Cardiology in the Young

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Rate and setting of neurodevelopmental and psychosocial encounters for children with CHD

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Abstract

Background: In North America, less than 30% of children with complex CHD receive recommended follow-up for neurodevelopmental and psychosocial care. While rates of follow-up care at surgical centres have been described, little is known about similar services outside of surgical centres. *Methods:* This cohort study used Maine Health Data Organization's All Payer Claims Data from 2015 to 2019 to identify developmental and psychosocial-related encounters received by children 0–18 years of age with complex CHD. Encounters were classified as developmental, psychological, and neuropsychological testing, mental health assessment interventions, and health and behaviour assessments and interventions. We analysed the association of demographic and clinical characteristics of children and the receipt of any encounter. *Results:* Of 799 unique children with complex CHD (57% male, 56% Medicaid, and 64% rural), 185 (23%) had at least one developmental or psychosocial encounter. Only 13 children (1.6%) received such care at a surgical centre. Developmental testing took place at a mix of community clinics/private practices (39%), state-based programmes (31%), and hospital-affiliated clinics (28%) with most encounters billing Medicaid (86%). Health and behavioural assessments occurred exclusively at hospital-affiliated clinics, predominately with Medicaid claims (82%). Encounters for mental health interventions, however, occurred in mostly community clinics/private practices (80%) with the majority of encounters billing commercial insurance (64%). *Conclusion:* Children with complex CHD in Maine access developmental and psychosocial services in locations beyond surgical centres. To better support the neurodevelopmental outcomes of their patients, CHD centres should build partnerships with these external providers.

Introduction

Children with complex CHD are at increased risk for neurodevelopmental impairments including developmental delays, learning disorders, behavioural dysregulation, and deficits in executive function and social cognition.[1] Neurodevelopmental impairments now represent the most prevalent morbidity in CHD, with nearly two-thirds of individuals with certain CHD subtypes requiring special education or psychosocial services by adolescence.[2] In 2012, the American Heart Association and American Academy of Pediatrics first published guidelines (updated in 2024[3]) aimed at improving neurodevelopmental outcomes among children with CHD. The guidelines recommended that those at greatest risk (children with cyanotic CHD or who require surgery in the first year of life, referred to in this study as complex CHD) receive periodic developmental surveillance and evaluation by a multidisciplinary team with expertise in psychological, developmental, and medical evaluations.[4]

Since 2012, many cardiac surgical centres have developed cardiac neurodevelopmental follow-up programmes focusing on screening, surveillance, and neurodevelopmental assessments. However, due to differences in resources and infrastructure, cardiac neurodevelopmental programmes are highly variable in their staffing of different disciplines, their capacity to see infants and children of different ages, and their ability to follow-up with referrals to interventions and supportive therapies.[5] Despite neurodevelopmental follow-up efforts, few children with complex CHD receive care consistent with the current guidelines. In a recent analysis of 16 of the most highly resourced, large, cardiac neurodevelopmental programmes in North America, less than 30% of children with complex CHD attended their first recommended neurodevelopmental visit at 11–30 months of age at their surgical centre.[6] Single-center studies suggest that follow-up in older children, teenagers, and adults is even lower[7,8], which may be in part because most neurodevelopmental programmes are structured around care for infants and younger children.[5] Further, longer distance from a cardiac surgical centre is associated with lower rates of return for neurodevelopmental services.[6]

The studies above refer only to neurodevelopmental care received through cardiac neurodevelopmental programmes, but children with complex CHD may also receive neurodevelopmental screening and support through primary care offices, private mental health providers, school- or state-based programmes, or elsewhere. Families of children with CHD living in rural areas located far from neurodevelopmental programmes at cardiac surgical centres may be more likely to choose local options for neurodevelopmental care. Additional neurodevelopmental service locations could represent an underappreciated source of support for children with CHD and could provide collaboration opportunities for cardiac surgical centres to facilitate guideline-concordant neurodevelopmental follow-up in a patient-centered manner. However, the rate of neurodevelopmental encounters outside of cardiac surgical centres is poorly described. We therefore utilised the Maine Hospital Data Organization's All Payer Claims Data to describe all neurodevelopmental and psychosocial encounters among children with complex CHD in Maine, the U.S. state with the second highest percentage of residents living in rural areas.[9]

Materials and methods

Setting

Maine is a northeastern state with a population of 1.4 million, 40% of whom live in nonmetropolitan areas.[9] More than a quarter of the state's child population is located more than 20 miles (32 km) from any paediatric cardiologist.[10] Children with CHD in Maine are served primarily by two regional paediatric centres located in the state's two largest cities, Portland and Bangor. Congenital cardiac surgery is performed only in Portland and some children will cross state lines to reach other surgical centres, the closest of which is in Boston, Massachusetts.

Ethical review

This study was determined as exempt from IRB review according to federal regulations by the MaineHealth IRB (Study Number: 1983570-1).

Study design and population

We conducted a retrospective cohort study using the Maine Health Data Organization's All-Payer Claims Data, a repository of health care claims data for residents with health insurance in Maine. The dataset contains health care claims paid for Maine residents by insurance companies licenced in Maine with greater than $2,000,000 of adjusted premiums or claims processed per calendar year. It also includes Medicare claims paid for Maine residents and MaineCare (Maine Medicaid) claims.[11] Using data from 1/1/2015 through 12/31/2019, we identified all individuals (0–18 years old on 1/1/15) with a CHD diagnosis code indicative of surgery within the first year of life, a criterion which placed them at the highest risk for neurodevelopmental disabilities based on American Academy of Pediatrics/American Heart Association guidelines.[4,12]

Patient-level characteristics

For each child, we assessed the following characteristics on 1/1/2017 (mid-way through the study period): age, sex, insurance type (categorized as commercial with or without Medicaid, or Medicaid only), and residential ZIP code. From patients' ZIP codes, we determined rurality (defined as living in an area with a rural-urban commuting area code of 2–10),[13] Childhood Opportunity Index 2.0 index (normed by state),[15] and on-road driving distance from a child's home to the nearest regional paediatric centre (Bangor or Portland) and surgical centre (Portland or Boston). Age was dichotomised as 0–5 years and over 5 years old. Distances were dichotomised as greater or less than 100 km.

Neurodevelopmental services

For each child included in the analysis, we assessed the receipt of seven discrete neurodevelopmental services.

Developmental, psychological, and neuropsychological testing encounters involve administration, scoring, and interpretation of standardised tests with normative comparison groups.

1. Developmental Testing (Current Procedural Terminology codes 96,112, 96,111, 96,113) comprises a large category of tests (e.g., parent questionnaires, direct child interactive testing) that may have been conducted across multiple specialties (e.g,. psychologists, paediatricians)
2. Psychological Testing (96,130, 96,131, 96,101, 96,103) is performed by psychologists or neuropsychologists and often includes a half- or full-day of testing focused on a mental health concern.
3. Neuropsychological Testing (96,132, 96,133, 96,118, 96,119, 96,120) is conducted by neuropsychologists and typically focuses on potential complications related to a medical diagnosis and involves half- or full-day testing of the child as well as parent and teacher questionnaires.

Mental health encounters are provided by a mental health professional (e.g., licenced social worker, psychologist, psychiatrist) and require a mental health diagnosis code.

1. Mental Health Assessments (90,791) typically involve a clinical interview focused on emotional, behavioural, or social concerns of the family and may include assessment of developmental milestones.
2. Mental Health Interventions (90,832, 90,834, 90,837, 90,849, 90,853, 90,839, 90,847) typically address specific symptoms or difficulties related to emotional, behavioural, social, or family functioning.

Health and behaviour codes require a medical diagnosis.

1. Health & Behavior Assessments (96,150, 96,156, 96,151) focus on behavioural and emotional adjustment related to a medical condition (e.g., a child is struggling with being in the hospital but the level of emotional difficulty does not rise to the level to meet diagnostic criteria for a mental health condition).
2. Health & Behavior Interventions (96,158, 96,164, 96,167, 96,170, 96,152, 96,153, 96,154, 96,155) aim to support adjustment to a medical condition or address other behavioral or emotional difficulties affiliated with the medical issue.

For each service encounter of interest, we determined the age of the patient on the encounter date, the insurance type associated with the encounter (Medicaid vs commercial), and the on-road distance from the patients' home ZIP code to the address affiliated with the encounter's provider in the 2019 National Plan and Provider Enumeration System.[16] We also manually categorised the facility type of each site as: community clinics and private practices;

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Table 1. Characteristics of children with CHD associated with any neurodevelopmental services[3]

Characteristic	Any Encounter[1] n (%)	No Encounter n (%)	p-value[2]	Receipt of specific neurodevelopmental services by unique individuals, n (%)						
				Developmental Testing	Psychological Testing	Neuropsychological Testing	Mental Health Assessment	Mental Health Intervention	Health and Behavior Assessment	Health and Behavior Intervention
Total population ($n = 799$)	185 (23%)	614 (77%)		27 (3%)	68 (9%)	36 (5%)	88 (11%)	78 (10%)	13 (1%)	7 (<1%)
Sex			0.3							
F	73 (21%)	271 (79%)		8 (2%)	23 (7%)	14 (4%)	33 (10%)	36 (10%)	6 (2%)	5 (2%)
M	112 (25%)	343 (75%)		19 (4%)	45 (10%)	22 (5%)	55 (12%)	42 (9%)	7 (2%)	2 (<1%)
Age in Jan 2017			<0.001							
Age 0–5	49 (17%)	247 (83%)		20 (7%)	19 (6%)	2 (<1%)	21 (7%)	12 (4%)	4 (1%)	0
Age ≥ 6	136 (27%)	367 (73%)		7 (1%)	49 (10%)	34 (7%)	67 (13%)	66 (13%)	9 (2%)	7 (1%)
Childhood Opportunity Index quintile[4]			0.3							
Very Low	51 (27%)	139 (73%)		9 (5%)	19 (10%)	8 (4%)	17 (9%)	17 (9%)	4 (2%)	2 (1%)
Low	32 (21%)	123 (79%)		2 (1%)	13 (8%)	3 (2%)	19 (12%)	13 (8%)	1 (<1%)	1 (<1%)
Moderate	40 (27%)	111 (73%)		7 (5%)	19 (13%)	11 (7%)	17 (11%)	13 (9%)	2 (1%)	1 (<1%)
High	28 (18%)	127 (82%)		4 (3%)	9 (6%)	4 (3%)	19 (12%)	15 (10%)	0	0
Very High	34 (23%)	114 (77%)		5 (3%)	8 (5%)	10 (7%)	16 (11%)	20 (14%)	6 (4%)	3 (2%)
Rurality			0.087							
Rural	109 (21%)	404 (79%)		15 (3%)	42 (8%)	20 (4%)	51 (10%)	47 (9%)	7 (1%)	6 (1%)
Urban	76 (27%)	210 (73%)		12 (4%)	26 (9%)	16 (6%)	37 (13%)	31 (11%)	6 (2%)	1 (<1%)
Insurance			0.14							
Commercial[5]	72 (23%)	277 (79%)		4 (1%)	12 (3%)	15 (4%)	44 (13%)	47 (13%)	8 (2%)	4 (1%)
Medicaid	113 (25%)	337 (75%)		23 (5%)	56 (12%)	21 (5%)	44 (10%)	31 (7%)	5 (1%)	3 (<1%)
CHD Diagnosis			0.3							
Single ventricle with arch obstruction	18 (30%)	43(70%)		5 (8%)	5 (8%)	7 (12%)	4 (7%)	7 (12%)	2 (3%)	2 (3%)
Single ventricle without arch obstruction	12 (20%)	47 (80%)		2 (3%)	2 (3%)	2 (3%)	5 (9%)	7 (12%)	1 (2%)	
Two ventricle with arch obstruction	47 (20%)	193 (80%)		4 (2%)	14 (6%)	8 (3%)	26 (11%)	23 (10%)	3 (1%)	2 (<1%)
Two ventricle without arch obstruction	108 (25%)	331 (75%)		16 (4%)	47 (11%)	19 (4%)	53 (12%)	41 (9%)	7 (2%)	3 (<1%)

(*Continued*)

Table 1. (*Continued*)

Characteristic	Any Encounter[1] n (%)	No Encounter n (%)	p-value[2]	Receipt of specific neurodevelopmental services by unique individuals, n (%)					
				Developmental Testing	Psychological Testing	Neuropsychological Testing	Mental Health Assessment	Mental Health Intervention	Health and Behavior Assessment	Health and Behavior Intervention
Distance from care centres										
Less than 100 km from nearest regional paediatric centre (Bangor, Portland, Boston)	167 (23%)	554 (77%)	>0.9	26 (3.6%)	62 (8.6%)	33 (4.6%)	78 (11%)	71 (9.8%)	11 (1.5%)	4 (7.9%)
Less than 100 km from nearest surgical centre (Portland, Boston)	112 (23%)	377 (77%)	0.9	23 (4.7%)	37 (7.6%)	19 (3.9%)	45 (9.2%)	45 (9.2%)	9 (1.8%)	3 (0.6%)

[1]n (%); Median (Interquartile Range).
[2]Pearson's Chi-squared test.
[3] n (%).
[4]Childhood opportunity index v. 2.0, normed by state.
[5]Includes 41 children with both Medicaid and Commercial insurance.

hospital clinics with paediatric subspecialists; hospital clinics without paediatrics subspecialists; medical centres with a behavioural health focus; and state-based or school-based early intervention or public education facilities.

Analysis

Using chi-squared tests and T-tests, we tested the association between patient-level characteristics and receipt of any neurodevelopmental service. We also calculated the receipt of each of the seven distinct neurodevelopmental services by patient-level characteristic.

Overall, and for each neurodevelopmental service encounter type, we calculated the median and interquartile range for patient ages, the distance from patients' home ZIP codes to the facility, the percentage of claims paid for by commercial insurance, and the percentage of service encounters by facility types. Because some services are more commonly provided to specific age groups,[5,18] we performed a stratified analysis of receipt of neurodevelopmental care in children ≤ 5 and > 5.

Analyses were performed using R v 4.2.1 (2023). Distances are calculated based on Google Maps driving distances using the *gmapsdistance* package.

Results

Patient-level characteristics

Among the 799 children with complex CHD who met inclusion criteria, the median age was 9.0 years (Interquartile Range 3.0–15.0 y). Sixty-four per cent of children lived in rural areas and 56% were publicly insured. Most children (55%) had biventricular anatomy without arch obstruction. The children were located a median of 50 and 69 miles from the nearest regional paediatric and surgical centre, respectively.

Approximately 23% (185 children) of children with complex CHD received at least one neurodevelopmental service during the study period (Table 1). The most frequently received neurodevelopmental services were mental health assessments (88 children, 11%), mental health interventions (78 children, 10%), and psychological testing (68 children, 8.5%).

The only patient-level characteristic associated with receipt of at least one neurodevelopmental service was age ≥ 6 years old. There was no association between sex, Childhood Opportunity Index 2.0 quintile, rurality, insurance type, type of CHD, or distance from the nearest regional or surgical centre and receipt of a neurodevelopmental service. Figure 1 shows the home locations of children who did and did not receive neurodevelopmental services.

When we stratified analysis by age, there was no significant association in either the 0–5 years of age cohort or the ≥ 6-year-old cohort between diagnoses, the distance to regional paediatric and surgical centres, childhood opportunity index, rurality, or insurance and the receipt of any service (Supplemental Tables 1 and 2).

Encounter-level characteristics

We identified 1182 neurodevelopmental and psychosocial service encounters among 185 children (Table 2). The most frequent types of service encounters were mental health interventions (776 visits among 78 children) and psychological testing (110 visits among 88 children). Community clinics were the most frequent site for encounters overall (64%) and the most frequent site for

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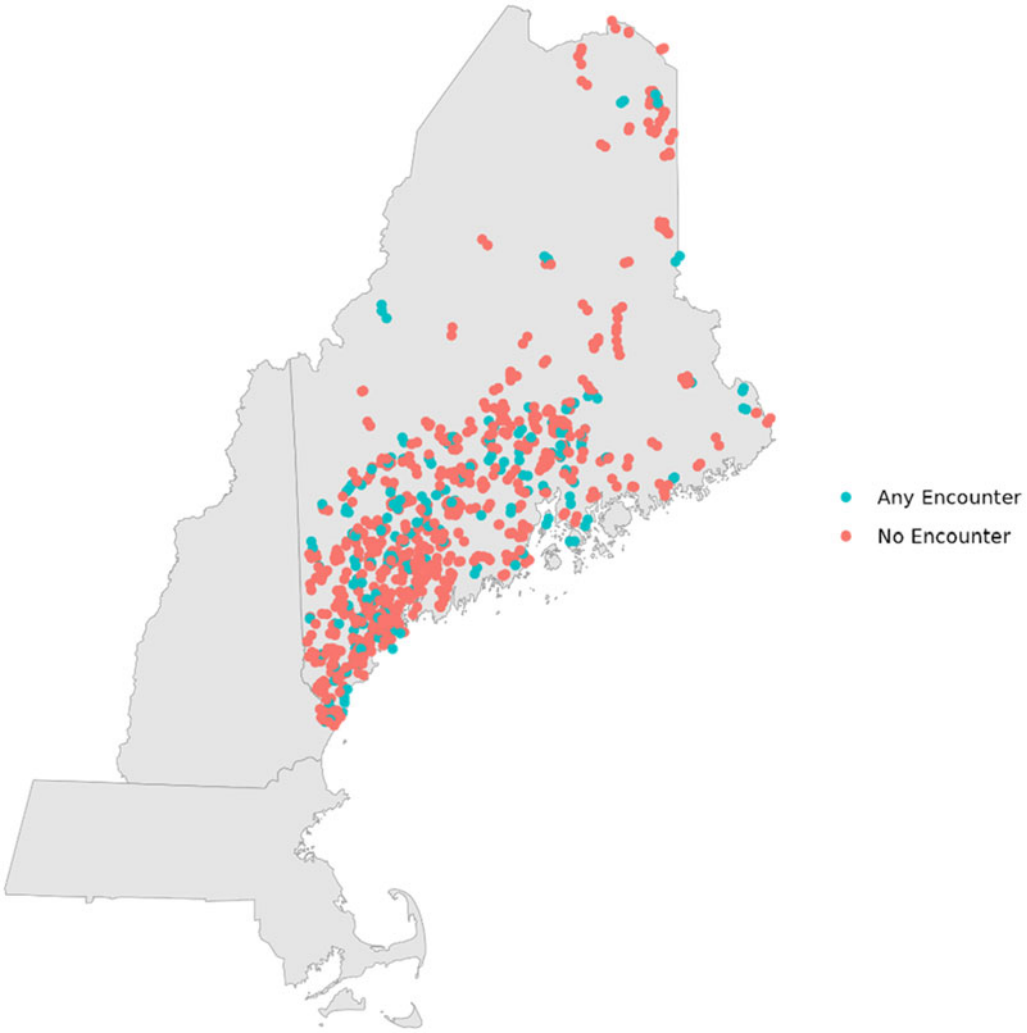

Figure 1. Home locations of 799 children with complex CHD with and without a neurodevelopmental encounter.

four of seven of the discrete types of neurodevelopmental visits, especially mental health interventions (80%). Developmental testing was distributed relatively evenly between three kinds of sites: community clinics/private practice (39%), state-based and school-based early intervention (31%), and hospital-based clinics with paediatric subspecialists (28%). Similarly, neuropsychological encounters generally took place in community clinics/private practices (48%) and at hospital-based clinics with paediatric subspecialists (47%). However, encounters for health and behavioural assessments and health and behavioural interventions took place almost exclusively at hospital clinics with paediatric specialty care (100 and 98% of encounters, respectively). Just as services varied in the range of facilities at which they took place, they also varied in the geographic range in which they took place. While some services, such as neuropsychological testing, took place mostly around major cities others, such as mental health assessments and interventions, were more distributed across Maine and the surrounding states. The geographic distributions of the sites of service encounters are shown in Figure 2.

The large number of encounters for mental health interventions was driven by multiple visits for a small number of individuals. Among the 78 individuals who attended mental health intervention encounters, the median number of encounters was four, while nine children accounted for more than half of all encounters.

Discussion

This study used all-payer claims data to explore utilisation of neurodevelopmental and psychosocial services among children with complex CHD in the rural state of Maine. Consistent with previous studies, few children with complex CHD access the neurodevelopmental services recommended by the American Heart Association, Cardiac Neurodevelopmental Outcome Collaborative, and American Academy of Pediatrics. Among children who did receive neurodevelopmental care, most did so in community-based settings. Few demographic or clinical factors predicted overall utilisation of this kind of care or location of care received in this cohort. Taken together, our findings support previous concerns that more than a decade after the American Heart Association and the American Academy of Pediatrics recommended periodic, multidisciplinary neurodevelopmental surveillance and evaluation for children with complex CHD, a minority of children are receiving this specialised care. Unlike previous studies, however, our findings show the previously described barrier of distance to paediatric cardiac centre, is less relevant when considering other local services.

Our approach differed significantly from the recent Cardiac Neurodevelopmental Outcome Collaborative assessment of neurodevelopmental care receipt by children with CHD, which reported on the rate of children receiving developmental care at 11–30-month

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Table 2. Characteristics of neurodevelopmental visits attended by children with CHD

				Facility Type				
	Age in Years at time of visit, Median (IQR)	Distance from home ZIP code to facility Median (IQR)	Commercial Insurance at time of visit, n (%)	Community clinic and private practice	Hospital clinic with peds subspecialty	Hospital clinic without peds subspecialty	Hospital or medical centre with psychiatric and behavioral health focus	State-based early intervention and education services
All visits (n = 1182)				768 (64%)	301 (25%)	59 (5%)	52 (4%)	16 (1%)
Discrete type of neurodevelopmental visits								
Developmental Testing ($n = 36$)	2 (1,3)	52 (6,100)	5 (14%)	14 (39%)	10 (28%)	1 (3%)	0	11 (31%)
Psychological Testing ($n = 110$)	8 (6,11)	47 (14,82)	11 (10%)	54 (49%)	35 (32%)	14 (13%)	3 (3%)	4 (4%)
Neuropsychological Testing ($n = 74$)	11 (8,13)	44 (14,168)	20 (27%)	36 (48%)	35 (47%)	4 (5.3%)	0	0
Mental Health Assessment ($n = 110$)	10 (7,14)	47 (19,136)	48 (43%)	34 (31%)	47 (43%)	20 (18%)	9 (8%)	0
Mental Health Intervention ($n = 776$)	12 (8,15)	45 (14,148)	507 (64%)	619 (80%)	97 (12%)	20 (3%)	40 (5%)	0
Health & Behavioral Assessment ($n = 10$)	9 (2,12)	186 (21,228)	7 (70%)	0	10 (100%)	0	0	0
Health & Behavioral Intervention ($n = 66$)	2 (1,5)	12 (12,84)	16 (24%)	0	65 (98%)	0	0	1 (2%)

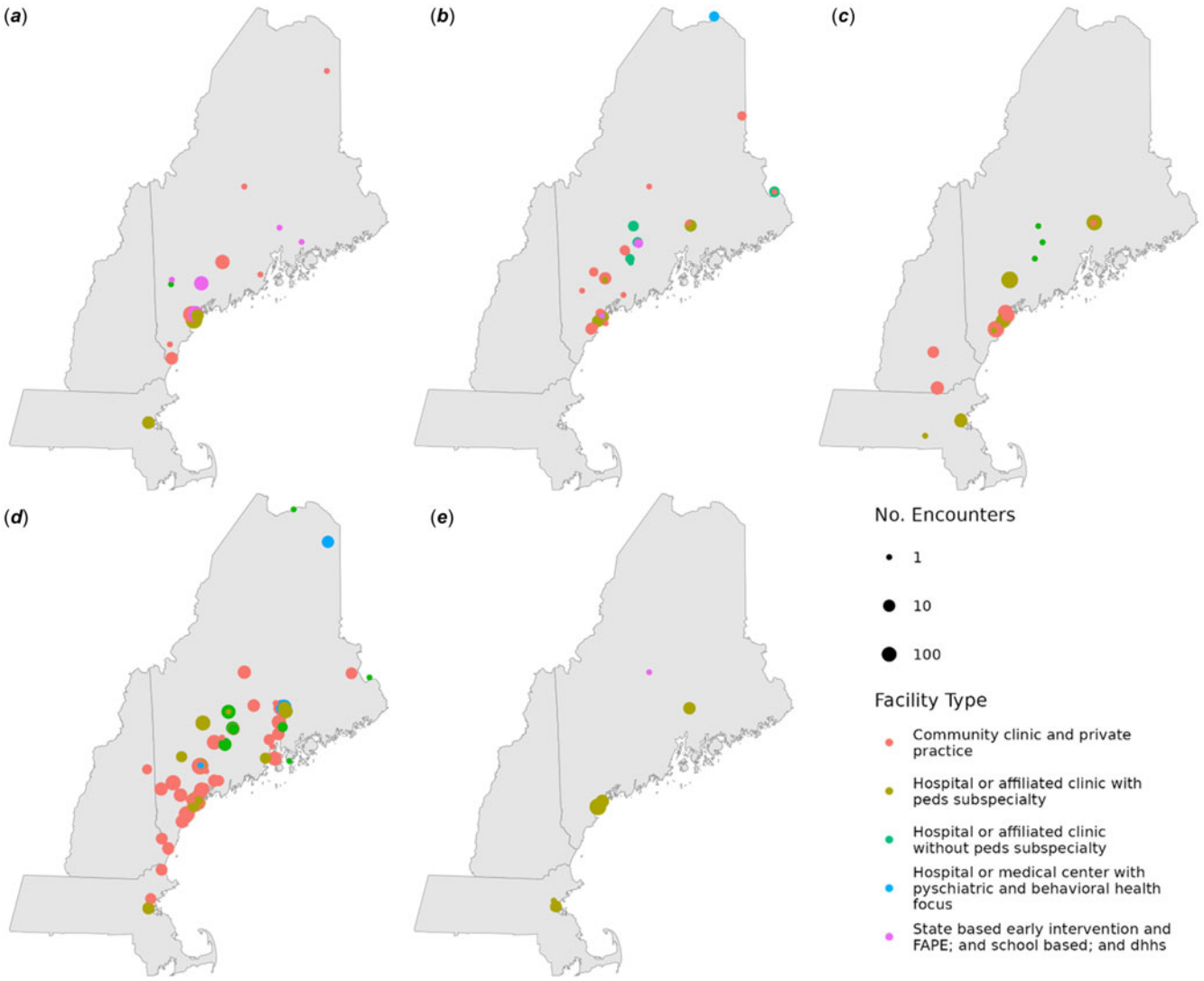

Figure 2. Sites of neurodevelopmental encounters provided to children in Maine with complex CHD. (***a***) Developmental testing; (***b***) psychologic testing; (***c***) neuropsychological testing; (***d***) mental health assessments and interventions; and (***e***) health and behavioural assessments and interventions.

visits conducted within their surgical centre.[6] In this context, children likely received care consistent with guidelines, and from providers with specialised training to work with this population. In contrast, we included children up to 18 years of age, and utilised claims data, which included care at any location. This older population received care largely related to mental health issues (e.g., emotional, behavioural, and social difficulties) rather than developmental challenges. In addition, we found that most neurodevelopmental services we identified occurred outside of the surgical centre, and via community-based providers who were unlikely to have CHD-specific training and less likely than surgical centres to have knowledge of Cardiac Neurodevelopmental Outcome Collaborative recommendations.[18,19]

One possible response to this finding might be to redouble efforts to support access to the more specialised neurodevelopmental services provided at surgical centres. However, given the degree to which children with CHD receive neurodevelopmental care from local providers, the low rate of follow-up to surgical centres, and the significant additional barriers which rural populations may face in accessing centralised surgical centres, CHD teams may consider collaborating with community providers to ensure that the local neurodevelopmental supports that children receive is consistent with guidelines and provided in the context of their cardiac disease. Offering educational opportunities for community providers on CHD and neurodevelopment is one way to engage with these potential partners, and this strategy is a natural extension of previous calls to educate cardiologists and primary care on the neurodevelopmental needs of children with CHD.[20] A notable negative finding in our cohort was the lack of an association between many variables associated with lower socioeconomic status and receipt of care, suggesting the barrier to local resources are lower than those to centralised services, as in previously described cohorts. Therefore, CHD teams may have the opportunity to improve rates of neurodevelopmental follow-up by better-leveraging infrastructure beyond the surgical centre to improve neurodevelopmental and psychosocial trajectory of more of their children with complex CHD. Such collaborations or referrals from CHD teams to local providers may in fact already be occurring, although such interactions would not be captured in a payer-based analysis such as this.

Most cardiac neurodevelopmental programmes have been designed for identification and delineation of developmental

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concerns that can then guide intervention. Rates of intervention at CHD surgical centres are not well known, nor are the rates of successful referral to services once developmental concerns have been identified. Children with CHD are more likely to receive special education services[2,21], but how the CHD neurodevelopmental programme augments those services or rates of service is poorly described. Our findings suggest that state-based early intervention programmes are a source of developmental testing in younger children. Our analysis did not include developmental intervention encounters, although these are likely an important component of those programmes as well as CHD neurodevelopmental programmes. Future studies should examine physical, occupational, and speech therapy services children with complex CHD receive in any setting. Ensuring that children with CHD who have developmental delays receive intervention to support these difficulties is critical.[22] Having clear and low barrier pathways from developmental testing to developmental intervention may support family engagement in these important services.

We assessed for factors which might be associated with access. We found no significant association between rurality, the Childhood Opportunity Index, and insurance type and neurodevelopmental care receipt, although this result must be interpreted within the context of very low overall rates of care. Notably, because claims data only include encounters paid for by insurers, this study does not include children of families paying for services entirely out-of-pocket.

The findings of this study should be considered within the limitations of claims data, which, in addition to not including those paying out-of-pocket or the uninsured, contain limited details on the reason behind healthcare receipt. Accordingly, we calculated the rates of neurodevelopmental and behavioural healthcare in all locations and for all reasons and did not attempt to determine which services were performed because of a patient's complex CHD. In addition, because this analysis focused on children with CHD only we did not directly compare our findings to baseline rates of service among a cohort of children without CHD. However, we identified rates of mental health interventions in children with CHD over five that were similar to those seen in the general population.[17] Together with our finding that children with CHD are most likely to obtain neurodevelopmental services in community locations, this suggests that children with CHD are utilising the same infrastructure and at similar rates as the general paediatric population. Importantly, since the CHD population carries an added risk for neurodevelopmental challenges relative to the general population, families with a child with CHD in Maine are likely underserved. This underscores the potential opportunity for CHD teams to partner with local providers to increase the use of local resources among this high-risk population.

Conclusions

A small percentage of children with complex CHD attend neurodevelopmental encounters. The most common type of neurodevelopmental encounter was mental health interventions, and the majority of neurodevelopmental encounters took place in a community or private practice, a setting in which few providers are likely to have specialised training in working with children with CHD. CHD centres hoping to support their patients' growth, development, and mental health should identify ways to partner with external providers.

Supplementary material. The supplementary material for this article can be found at https://doi.org/10.1017/S1047951124036321.

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Competing interests. The authors confirm that they have no conflicts of interest to report.

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