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Financial burdens and mental health needs in families of children with congenital heart disease

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Abstract

Objective: To examine the financial burdens and mental health needs of families of children with special healthcare needs (CSHCN) with congenital heart disease (CHD).

Methods: Data from the 2009–2010 National Survey of Children with Special Health Care Needs (NS-CSHCN) were used to examine parent-reported financial burdens (out-of-pocket expenses, financial problems, employment impact, caregiving hours) and family members' need for mental health services in families of CSHCN with CHD. Multivariable logistic regression was used to compare financial burdens and family members' need for mental health services among CSHCN with and without CHD. Among CSHCN with CHD, multivariable logistic regression, stratified by age (0-5 and 6–17 years), was used to assess characteristics associated with the outcomes.

Results: Overall, families of 89.1% of CSHCN with CHD experienced at least one financial burden and 14.9% needed mental health services due to the child's condition. Compared with CSHCN without CHD, those with CHD had families with a higher prevalence of all financial burdens (adjusted prevalence ratio [aPR] range: 1.4–1.8) and similar family member need for mental health services (aPR = 1.3, 95% CI [1.0, 1.6]). Across both age groups, insurance type, activity limitations, and comorbidities were significantly associated with financial burdens and/or family members' need for mental health services.

Conclusions: CSHCN with CHD, compared with those without CHD, lived in families with more financial burdens. Interventions that reduce financial burdens and improve mental health of family members are needed, especially among CSHCN with CHD who are uninsured and have comorbidities or activity limitations.

KEYWORDS
congenital heart disease, caregiver burden, financial burdens, mental health

1 | INTRODUCTION

Caring for a child with congenital heart disease (CHD) may place financial and mental strain on families. Treatment costs can be high as a significant proportion of children with CHD require one or more surgeries. According to the 2012 Kids' Inpatient Database, total hospital costs including both cardiac and noncardiac procedures and medical treatment exceeded 6 billion dollars for children with CHD.[1] Additionally, many children with CHD have one or more comorbidities, such as developmental delay or other congenital anomalies that contribute to the complexity and cost of care.[2,3] Compared with other US children, children with CHD use five times the home health services, eight times the special medical equipment, three times more prescription medications, and 1.5 times more special education services.[2,4] Having a child with special health care needs may require parents to work fewer hours per week and/or miss work for medical appointments.[5] In addition to the financial burdens of having a child with CHD, families may experience elevated levels of psychological distress due to the child's physical, medical, educational, and financial needs.[6]

Abbreviations: CHD, congenital heart disease; NS-CSHCN, National Survey of Children with Special Health Care Needs; CSHCN, children with special health care needs; CHIP, Child Health Insurance Program..

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A growing body of literature is addressing the financial burdens and mental health needs of families of children with CHD.[6] A few studies have reported general financial difficulties related to having a child with CHD[7] as well as specific burdens such as large out-of-pocket expenses and decreases in salary due to reducing hours or stopping work to care for the child.[8] Close to 50% of families of children with special healthcare needs (CSHCN) experience some type of financial burden,[9] but the magnitude of financial impact of CHD on families is not well documented. Increased risk of caregiver psychological distress, particularly around critical periods of illness such as diagnosis and surgery, persisting up to three years after the newborn period has been documented.[10–13] Very little information exists, however, on the need for mental health services. Understanding the unique financial burdens and mental health needs of US families of children with CHD may help hospitals, public health practitioners, advocacy organizations, mental health providers, and others intervene to provide support. Therefore, we used data from the 2009–2010 National Survey of Children with Special Health Care Needs (NS-CSHCN) to examine the financial burdens and mental health needs of families of CSHCN with CHD.

2 | METHODS

2.1 | Data source and design

The 2009–2010 NS-CSHCN, sponsored by the Centers for Disease Control and Prevention, was used to describe the financial burdens and mental health needs of families of CSHCN with CHD.[14] The NS-CSHCN is a cross-sectional telephone survey designed to identify prevalence, well-being, and healthcare needs of CSHCN, including the effect on families. The survey is included in the State and Local Area Integrated Telephone Survey in all 50 states and the District of Columbia. Households with children less than 18 years were identified through random digit dialing. A five-question screener was used to identify CSHCN, defined by the Maternal and Child and Health Bureaus as children having "a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally."[15] Interviews were completed for 40 242 households. Further information on the NS-CSHCN is detailed in the NS-CSHCN 2009–2010 Manual (http://www.cdc.gov/nchs/data/series/sr_01/sr01_057.pdf).[14]

2.2 | Sample population

We examined CSHCN with and without CHD. CSHCN with CHD were identified by a parent or caregiver answering "yes" to the question: "Has a doctor or other healthcare care provider *ever* told you that [CHILD] had a heart problem, including CHD?" The majority of heart problems in young children are congenital. For example, approximately 30 000 children in the United States have cardiomyopathy and 5000 children under 5 years develop Kawasaki disease, while over one million children have CHD.[16] However, children with acquired heart problems are included in this sample and the relative distribution of congenital and acquired heart problems in children up to age 17 years is unknown.

2.3 | Measures

2.3.1 | Financial burdens and need for mental health services

We examined four indices of financial burden: out-of-pocket expenses, financial problems, employment impact, and caregiver hours. Out-of-pocket expenses were defined as parent-reported expenditures in the previous 12 months above and beyond health insurance premiums or reimbursed healthcare costs ($<$\$250, \$251–500, \$500–1000, $>$\$1000, and dichotomized as $<$ or $\geq$ \$1000). Financial problems were defined as the parent or caregiver responding "yes" to the question: "Do you have any financial problems due to the child's condition?" Employment impact was defined as the parent or caregiver answering "yes" to (1) cutting down on hours, and/or (2) stopping work due to the child's condition. Caregiver hours was defined as the amount of time a parent or caregiver reported providing in-home care or care coordination for the child ($<$1, 1–4, 5–10, $\geq$11 hours/week, and dichotomized as $<$ or $\geq$11 hours/week). We also assessed need for mental health services, defined as the parent or caregiver responding "yes" to any family members needing mental health services or counseling due to the child's condition. All outcomes were assessed for the prior 12 months.

2.3.2 | Child and family characteristics

We examined child and family characteristics, identified through literature review and a priori theory, as potential confounders of the association between CHD and financial burdens and mental health needs, as well as potential predictors among CSHCN with CHD. Child characteristics included age, sex, race/ethnicity, insurance type (any private, public, uninsured), medical home status, effect of condition on daily activities compared with children of the same age, and type of comorbidities (physical-only, developmental-only, physical and developmental, or none). Comorbidities were defined as a parent reporting ever being told by a provider that their child had at least one of the following conditions: physical conditions (asthma, diabetes, epilepsy or seizure disorder, migraines or frequent headaches, blood problems, cystic fibrosis, cerebral palsy, muscular dystrophy, arthritis or joint problems, allergies, and head injury, concussion or traumatic brain injury), or developmental conditions (attention deficit disorder or attention deficit hyperactivity disorder, depression, anxiety, behavioral or conduct problems, autism or an autism spectrum disorder, developmental delay, an intellectual disability or mental retardation, Down syndrome). Among children less than 2 years, Down syndrome was the only condition inquired about in the developmental category. Family characteristics included relationship to person completing survey (mother, father, other relative or guardian), family structure (two parents, mother only, and other [including father only]), highest education level in the household, and family's income as a percent of the federal poverty level (FPL).

2.4 | Data analysis

Weighted proportions were calculated for all child and family characteristics, financial burdens, and mental health needs, stratified by CHD status. Differences were assessed using chi-square tests. Among

CSHCN with CHD, we used multivariable logistic regression to assess characteristics associated with each financial burden and mental health need. Insurance type was not included in the employment impact model due to the known relationship between employment and insurance. Models were stratified by age (<5 years vs ≥ 5 years) due to the expected increase in stress and financial problems surrounding surgery (<5 years for most CSHCN with CHD). All analyses were performed using SAS-callable SUDAAN v. 9.3. Weights and design parameters were included per NS-CSHCN guidelines to produce nationally representative, population-based estimates and to account for complex sampling.[14] As a secondary analysis of de-identified data, human subjects review was not required for this analysis.

3 | RESULTS

A total of 40 242 parents of CSHCN completed the 2009–2010 NS-CSHCN household interview. Interviews missing responses for CHD status ($n = 34$), financial or mental health outcomes ($n = 1990$), or potential predictors ($n = 1640$) were excluded. Children with missing data were more likely to have characteristics of lower socioeconomic status (public insurance, a family member with less than a high school education, lower FPL, mother-only family structure), be Hispanic ethnicity, and have a condition that affects activities consistently, often a great deal ($P < .001$). A total of 36 578 (90.9%) CSHCN were included in this analysis, of whom 1956 (representing 5.5% of US CSHCN) had CHD.

All child and family characteristics can be found in Table 1. CSHCN with CHD were most commonly 6–17 years old (73.0%), male (52.0%), and white, non-Hispanic (62.3%), and had some type of private insurance (59.7%) (Table 1). Only 39.5% had a medical home, 88.6% had a physical and/or developmental comorbidity, and 41.6% had a condition consistently affecting daily activities, often a great deal. Compared with CSHCN without CHD, CSHCN with CHD were significantly more likely to be 0–5 years of age ($P < .001$), female ($P < .001$), lack a medical home ($P = .04$), have both a physical and developmental comorbidity ($P < .001$), a condition affecting daily activities consistently, often a great deal ($P < .001$), a mother completing the survey ($P = .003$), and have a two-parent family structure ($P = .04$) (Table 1). No significant differences were found by race/ethnicity, insurance type, highest education level in the household, or FPL.

In the past 12 months, 89.1% of CSHCN with CHD lived in families with at least one financial burden: 30.4% had out-of-pocket healthcare expenses over $1000, 35.0% reported financial problems due to their child's condition, 42.8% reported an employment impact, and 23.1% spent $\geq$11 hours/week providing or coordinating care (Table 2). Of CSHCN with CHD, 14.9% had one or more family members who needed mental health services due to the child's condition. CSHCN with CHD with one or more parent-reported financial burdens were almost three times as likely as those reporting none to have family members who needed mental health services (14.9% and 5.4%, respectively). Compared with CSHCN without CHD, CSHCN with CHD had a significantly higher prevalence of all types of parent-reported financial burdens (adjusted prevalence ratio [aPR] range: 1.4–1.8) and an increase in family member need for mental health services (aPR = 1.3, 95% CI [1.0, 1.6]), although the 95% CI included 1.0 (Table 2).

Among CSHCN with CHD, child and family characteristics independently associated with greater financial burdens and need for mental health services varied by age group (0–5 years, 6–17 years) and outcome (Table 3). In both age groups, annual out-of-pocket medical expenses over $1000 and financial problems were more common among uninsured CSHCN with CHD (aPRs 1.6–2.0). Financial problems were also associated with 0–5 year-olds who lacked a medical home, were non-Hispanic "other" race, and had comorbidities. Among 6–17 year-olds, financial problems were associated with the child having a condition that affected daily activities, single-parent mothers, more highly educated families, and lower income. In both age groups, employment impact among caregivers was more common among CSHCN whose condition affected daily activities consistently, often a great deal (aPRs 2.2–2.5). For 6–17 year-olds, caregiver employment impact was more common among children who were Hispanic, had more highly educated families, and lower family income.

In CSHCN with CHD in both age groups, caregiver time $\geq$11 hours/week was more common among CSHCN whose condition affected daily activities (aPRs 3.2–11.7) (Table 3). Among 0–5 year-olds, caregiver time $\geq$ 11 hours/week was also more common among children who were uninsured and "other" race. Reporting that a family member needed mental health services due to the child's condition was more common in 0–5 year-olds who were "other" race and uninsured, and in 6–17 year-olds who had a physical and/or developmental comorbidity and among CSHCN with CHD whose parent reported financial problems.

4 | DISCUSSION

This analysis provides the first known population-based parent-reported estimates of the family financial burdens and family need for mental health services among CSHCN with CHD and compements other studies among smaller clinical samples. The results indicate that financial burdens, including high out-of-pocket expenses, financial problems, employment impact, and caregiving time, are common and reported more often by families of CSHCN with CHD than by families of CSHCN without CHD. The majority of CSHCN with CHD had families with at least one type of financial burden and 35% had families that reported financial problems due to the child's condition. Additionally, one or more family members of 14.9% of CSHCN with CHD needed mental health services due to the child's condition. While factors associated with the four indices of financial burden and need for mental health services varied by child's age, families most commonly reporting these outcomes had children who were uninsured and had comorbidities or a condition affecting daily activities.

A high prevalence of financial burdens reported by families of CHSCN with CHD is consistent with qualitative reports of medical and nonmedical expenses among families of children with CHD.[8] High relative treatment costs may contribute to the high prevalence of financial burdens. In the 2012 Kids' Inpatient Database, CHD accounted for

TABLE 1 Characteristics of children with special healthcare needs ages 0–17 years by congenital heart disease status, NS-CSHCN, United States, 2009–2010

	Congenital heart disease		
	Yes N = 1956 (weighted %, 95% CI)	**No N = 34 622 (weighted %, 95% CI)**	**Chi-square *P* value**
Child characteristics			
Age (years)			<.001
0–5	27.0 (23.6, 30.7)	20.6 (19.8, 21.4)	
6–17	73.0 (69.3, 76.4)	79.4 (78.6, 80.2)	
Sex			<.001
Male	52.0 (48.0, 55.6)	59.8 (58.8, 60.7)	
Female	48.0 (44.0, 52.0)	40.2 (39.3, 41.2)	
Race/ethnicity			.37
White, non-Hispanic	62.3 (58.1, 66.3)	60.2 (59.2, 61.2)	
Black, non-Hispanic	13.4 (10.9, 16.4)	16.0 (15.2, 16.8)	
Hispanic	16.5 (13.3, 20.4)	16.0 (15.2, 16.9)	
Other[a]	7.8 (5.6, 10.7)	7.9 (7.3, 8.4)	
Insurance type			.07
Any private	59.7 (55.6, 63.8)	63.2 (62.2, 64.2)	
Public	37.8 (33.8, 42.0)	33.4 (32.5, 34.4)	
Uninsured	2.5 (1.7, 3.8)	3.4 (3.0, 3.8)	
Medical home[b]			.04
Yes	39.5 (35.8, 43.4)	43.7 (42.7, 44.6)	
No	60.5 (56.6, 64.3)	56.4 (55.4, 57.3)	
Type of comorbidities[c]			<.001
None	11.4 (9.4, 13.8)	8.1 (7.5, 8.7)	
Developmental	12.6 (10.5, 15.1)	17.4 (16.7, 18.1)	
Physical	28.4 (24.9, 32.2)	40.0 (39.1, 41.0)	
Both	47.6 (43.6, 51.6)	34.6 (33.6, 35.5)	
Condition affects daily activities			
Never affected	21.9 (19.0, 25.1)	35.3 (34.4, 36.2)	<.001
Moderately affect, some of the time	36.5 (32.8, 40.4)	38.8 (37.8, 39.7)	
Consistently affect, often a great deal	41.6 (37.7, 45.7)	26.0 (25.1, 26.9)	
Family characteristics			
Person completing survey[d]			.003
Mother	82.8 (79.7, 85.5)	77.6 (76.8, 78.4)	
Father	12.2 (9.9, 15.0)	15.5 (14.8, 16.2)	
Other relative or guardian	5.0 (3.7, 6.8)	6.9 (6.4, 7.4)	
Family structure			.04
Two parents (biological, adoptive, or stepparent)	68.0 (64.2, 71.6)	67.3 (66.3, 68.3)	
Mother only (no father present)	26.8 (23.3, 30.4)	25.2 (24.3, 26.1)	
Other structures (including father only)	5.3 (3.8, 7.2)	7.5 (7.0, 8.1)	
Highest education of any household member			.54
<High school	12.1 (9.2, 15.6)	10.2 (9.5, 11.0)	
High school	18.8 (15.8, 22.3)	19.6 (18.8, 20.4)	
>High school	69.1 (65.0, 73.0)	70.2 (69.2, 71.2)	
Federal poverty status[e]			.17
<100% FPL	24.1 (20.7, 27.8)	21.0 (20.2, 21.9)	
100%–199% FPL	23.2 (19.8, 27.1)	21.7 (20.9, 22.5)	
200%–399% FPL	27.0 (23.8, 30.6)	29.0 (28.1, 29.8)	
≥400% FPL	25.7 (22.5, 29.1)	28.3 (27.5, 29.2)	

Abbreviations: CI, confidence interval; FPL, federal poverty level.

[a] Other includes respondents identified as Asian, Alaskan Native, American Indian, Native Hawaiian, Pacific Islander, or mixed race.

[b] Meets Maternal and Child Health Bureau criteria for a medical home.

[c] Developmental comorbidities include attention deficit disorder or attention deficit hyperactivity disorder, depression, anxiety, behavioral or conduct problems, autism or an autism spectrum disorder, developmental delay, an intellectual disability or mental retardation, Down syndrome; physical comorbidities include asthma, diabetes, epilepsy or seizure disorder, migraines or frequent headaches, blood problems, cystic fibrosis, cerebral palsy, muscular dystrophy, arthritis or joint problems, allergies, and head injury, concussion or traumatic brain injury.

[d] Biological, adoptive, step, or foster parent.

[e] Based on US Department of Health and Human Services poverty guidelines.

TABLE 2 Family financial burdens and mental health needs in the past 12 months, by congenital heart disease status, NS-CSHCN, United States, 2009–2010

	Congenital heart disease			
	Yes N = 1956 (weighted %, 95% CI)	No N = 34 622 (weighted %, 95% CI)	Crude PR (95% CI)	Adjusted[c] PR (95% CI)
Out-of-pocket payments for all health-related needs of the child[a]			1.4[b] (1.2, 1.6)	1.4[b] (1.2, 1.6)
<\$250	39.6 (35.7, 43.6)	44.3 (43.3, 45.3)		
\$251–\$500	18.1 (15.2, 21.4)	21.6 (20.9, 22.4)		
\$501–\$1000	12.0 (9.7, 14.6)	11.9 (11.4, 12.5)		
>\$1000	30.4 (26.9, 34.2)	22.2 (21.4, 22.9)		
Financial problems caused by child's condition			1.7 (1.5, 1.9)	1.7 (1.6, 1.9)
Yes	35.0 (31.4, 38.9)	20.8 (20.0, 21.6)		
No	65.0 (61.1, 68.6)	79.2 (78.4, 80.1)		
Family members stopped working/cut hours to care for child			1.8 (1.6, 2.0)	1.7 (1.6, 1.9)
Yes	42.8 (38.8, 46.8)	23.9 (23.0, 24.8)		
No	57.3 (53.2, 61.2)	76.1 (75.2, 77.0)		
Hours/week providing or coordinating care for child			1.9[b] (1.6, 2.2)	1.8[b] (1.5, 2.1)
<1	29.4 (26.1, 32.9)	39.6 (38.7, 40.6)		
1–4	34.6 (30.9, 38.4)	37.6 (36.6, 38.5)		
5–10	13.0 (10.5, 15.9)	10.3 (9.7, 11.0)		
≥11 hours/week	23.1 (19.5, 27.1)	12.5 (11.8, 13.2)		
Family members needed mental health services due to child's condition			1.3 (1.0, 1.6)	1.3 (1.0, 1.6)
Yes	14.9 (12.0, 18.3)	11.6 (10.9, 12.2)		
No	85.2 (81.7, 88.1)	88.4 (87.8, 89.1)		

Abbreviations: PR, prevalence ratio; CI, confidence interval; FPL, federal poverty level.

[a] Copayments, dental or vision care, medications, special foods, adaptive clothing, durable equipment, home modifications, and any kind of therapy within the past 12 months.

[b] Using dichotomized variable (>\$1000 vs ≤\$1000 and ≥11 hours/week vs <11 hours/week).

[c] Adjusted for age, gender, race/ethnicity, insurance type, medical home, person completing survey, family structure, family education level.

23.3% of global hospital costs, but only 4.4% of hospital discharges,[1] and in the 2013 National Inpatient Sample, CHD accounted for the highest percentage of birth defect–associated hospitalizations.[17] In the current analysis, almost half of CSHCN with CHD had both physical and developmental comorbidities, which may also contribute to high relative financial burdens. Compared with the general US child population, children reported by parents to have CHD are four times more likely to have autism, nine times more likely to have an intellectual disability, and 14 times more likely to have activity limitations.[2] Children in metropolitan Atlanta with validated diagnoses of CHD and without non-cardiac defects, including chromosomal or syndromic conditions, were found to be 1.5 times more likely to use special education services, including 1.3 times more likely to receive services for autism and 3.8 times more likely to receive services for intellectual disability.[4]

Similar to prior studies of CSHCN, insurance type and disease severity were associated with financial burdens in families of CSHCN and CHD.[9,18] In this report, uninsured CSHCN with CHD had a 1.5 to 2 times higher prevalence of large out-of-pocket expenses and financial problems in their families than those privately insured. Although some CSHCN are eligible to be covered under state Child Health Insurance Programs (CHIP) and Medicaid based on level of disability and income, others do not qualify based on income, and a large portion of eligible children are not enrolled.[19] In 2010 an estimated 400 000 CSHCN remained uninsured.[9] CSHCN with CHD with more functional limitations and comorbidities had families that reported significantly more financial burdens, similar to children with other chronic conditions.[20] Functional limitations are common in children with severe types of CHD, such as hypoplastic left heart syndrome, who also have high financial burdens.[7,21] With the increased survival of children born with severe types of CHD,[22] disease complexity and lifetime treatment costs are expected to increase and, in turn, increase financial burdens among families. Education level was also associated with financial burdens in families of CSHCN with CHD. Families of 6–17 year olds with higher education levels had higher financial burdens. While unexpected, this finding could be related to the known relationship between higher education level and higher salary.[23] These families may have a caregiver that is able to quit or cut works hours because the household earns enough income which may lead to perceived financial problems.

Our finding that many families of CSHCN with CHD need mental health services due to their child's condition supports prior studies reporting the psychological impact of caring for a child with CHD. Parents of children with CHD may exhibit psychological distress, anxiety, depression, and posttraumatic stress disorder, particularly around

TABLE 3 Associations between demographic characteristics and financial burdens and need for mental health services among families of children with congenital heart disease, NS-CSHCN, United States, 2009–2010

	Out-of-pocket expenses >$1000		Family experienced financial problems		Family members stopped working or cut hours to care for child		Family member spends ≥11 hours/week providing or coordinating care		Family members needed mental health services due to child's condition	
	Age 0–5 years aPR (95% CI)	Age 6–17 years aPR (95% CI)	Age 0–5 years aPR (95% CI)	Age 6–17 years aPR (95% CI)	Age 0–5 years aPR (95% CI)	Age 6–17 years aPR (95% CI)	Age 0–5 years aPR (95% CI)	Age 6–17 years aPR (95% CI)	Age 0–5 years aPR (95% CI)	Age 6–17 years aPR (95% CI)
Child's sex										
Female	1.3 (0.9, 1.7)	1.2 (1.0, 1.5)	0.9 (0.7, 1.3)	1.0 (0.8, 1.2)	1.1 (0.9, 1.4)	1.0 (0.8, 1.2)	1.0 (0.7, 1.4)	0.8 (0.6, 1.1)	1.5 (0.9, 2.4)	1.4 (1.0, 2.1)
Male	1	1	1	1	1	1	1	1	1	1
Child's race/ ethnicity										
White, Non-Hispanic	1	1	1	1	1	1	1	1	1	1
Black, Non-Hispanic	0.8 (0.3, 2.4)	0.7 (0.4, 1.3)	1.1 (0.6, 2.0)	0.9 (0.6, 1.4)	1.2 (0.7, 1.9)	0.9 (0.6, 1.3)	1.4 (0.9, 2.4)	1.0 (0.6, 1.6)	0.5 (0.1, 2.2)	0.7 (0.4, 1.3)
Hispanic	0.8 (0.4, 1.6)	0.7 (0.5, 1.1)	0.7 (0.4, 1.2)	1.0 (0.7, 1.4)	0.8 (0.5, 1.2)	1.3 (1.0, 1.7)	0.8 (0.4, 1.5)	1.2 (0.8, 1.9)	1.1 (0.4, 3.3)	0.9 (0.4, 1.8)
Other[a]	1.5 (0.8, 2.6)	0.9 (0.6, 1.5)	2.0 (1.4, 3.0)	1.2 (0.8, 1.8)	1.0 (0.7, 1.6)	1.2 (0.8, 1.9)	1.8 (1.1, 2.9)	1.2 (0.7, 1.9)	2.3 (1.3, 4.2)	1.4 (0.9, 2.4)
Child's insurance type										
Any private	1	1	1	1			1	1	1	1
Public	0.5 (0.3, 1.0)	0.5 (0.3, 0.9)	0.7 (0.5, 1.1)	0.7 (0.5, 1.0)	–[e]	–[e]	1.5 (0.9, 2.4)	1.5 (1.0, 2.3)	1.5 (0.8, 3.1)	0.9 (0.5, 1.7)
Uninsured	2.0 (1.1, 3.5)	1.6 (1.0, 2.4)	1.7 (1.0, 2.8)	2.0 (1.5, 2.7)			3.0 (1.7, 5.3)	1.2 (0.5, 2.8)	5.2 (1.8,14.8)	0.9 (0.4, 2.6)
Medical home[b]										
Yes	1	1	1	1	1	1	1	1	1	1
No	0.9 (0.6, 1.3)	0.8 (0.7, 1.1)	1.8 (1.2, 2.5)	1.2 (0.9, 1.5)	1.2 (0.9, 1.5)	1.1 (0.9, 1.4)	1.4 (0.9, 2.1)	1.2 (0.8, 1.8)	1.2 (0.6, 2.2)	1.3 (0.8, 2.0)
Types of co-morbidities[c]										
None	1	1	1	1	1	1	1	1	1	1
Developmental	1.0 (0.5, 2.2)	0.8 (0.5, 1.2)	1.4 (0.7, 3.0)	0.7 (0.4, 1.1)	1.1 (0.7, 1.8)	1.1 (0.6, 1.9)	0.9 (0.3, 2.6)	1.1 (0.4, 2.7)	0.7 (0.2, 2.6)	18.3 (3.8, 87.4)
Physical	1.5 (0.9, 2.7)	0.9 (0.6, 1.3)	2.3 (1.3, 4.3)	0.8 (0.6, 1.3)	1.0 (0.7, 1.5)	0.9 (0.5, 1.6)	1.4 (0.7, 2.7)	1.1 (0.4, 3.0)	1.6 (0.7, 3.7)	6.4 (1.2, 33.8)
Both	1.8 (0.9, 3.3)	1.0 (0.7, 1.4)	2.5 (1.3, 4.7)	0.9 (0.6, 1.4)	1.2 (0.8, 1.8)	1.2 (0.7, 1.9)	1.6 (0.8, 3.2)	1.6 (0.7, 3.6)	1.2 (0.5, 3.3)	26.9 (5.9,123.4)[f]
Condition affects daily activities										
Never affected	1	1	1	1	1	1	1	1	1	1
Moderately affect, some of the time	1.0 (0.6, 1.6)	1.1 (0.8, 1.5)	1.3 (0.8, 2.1)	1.6 (1.0, 2.4)	1.9 (1.2, 3.0)	1.6 (1.0, 2.5)	7.2 (3.1, 16.7)	3.2 (1.4, 7.0)	1.8 (0.8, 4.1)	1.8 (0.8, 4.3)
Consistently affect, often a great deal	1.3 (0.8, 2.1)	1.3 (1.0, 1.9)	1.4 (0.9, 2.3)	2.5 (1.6, 3.8)	2.2 (1.4, 3.5)	2.5 (1.6, 4.0)	11.7 (5.1, 26.9)	8.4 (4.1, 17.0)	2.3 (0.9, 6.3)	2.0 (0.9, 4.5)

(Continues)

TABLE 3 (Continued)

	Out-of-pocket expenses >$1000		Family experienced financial problems		Family members stopped working or cut hours to care for child		Family member spends ≥11 hours/week providing or coordinating care		Family members needed mental health services due to child's condition	
	Age 0–5 years aPR (95% CI)	Age 6–17 years aPR (95% CI)	Age 0–5 years aPR (95% CI)	Age 6–17 years aPR (95% CI)	Age 0–5 years aPR (95% CI)	Age 6–17 years aPR (95% CI)	Age 0–5 years aPR (95% CI)	Age 6–17 years aPR (95% CI)	Age 0–5 years aPR (95% CI)	Age 6–17 years aPR (95% CI)
Family structure										
Two parents	1	1	1	1	1	1	1	1	1	1
Mother only	1.1 (0.6, 2.0)	1.2 (0.9, 1.6)	0.7 (0.4, 1.2)	1.4 (1.0, 1.8)	0.9 (0.6, 1.3)	1.0 (0.8, 1.3)	0.9 (0.6, 1.5)	1.2 (0.9, 1.8)	0.8 (0.3, 2.1)	1.1 (0.7, 1.8)
Other structures	1.5 (0.8, 2.8)	0.3 (0.1, 0.7)	1.5 (0.9, 2.4)	1.2 (0.6, 2.2)	1.5 (0.9, 2.3)	0.8 (0.5, 1.3)	1.0 (0.4, 2.8)	1.1 (0.5, 2.2)	0.8 (0.2, 3.5)	1.6 (0.8, 3.2)
Highest education of any household member										
<High school	1	1	1	1	1	1	1	1	1	1
High school	0.3 (0.1, 1.4)	0.9 (0.5, 2.0)	1.2 (0.6, 2.6)	1.6 (0.9, 3.0)	1.0 (0.6, 1.7)	2.0 (1.1, 3.7)	2.1 (0.6, 7.2)	1.2 (0.6, 2.2)	0.2 (0.1, 0.9)	0.4 (0.2, 1.0)
>High school	0.7 (0.2, 2.4)	1.1 (0.6, 2.1)	1.2 (0.6, 2.5)	1.9 (1.0, 3.3)	1.0 (0.6, 1.7)	2.1 (1.2, 3.8)	2.3 (0.7, 7.8)	1.2 (0.6, 2.2)	0.5 (0.2, 1.1)	0.9 (0.5, 1.8)
Federal poverty status[d]										
<100% FPL	0.4 (0.2, 1.1)	0.4 (0.2, 0.8)	1.5 (0.8, 3.0)	1.7 (1.1, 2.8)	1.1 (0.7, 1.6)	1.6 (1.1, 2.2)	1.0 (0.5, 1.9)	1.5 (0.7, 2.9)	0.4 (0.2, 1.2)	1.2 (0.7, 2.3)
100%–199% FPL	0.8 (0.4, 1.4)	0.6 (0.4, 0.9)	1.6 (0.8, 3.0)	1.4 (0.9, 2.0)	1.1 (0.8, 1.6)	1.5 (1.1, 2.1)	1.1 (0.5, 2.1)	1.5 (0.8, 2.7)	0.8 (0.3, 2.5)	1.0 (0.5, 2.0)
200%–399% FPL	1.1 (0.8, 1.6)	0.8 (0.6, 1.0)	1.8 (1.0, 3.1)	1.6 (1.2, 2.2)	0.9 (0.7, 1.3)	1.2 (0.9, 1.6)	1.2 (0.7, 1.9)	1.2 (0.7, 2.1)	2.0 (0.9, 4.4)	0.8 (0.5, 1.4)
≥400% FPL	1	1	1	1	1	1	1	1	1	1
Financial problems										
Yes	–	–	–	–	–	–	–	–	1.2 (0.7, 2.2)	2.1 (1.3, 3.3)
No									1	1

All models also adjusted for all variables in table as well as person completing the survey: mother, father, or other family member/guardian, and financial problems was added to mental health needs model.

Abbreviations: aPR, adjusted prevalence ratio; CI, confidence interval; FPL, federal poverty level.

[a] Other includes respondents identified as Asian, Alaskan Native, American Indian, Native Hawaiian, Pacific Islander, or mixed race.

[b] Meets Maternal and Child Health Bureau criteria for a medical home.

[c] Developmental comorbidities include attention deficit disorder or attention deficit hyperactivity disorder, depression, anxiety, behavioral or conduct problems, autism or an autism spectrum disorder, developmental delay, an intellectual disability or mental retardation, Down syndrome; physical comorbidities include asthma, diabetes, epilepsy or seizure disorder, migraines or frequent headaches, blood problems, cystic fibrosis, cerebral palsy, muscular dystrophy, arthritis or joint problems, allergies, and head injury, concussion or traumatic brain injury.

[d] Based on US Department of Health and Human Services poverty guidelines.

[e] Insurance type removed from employment impact model based on expected relationship between insurance and employment. Fifty percent of families with uninsured children had employment changes compared with 37% of children with private insurance.

[f] Low numbers in cells led to wide confidence intervals that may influence precision of estimates.

the time of diagnosis and surgery.[6,24] They face uncertainty about the child's condition and prognosis, parenting stress, and strain on siblings.[8,25] In our analysis, 6–17 year-olds with CHD whose caregiver reported financial problems were twice as likely to report a family member need for mental health services as those without family financial problems. In other studies, financial and socioeconomic stressors explain more variation in the psychological impact on families than CHD severity.[25,26]

Ensuring that CSHCN with CHD have adequate health insurance coverage and are connected to appropriate services may help reduce both the financial and mental strain experienced by their families. Despite the fact that many resources are available for CSHCN, 2.5% of CSHCN with CHD were uninsured in this analysis. According to a 2004 publication, 15% of eligible CSHCN were reportedly not enrolled in Medicaid or CHIP programs during 2000–2001.[27] CSHCN may also qualify for Medicaid based on disability or through special waivers and be eligible for early intervention programs and case management.[28] Family members, however, may not be aware of all available resources, and thus, education and outreach may help reduce financial burdens for this small, but vulnerable part of the population. Also, ensuring that all CSHCN have a medical home, per national recommendations, may reduce out-of-pocket expenses due to care coordination and decreasing unnecessary high cost, repetitive, or emergent interventions.[29,30] Screening family members for mental health needs may be beneficial at pediatric visits. These types of caregiver screenings have already been established for the postpartum period,[31] and other types of childhood conditions.[32] Psychological therapies are known to improve mental well-being in parents of children with CHD and other chronic conditions, and those who screen positive may then be connected with appropriate care.[6,33] Discussion of potential familial financial and psychological outcomes associated with having a child with CHD, in addition to physiologic and neurodevelopmental outcomes, may also be warranted during prenatal counseling.

Limitations

We acknowledge several limitations in this report. First, all diagnoses and outcomes are reported by a caregiver. Types of conditions, including CHD or other heart problems, may have been underreported due to the respondent not knowing or recalling the lifetime conditions of the CSHCN or over-reported due to misinterpretation of health information such as a nonpathologic cardiac murmur. Underreporting or over-reporting of outcomes may have also occurred due to the respondent being unaware of the financial or mental health needs of other family members. Although many children with CHD have comorbidities secondary to their heart condition, we cannot determine the relative contributions of the heart condition or other comorbidities to financial burdens or mental health needs. Second, this report is generalizable only to CSHCN with CHD, not all children with CHD, and the type and severity of CHD are unknown. The proportion of CSHCN with acquired heart problems in this sample is also unknown, although CHD is the most common form of pediatric heart disease.[16] Third, all outcomes were assessed in a 12-month time frame, and do not represent lifetime financial burdens or mental health needs and should be interpreted accordingly. Lastly, respondents were neither asked about specific mental health diagnoses, nor whether a clinician determined the family member's need for mental health care.

5 | CONCLUSION

An estimated one million US children currently live with CHD, and the majority of children with CHD require lifelong care.[34,35] Families of CSHCN with CHD may have substantial out-of-pocket expenses, financial problems, employment impact, caregiving hours, and mental health needs. Policies and interventions that reduce financial impact and improve family mental health are needed, especially among families with children who are uninsured, have comorbidities, or a condition affecting daily activities. Strategies to intervene through existing state early intervention or Women's, Infants, Children's (WIC) programs may be particularly useful for identifying families most at risk. Also, continued outreach to families of CSHCN to raise awareness of available services may help to relieve financial burdens. The population of CSHCN with CHD is expected to increase with the improved survival of children with the most severe types of CHD, and, thus, interventions to improve family outcomes are needed.

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CONFLICT OF INTEREST

None.

AUTHOR CONTRIBUTIONS

All authors substantially contributed to and are responsible for the content of the manuscript, including the concept, design, analysis and interpretation of data, drafting or revising of the manuscript, and have approved the final manuscript as submitted.

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