer for surveillance were prompted to indicate reasons.

All participants, regardless of whether or not their practice had a neurodevelopmental follow-up clinic, were then asked questions about their personal practice of the American Heart Association recommendations outlined in Table 1. This included the frequency at which they refer patients who require or who underwent significant cardiac surgery for post-operative inpatient/outpatient physical therapy (Never, Rarely, Sometimes, Often or Very Often, Always or Almost Always). In addition, all participants stated the extent to which they refer infants who required open heart surgery and children with other cyanotic heart lesions who did not undergo open heart surgery as a neonate/infant for evaluation of developmental disorder, disability, or delay (Never, Rarely, Sometimes, Often or Very Often, Always or Almost Always). The distinction between infants and children was based on the high-risk categorisation in accordance with the American Heart Association guidelines, and questions regarding referral patterns were not limited to these two categories.

Part 3: Each participant was asked who they believe has the primary responsibility for conducting developmental surveillance (Primary Care Physician, Paediatric Cardiologist, Paediatric Neurologist or Developmental & Behavioral Paediatrician, Cardiac Neurodevelopmental Follow-up Clinic, Other) and

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whether they feel that they themselves are responsible for conducting developmental surveillance and/or making developmental evaluation referrals for patients with CHD (No = 0, Yes = 1). Participants then stated their familiarity with the American Heart Association guidelines (Not Familiar, Somewhat Familiar, Very Familiar) and the extent to which they were concerned about patients with CHD not being properly referred for developmental evaluation (Not at all concerned, Somewhat concerned, Moderately Concerned, Very Concerned). Familiarity and concern level were converted to a numeric scale with the lowest option given a score of 0.

Part 4: Participants were asked to complete a brief, non-identifiable demographics section regarding their gender and race/ethnicity. Demographics are presented as a percentage of the sample. Lastly, participants were given the opportunity to access the American Heart Association guidelines to gain more information on neurodevelopmental assessment and outcomes for children with CHD.

Analysis

Most results of this study were reported as percentages based on the responses to the questions asked in Parts 1 to 4 of this survey, as outlined in the Measures section above. It was hypothesised that those with more years in practice, who have larger patient volume, who teach more, who are more familiar with American Heart Association guidelines, and/or those who feel a sense of responsibility to make referrals or surveil were more likely to make referrals for neurodevelopmental evaluation and services such as physical therapy. This was assessed using linear regressions for each of seven variables (numbers of years in practice, number of outpatients seen in a typical week, number of hours of teaching in a typical week, concern level about patient referral, familiarity with American Heart Association guidelines, sense of responsibility for conducting surveillance, and sense of responsibility for making referrals) as the independent variables and referral frequency for both neurodevelopmental evaluation (infants and children) and physical therapy (inpatient and outpatient) as the dependent variables. A subset analysis on providers without an in-house neurodevelopmental clinic was also conducted. Statistical significance is determined at $p < 0.05$. Statistical analyses were conducted using the *R Environment for Statistical Computing*.[7]

Results

Of the 1645 e-mails sent, a total of 142 participants responded to the survey request, of whom 129 were included in the data analysis and 13 were excluded for incomplete responses. The cohort was 36% female and included practitioners from 37 states in the United States. Fifty-three per cent of participants had completed advanced fellowship training in paediatric cardiology (i.e. cardiac critical care, interventional cardiology, and advanced imaging). Overall, 72% of participants worked in an urban setting, 80% had been in practice for at least 5 years, 30% spent at least 4 hours teaching or supervising paediatric cardiology fellows, and 85% belonged to a hospital-based practice. In a typical week, 24% of participants see 10 or fewer outpatients, 50 % 11–30 outpatients, and 26% more than 30 outpatients.

Sixty-nine per cent of paediatric cardiologists had a neurodevelopmental cardiac follow-up programme. The clinics served different ages, which may reflect other programmes such as neonatal ICU follow-up that transition into neurodevelopmental cardiac follow-up. In addition, 88% of programmes included children requiring open heart surgery, 60% included children with cyanotic lesions who did not undergo open heart surgery as an infant/neonate, and 25% included children with acyanotic lesions not requiring open heart surgery. A majority of the programmes had a developmental paediatrician (35%) or a paediatric cardiologist (35%) as a director.

Forty paediatric cardiologists (31%) stated their institution did not have a neurodevelopmental follow-up clinic. Of these, 25% indicated they generally did not refer CHD patients for neurodevelopmental follow-up (Group 1), 45% performed neurodevelopmental surveillance and referred to a specialist/early intervention if warranted (Group 2), and 30% generally referred all CHD patients for surveillance (Group 3). Of Groups 2 and 3, 48% referred to a "primary care physician," 28% to a "developmental paediatrician/neurologist," and 17% to "early intervention." With regard to the reasons why Group 1 did not make neurodevelopmental follow-up referrals, 50% stated that they believe the primary care physician is responsible for conducting developmental surveillance and making neurodevelopmental referrals was not a part of their paediatric cardiology training.

Across all respondents (with or without a neurodevelopmental follow-up clinic), the frequencies at which paediatric cardiologists refer infants requiring open heart surgery and cyanotic children who did not undergo open heart surgery as an infant/neonate to neurodevelopmental evaluation vary widely among care providers. The same holds true for referral patterns to post-operative physical therapy (Table 2). Approximately 31% of paediatric cardiologists reported being very familiar with the American Heart Association guidelines, 54% of participants stated they were "somewhat familiar," and 15% were "not familiar" with the American Heart Association statement. In addition, 55% of participants reported that they were either "moderately concerned" or "very concerned" about their patients with CHD not being properly referred for possible developmental delays. Forty-three per cent of paediatric cardiologists in the study did not feel responsible for neurodevelopmental surveillance, and 11% did not feel responsible for neurodevelopmental referrals. In terms of whom participants believe is responsible for referral, 59% reported primary care physicians, 24% neurodevelopmental follow-up clinics, 10% paediatric cardiologists, and 7% paediatric neurologists/developmental paediatricians.

Table 3 presents the relationships between referral frequencies and the seven relevant variables as determined by univariate linear regressions. Regarding referral practices, the number of hours spent teaching in a typical week and familiarity with the American Heart Association guidelines were both significantly associated with higher rates of referral of both infants requiring open heart surgery and children who did not require open heart surgery as an infant ($p < 0.05$ and $p < 0.001$, respectively). The sense of responsibility for referral for evaluation was only significantly associated with increased referral of infants requiring open heart surgery ($p < 0.05$). Regarding referral to inpatient and outpatient physical therapy, the number of years in practice was negatively associated with referral to inpatient therapy ($\beta = -0.26$, $p < 0.05$), while number of hours teaching in a typical week was positively associated with both inpatient ($\beta = 0.27$, $p < 0.01$) and outpatient physical therapy referral ($\beta = 0.17$, $p < 0.05$).

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Table 2. Participant reported referral frequencies for neurodevelopmental evaluation and post-operative physical therapy, % (n)

Referral frequency for evaluation of neurodevelopmental disorder, disability, or delay[a]					
	Never	**Rarely (1–20%)**	**Sometimes (21–50%)**	**Often or Very Often (51–80%)**	**Always or Almost Always (81–100%)**
Infants (less than 12 months) requiring open heart surgery	0% (0)	9.2% (11)	20.8% (25)	11.7% (14)	58.3% (70)
Children (over 12 months) who did NOT require open heart surgery as an infant	0.8% (1)	27.1% (32)	27.5% (33)	20.8% (25)	22.5% (27)
Referral frequency for post-operative physical therapy for patients who require or had significant cardiac surgery[b]					
	Never	**Rarely (1–20%)**	**Sometimes (21–50%)**	**Often or Very Often (51–80%)**	**Always or Almost Always (81–100%)**
Inpatient physical therapy	10.4% (13)	22.4% (28)	18.4% (23)	23.2% (29)	25.6% (32)
Outpatient physical therapy	4.8% (6)	36.0% (45)	27.2% (34)	22.4% (28)	9.6% (12)

[a]Participants were asked "How often would you or your staff refer infants requiring open heart surgery and children who did NOT require open heart surgery as an infant for evaluation of developmental disorder, disability, or delay?".
[b]Participants were asked "For patients who require or had significant cardiac surgery, how often do you or your staff refer patients post-operatively for inpatient and outpatient physical therapy?".

Table 3. Results of linear regressions performed between referral frequencies (neurodevelopmental evaluation and post-operative physical therapy) and seven relevant variables

Referral frequency for evaluation of neurodevelopmental disorder, disability, or delay				
	Infants (less than 12 months) requiring open heart surgery		**Children (over 12 months) who did NOT require open heart surgery as an infant**	
# of years in practice	$\beta = -0.14$	$p = 0.19$	$\beta = -0.14$	$p = 0.06$
# of outpatients in a typical week	$\beta = 0.04$	$p = 0.75$	$\beta = 0.12$	$p = 0.10$
# of hours of teaching in a typical week	$\beta = 0.16$	$p = 0.04$	$\beta = 0.22$	$p = 0.03$
Concern about patient referral	$\beta = 0.59$	$p = 0.39$	$\beta = 0.19$	$p = 0.018$
Familiarity with AHA guidelines	$\beta = 0.09$	$p < 0.001$	$\beta = 0.18$	$p < 0.001$
Sense of responsibility for referral for evaluation	$\beta = 0.72$	$p = 0.02$	$\beta = 0.03$	$p = 0.20$
Sense of responsibility for surveillance for evaluation	$\beta = -0.09$	$p = 0.66$	$\beta = -0.01$	$p = 0.72$
Referral frequency for post-operative physical therapy for patients who require or had significant cardiac surgery				
	Inpatient physical therapy		**Outpatient physical therapy**	
# of years in practice	$\beta = -0.26$	$p = 0.04$	$\beta = -0.14$	$p = 0.19$
# of hours of teaching in a typical week	$\beta = 0.27$	$p = 0.006$	$\beta = 0.17$	$p = 0.03$
Concern about patient referral	$\beta = 0.10$	$p = 0.09$	$\beta = 0.23$	$p = 0.43$
Familiarity with AHA guidelines	$\beta = 0.22$	$p = 0.60$	$\beta = 0.08$	$p = 0.12$
Sense of responsibility for referral for evaluation	$\beta = 0.42$	$p = 0.05$	$\beta = 0.62$	$p = 0.30$
Sense of responsibility for surveillance for evaluation	$\beta = 0.23$	$p = 0.79$	$\beta = -0.05$	$p = 0.36$

Discussion

Our study revealed that a majority of respondents worked at a centre with a formal neurodevelopmental cardiac follow-up programme in place for treating patients of varying ages. The participating clinics were primarily run by paediatric cardiologists or developmental paediatricians. These programmes have the potential to positively impact the patients and families participating in them.[8] In a study on the risk and prevalence of developmental issues in children with CHD, many of the delays found in the sample were subtle and others only emerged over time.[9] Thus, it would have been difficult to detect these problems if formal evaluation with regular follow-ups did not take place, highlighting the importance of these clinics and longitudinal developmental evaluation. It is imperative for all clinicians treating patients with CHD to

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support and encourage developmental follow-up as it can help identify patients with subtle or impending issues. Because some developmental issues may only emerge as a child ages, long-term problems can be mitigated through developmental assessment that monitors patients over time and provides services when necessary.[10]

Of those who did not have a neurodevelopmental follow-up clinic, less than half reported conducting any developmental surveillance, with the remainder either referring all CHD patients for surveillance or not making referrals at all. One of the most cited explanations by participants who did not refer was that they believe primary care physicians are primarily responsible for conducting developmental surveillance. Consistent with these results, our analysis also demonstrated that approximately half of participants who made referrals for developmental surveillance did so to primary care physicians. While the American Academy of Pediatrics recommends that primary care physicians incorporate developmental surveillance into well-child preventive care visits at 9, 18, and 30 months, paediatricians are not necessarily adhering to these guidelines, and thus, the developmental issues of CHD patients may go undetected.[11] In addition, these guidelines only suggest surveillance up to 30 months (2.5 years). Therefore, developmental concerns among CHD patients that arise after this age may go unidentified by primary care physicians. Furthermore, compared to paediatric cardiologists, primary care physicians may not necessarily be as sensitive to developmental issues that are commonly seen in the paediatric CHD population.

Concerns exist regarding the underutilisation of developmental surveillance testing by primary care physicians for paediatric CHD patients. Recent studies have indicated that developmental screening by paediatricians has increased over the past two decades.[12,13] Despite improved screening practices, less than half of paediatricians are developmentally screening patients under 36 months of age.[12] This statistic is particularly concerning given the number of paediatric cardiologists from our sample who believe the responsibility of developmental surveillance and referral lies with primary care physicians. However, paediatricians may also face barriers to screening, including time limitations and inadequate reimbursement, further complicating who holds the responsibility.[13] The COVID-19 pandemic has potentially created even more barriers to developmental screening, with limited in-person patient visits. In addition, paediatricians may not be as familiar with the long-term neurodevelopmental implications of CHD surgery and ICU stay. It is imperative that paediatric cardiologists are aware of these findings before placing the onus of developmental surveillance for children with CHD solely on primary care physicians. Collaboration is necessary among paediatric cardiologists and paediatricians to ensure CHD patients receive proper developmental evaluation and services.

Over two-thirds of our sample of paediatric cardiologists were not or were only somewhat familiar with the American Heart Association guidelines. The reason for this lack of familiarity is complex and could be attributed to multiple causes, such as neurodevelopment evaluation not being integrated into paediatric cardiology training programmes. Additionally, over half of respondents expressed being at least moderately concerned about patients with CHD not being properly referred for detection of developmental delays. While most participants reported feeling responsible for developmental referrals, almost half expressed that they did not feel responsible for developmental surveillance. Frequency of neurodevelopmental evaluation referral of both infants and children was significantly higher when participants were more familiar with the American Heart Association guidelines and had more teaching responsibilities. Teaching activities often include working with fellows in training and/or being involved in a university programme. It is possible that current trainees in academic centres are more likely to follow current guidelines. Given these findings, it is vital for paediatric cardiologists to become more familiar with the guidelines, as it may increase the number of CHD patients they refer to promote the best developmental outcome.

Our results also suggest children with CHD are less frequently referred for post-operative physical therapy than current guideline recommendations, with more referrals being associated with greater teaching responsibilities among paediatric cardiologists. While physical therapy is a standard post-operative care step for adult patients recovering from open heart surgery and has been shown to be beneficial for their recovery,[14,15] this practice seems less common for paediatric CHD patients. It is well-known that patients with CHD experience tiredness, fatigue, loss of energy, and post-operative pulmonary issues, which can be improved with increased physical fitness.[16,17] While there has been limited research on the impact of post-operative physical therapy on children after significant cardiac surgery, one study did find that physical therapy increased peak oxygen uptake and physical endurance for children with CHD.[18] The results suggested that aerobic exercise positively impacted children with CHD, but more research in this field is necessary to determine whether physical therapy is useful to children with CHD specifically following cardiac surgery. While the American Heart Association statement did not contain specific guidelines for physical therapy referrals, it did highlight studies that have shown that persistent impairments in fine and gross motor skills frequently occur among children with complex CHD following surgery. The statement also cited research that indicated that these children were six times more likely to experience motor problems than healthy control subjects.[19–21] In addition, the guidelines emphasise that physical therapy can be beneficial for children with motor issues. If future studies confirm its benefits, physical therapy following cardiac surgery should be a standard of care for paediatric CHD patients.

This study must be interpreted within the context of its limitations. Our sample of paediatric cardiologists was limited in size and thus may not reflect the current paediatric cardiology workforce, as respondents represent 5.6% of the paediatric cardiologist population. Larger studies are recommended. There may also be survey bias regarding the demographics and personal practices of the physicians who had the time and/or interest to opt-in to participating in this survey. Moreover, over 80% of survey respondents were hospital-based, suggesting that they likely work in academic settings that have systems for referrals or neurodevelopmental follow-up clinics. In addition, it is possible that survey respondents came from the same programme. An additional limitation is that participants may have overestimated their levels of referral and surveillance. Future studies should examine this topic. Lastly, among paediatric cardiologists who indicated that they practiced at a neurodevelopmental follow-up clinic, further questions regarding their referral practices were not included in the survey. Despite these limitations, our sample included physicians from a multitude of states, representing a variety of clinical settings and training levels contributing to the strength of this study. In addition, Medical Marketing Services, which was used to distribute the survey, has been successfully utilised in previous studies of a large sample of physicians.[22–23]

We encourage the American Academy of Pediatrics to incorporate developmental surveillance and screening recommendations

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specifically for children with CHD into their guidelines in order to aid clinicians in making comprehensive assessments. Lastly, more research on the benefits of post-operative physical therapy would be helpful in determining its importance for paediatric CHD patients following cardiac surgery.

Conclusion

The majority of paediatric cardiologists in our sample had a neurodevelopmental follow-up programme in place for developmental surveillance and evaluation of CHD patients. However, previous research has shown that the presence of an ND programme does not necessarily mean that there is ongoing surveillance of all individuals and equitable follow-up.[24] Our results revealed a disparity among physicians who did not have an established follow-up programme, with a quarter referring none of their CHD patients for any developmental screening. Although many participants were at least moderately concerned about CHD patients not being properly referred, over half of the sample was not very familiar with the American Heart Association guidelines that outline proper referral practices. Additionally, while the majority of participants felt responsible for developmental referrals, a significantly lower percentage felt responsible for surveillance. Early and recurring surveillance may bring long-term benefits to patients impacted by CHD, and awareness of the American Heart Association guidelines is a necessary step toward making referrals standard practice.

Reduction in mortality is no longer the only goal in care of children with CHD; advances in cardiac care have allowed children to not only survive, but live long, fulfilling lives. The measured outcome is by the quality of life that is preserved. There is mounting evidence about long-term adverse neurodevelopmental outcomes for children undergoing CHD surgical repair early in childhood. An interdisciplinary effort among cardiac surgeons, cardiologists, paediatricians, developmental & behavioural paediatricians, neurologists and parents, all working toward the goals of improving outcomes is required. Collaboration has always been instrumental to the advancement of paediatric cardiology, but a greater effort is needed in this domain. Paediatricians cannot forget that children with CHD who need surgical repair are at significant risk of neurodevelopmental issues and should be monitored closely and receive early intervention when indicated to maximise function. We recommend paediatric cardiologists become familiar with American Heart Association guidelines and, when caring for patients with CHD, share these recommendations with colleagues and primary care providers upon referral in order to meet the developmental needs of the paediatric CHD population.

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Conflicts of interest. None.

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