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Long Term Outcomes in Children with Congenital Heart Disease: National Health Interview Survey

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Abstract

Objective—To assess the extent of long-term morbidity in children with congenital heart disease (CHD).

Study Design—We used data from the 1997–2011 National Health Interview Survey to study long-term outcomes in children aged 0–17 years with CHD. Parents were asked whether their child was diagnosed with CHD. We assessed comorbidities including autism/autism spectrum disorders (ASD); healthcare utilization including number of emergency room visits; and daily life aspects including number of days of school missed. These outcomes were compared for children with and without reports of CHD using odds ratios and chi-squared statistics.

Results—Our study included 420 children with and 180,048 children without reports of CHD; with no significant differences in age and sex. The odds of reporting worse health and greater than 10 days of school/daycare missed in the last year were three times as high for children with CHD compared to children without CHD. Children aged 2–17 with CHD were more likely than children without CHD to have had a diagnosis of ASD (crude odds ratio [OR]: 4.6, 95% confidence interval [CI]: 1.9–11.0), or intellectual disability (OR: 9.1, 95% CI: 5.4–15.4). The prevalence of emergency room, home, and doctors' visits were significantly higher in children with CHD compared to those without CHD.

Conclusions—Reported adverse outcomes were higher in children with congenital heart disease. These findings, particularly those regarding neurodevelopmental outcomes, may be helpful for parents, healthcare providers, and others in assessing the specific needs of children and teenagers with CHD.

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Contributors' Statement:

Hilda Razzaghi: Dr. Razzaghi conducted the analysis and was involved in study design.

Matt Oster: Dr. Oster provided clinical expertise on congenital heart defects and was involved in study design and developing the manuscript.

Jennita Reefhuis: Dr. Reefhuis was involved in the study design and developing the manuscript.

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Keywords

congenital heart defects; children; NHIS; comorbidities; neurodevelopmental outcome

Introduction

Congenital heart disease (CHD) includes both structural and non-structural anomalies present at birth. Structural anomalies of the heart, or congenital heart defects are the most common type of birth defect in the United States [1, 2] and the leading cause of infant mortality associated with birth defects [3]. With new surgical techniques and medical therapies, mortality rates have decreased for children with congenital heart defects[4, 5]; an estimated 85% of these children survive into adulthood [6, 7]. It was estimated that 650,000 to 1.3 million adults were living with a congenital heart defect in the United States in 2002 [1]. These survivors are at increased risk of having physical and developmental disabilities [8–11]. The prevalence and severity of the comorbidities increase with the complexity of the defect [12]. Given the increases in survival, there are more adults living with CHD who have comorbidities and higher hospital admission rates than the general population [13–16]. In addition, recent literature shows increased risks of neurodevelopmental outcomes including difficulties with language, attention, academic achievement, fine and gross motor skills and psychosocial factors for children of various ages with CHD[17–20].

The National Health Interview Survey (NHIS) includes a representative sample of children aged 0–17 years and has included a question about a diagnosis of a congenital heart disease for many years. The purpose of our study was to assess social and daily life, comorbidities, neurodevelopmental outcomes and healthcare utilization among children with CHD using a nationally, representative sample in order to have data that are useful for policy and public health/planning prupses in regards to CHDs in children.

Methods

Data Source

We used data from the National Health Interview Survey (NHIS), a cross-sectional study, from 1997 through 2011. NHIS is an annual multistage probability sample survey of the civilian, noninstitutionalized population of the United States conducted by the National Center for Health Statistics (NCHS) of the U.S. Centers for Disease Control and Prevention. NHIS conducts computer-assisted personal interviews with three main components: the Family Core, the Sample Adult Core, and the Sample Child Core. In addition to these main components, there are supplemental sets of questions that are added each year and can differ from one year to the next. The Family Core includes an adult from the family who responds to the questionnaire as a proxy for the entire family; the Family Core includes questions on health status, income and assets, limitations, injuries and more. In addition, the Sample Adult Core includes one random adult (18 years or older) and the Sample Child Core includes one random child (17 years or younger) from the family for participation. A knowledgeable adult in the family answers the questions in the Sample Child Core component about the sample child (SC). A series of questions including those on health

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status, limitations, injuries, healthcare access and utilization, and health insurance are similar in the Sample Adult Core and Sample Child Core; however, questions regarding health conditions are different and specific to each core. A new sample design was implemented for NHIS in 2006, however the fundamental structure was very similar to the previous sample design (1995–2005) [http://www.cdc.gov/nchs/nhis/about_nhis.htm]. The NCHS Research Ethics Review Board approved the NHANES protocol.

Study sample

The current study includes information collected on all children 0–17 years of age from the Sample Child Core component from 1997 to 2011. Children with Down Syndrome (n-298) were excluded from our analysis, 21 of whom also had CHD. Information regarding other birth defects or genetic syndromes is not available in NHIS. We examined only those questions that were relevant to our study objective and were included in years 1997–2011. The questions examined for this analysis are included in Appendix A.

Congenital heart disease (CHD)

One of the questions asked in the Sample Child Core component of NHIS was “Has a doctor or other health professional ever told you that SC had congenital heart disease?”. There were a total of 441 children for whom CHD diagnosis was mentioned (cases) and 180,325 for whom this question was answered negatively (controls).

Covariates

Demographic information including age, sex, and race/ethnicity of the SC were reported at the time of the interview. We categorized race and ethnicity into the following categories: non-Hispanic white, non-Hispanic black, Hispanic and other race/ethnicity. For children with and without CHD diagnosis we assessed the following questions: whether health was better, worse, or about the same in the last year; days of school (or daycare) missed in the last year; special equipment need; impairment or health problem limiting physical activity; and whether child has had a problem that requires prescription medication for over three months. We also reported on comorbidities including cerebral palsy, sickle cell anemia, asthma, allergies, and ear infections. Neurodevelopmental outcomes assessed were autism/autism spectrum disorders (ASD), Attention-Deficit/Hyperactivity Disorder or Attention-Deficit Disorder (ADHD/ADD), and intellectual disability. We also examined a variety of elements to assess healthcare utilization including number of emergency room visits, home care, and frequency of healthcare provider visits in the last year.

Statistical Analysis

Analyses were conducted using SAS (version 9.3; Research Triangle Institute, Research Triangle Park, Cary, NC). Survey sample weights and the appropriate sample design variables were used in the analysis to account for the complex survey design, oversampling, and differential nonresponse and noncoverage, in order to obtain nationally representative estimates of the U.S. civilian non-institutionalized population. Taylor series linearization method was used to calculate 95% confidence intervals (CIs) for the estimated prevalences, and chi-square statistics were used to compare cases to controls.

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Results

We analyzed data on 180,468 children ages 0–17 years, from 1997–2011 with completed NHIS interviews: 420 children with reported CHD and 180,048 children without a report of CHD. Age and sex distributions were not significantly different for those with CHD compared to those without (p=0.99 and p=0.54, respectively); the majority of cases and controls were non-Hispanic white (Table 1). When comparing aspects of daily life, cases were three times as likely to report worse health in the last year compared to controls (Odds Ratio [OR]: 3.3; 95% confidence interval (95% CI): 1.8–6.0) and were also three times as likely to have missed more than 10 days of school/day care (OR: 2.9; 95% CI: 2.1–4.1) (Table 2). Special equipment use and having an impairment limiting crawling, walking, and running were reported more frequently among cases compared to controls (Table 2). Of those children with impaired crawling, walking, and running abilities, 98% had impairments that had lasted or would last more than 12 months.

Studying other conditions and comorbidities that were queried in NHIS, we found that asthma and ear infections (Table 2) and neurodevelopmental issues (Table 3) were reported more often for cases than controls. For children under the age of 2 years, respondents for cases were as likely to have reported three or more ear infections in the last year compared to controls (OR: 2.4; 95% CI: 1.2–5.2) (Table 2). Among neurodevelopmental outcomes in children 2–17 years of age, children with CHD diagnoses had higher odds of ASD (OR: 4.6; 95% CI: 1.9–11.0), ADHD/ADD (OR: 1.6; 95% CI: 1.1–2.4), and intellectual disability (OR: 9.1; 95% CI: 5.4–15.4) compared to the controls (Table 3).

We also examined healthcare utilization patterns (Table 3). Children with reported CHD were two times as likely than children without CHD to have seen a healthcare professional who treated a variety of illnesses in the last year (OR: 1.9; 95% CI: 1.3–2.7). There was a significant difference in where the children were taken when sick even though for the majority of cases and controls “Doctor’s office” ($p<0.0001$) was reported. Emergency room visits, doctors’ office visits, as well as home care were more common in cases when compared to children without CHD diagnosis (Table 3). Furthermore, cases were three times as likely to have seen a healthcare provider in the last 12 months compared to controls (OR: 3.2; 95% CI: 1.7–6.0) and of those children with healthcare provider visits, almost 35% of the cases and 16% of the controls visited the healthcare provider more than five times.

Children in all age groups with CHD were more likely to report worse health in the last 12 months compared to children without CHD (Figure 1). Those 12–17 years of age had the highest percentage of school days missed, and the group with the highest need for special equipment use were children 6–11 years of age with CHD compared to the other age groups (Figure 1). The prevalence of ADHD/ADD, intellectual disability, and learning disability increased with increasing age, and all three of these conditions were most commonly noted among those 12–17 years of age (Figure 1).

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Discussion

Using data from the representative National Health Interview Survey, we found that children with CHD between the ages of 0 and 17 years are more likely to miss school days and need special equipment compared to children without CHD. We found that children with CHD are also more likely to have comorbidities including asthma and developmental disabilities such as ASD, ADHD/ADD, and intellectual disability. As survival beyond infancy has increased, children with CHD appear to be at increased risk for neurodevelopmental and psychosocial morbidity, requiring treatment which often affects quality of life as well as increased healthcare utilization and cost.

There have been many studies on quality of life (QOL) in children with CHD, including congenital heart defects, and their parents [18, 21–26]; however, these studies have been in select populations and have yielded mixed results. We examined, in NHIS, days of school missed, whether health was better or worse in the past year, need of special equipment, and impairment limiting physical activity, including crawling, walking, and running, and used the information to gain an understanding of daily life for children with CHD. Our finding that children with CHD were three times as likely to report declining health in the past year and were more likely to miss a greater number of school days, in combination with our finding of declining numbers of regular visits with healthcare providers in the older age groups, is concerned given that children with CHD should be under routine medical care [27]. Additionally, an eight-fold increased odds of special equipment need and a fourteen-fold increased odds of impairment limiting physical activity are concerning and have implications throughout the life of the child and young adult.

In terms of quality of life, another important contributing factor is the presence of other comorbidities. To our knowledge, many of the comorbidities including cerebral palsy, sickle cell anemia, allergies, and ear infections had not been examined before in association with CHD. Our finding that children with CHD had increase prevalence of asthma was similar to that of Nieminen et al. [28] in regards to congenital heart defects. Although the numbers of cases with cerebral palsy and sickle cell anemia were small, we found higher rates of these comorbidities in children with CHD compared to those without CHD. In general, higher rates of comorbidities observed in children with CHD compared to those without CHD may in part be due to increased healthcare contact for children with CHDs.

Many studies have found increased risks of ASD, ADHD/ADD, and speech and language disorders in children with congenital heart defects [29–32]. Our results are in agreement with recent studies reporting greater prevalences of ASD and attention problems in children with congenital heart defects [20, 29–31, 33]. We observed an approximate five-fold increases odds of ASD and an almost two-fold increased odds of ADHD/ADD in children with CHD compared to those without CHD. Our findings support earlier recommendations for careful surveillance and screening for these conditions for children with CHD [34]. Furthermore, our finding that among children with CHD, healthcare utilization was lowest among adolescents (12–17) compared to children 0–5 and 6–11 year old is consistent with findings from other studies in the United States [35] and in other countries [36–38].

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Strengths of our study are the fact that NHIS provides a large representative sample of the non-institutionalized U.S. population with regards to age, geography, and disease severity. The large sample size as well as the inclusion of information on comorbidities, including neurodevelopmental outcomes, healthcare utilization, and social and daily aspects of the child's life made it possible to assess these important health outcomes in relation to CHD. Although the large sample size including 17 years of data is a strength of our study; it could affect our findings as we were not able to account for increased awareness of neurodevelopmental outcomes or improvements in medical techniques. The main limitation of our study is the lack of detail in the question on CHD and the lack of confirmation of the diagnosis which could lead to either overestimation or more likely underestimation of the prevalence of CHD. The questionnaires did not distinguish whether the congenital heart disease was a structural anomaly (congenital heart defect) or nonstructural problem such as an arrhythmia. Thus our results do not represent findings for all congenital heart defects or for specific types of defects. Furthermore, the questions lacked detail on whether emergency room visits or doctor's visits was due to the CHD or due to an unrelated condition. In addition, we were not able to compare our findings for CHD to those of other types of birth defects using the National Health Interview Survey because the only types of birth defects ascertained were CHD and Down Syndrome. Finally, there was not any information in NHIS on any other birth defects and genetic or syndromic conditions; thus the results may be biased by subjects having a other conditions such as prematurity or higher incidence of underlying genetic abnormalities. To our knowledge this is the first time the CHD question from NHIS is being used, and from our analysis it appears to have some limitations. Future studies comparing our findings for CHD to those of other defects are warranted.

Overall, we observed greater prevalences of comorbidities, including neurodevelopmental disabilities, in children with CHD. Children with CHD were more likely than children without CHD to miss school days and utilize healthcare, especially at younger ages. Additional information on comorbidities, healthcare utilization, and the impact on the daily life of children/adults with CHD would be extremely helpful for patients and their parents as they plan for the future as well as for their healthcare providers and public health professionals for planning purposes. Thus, pediatricians should be aware that children with CHD might need additional care beyond the immediate effects of the CHD and deserve close monitoring well beyond early childhood.

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Abbreviations

ADHD	attention-deficit/ hyperactivity disorder
ADHD/ADD	Attention Deficit Hyperactivity Disorder/Attention Deficit Disorder
ASD	autism/autism spectrum disorders

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CHD	congenital heart disease
CI	confidence interval
NHIS	National Health Interview Survey
OR	odds ratio
QOL	quality of life
SC	sample child

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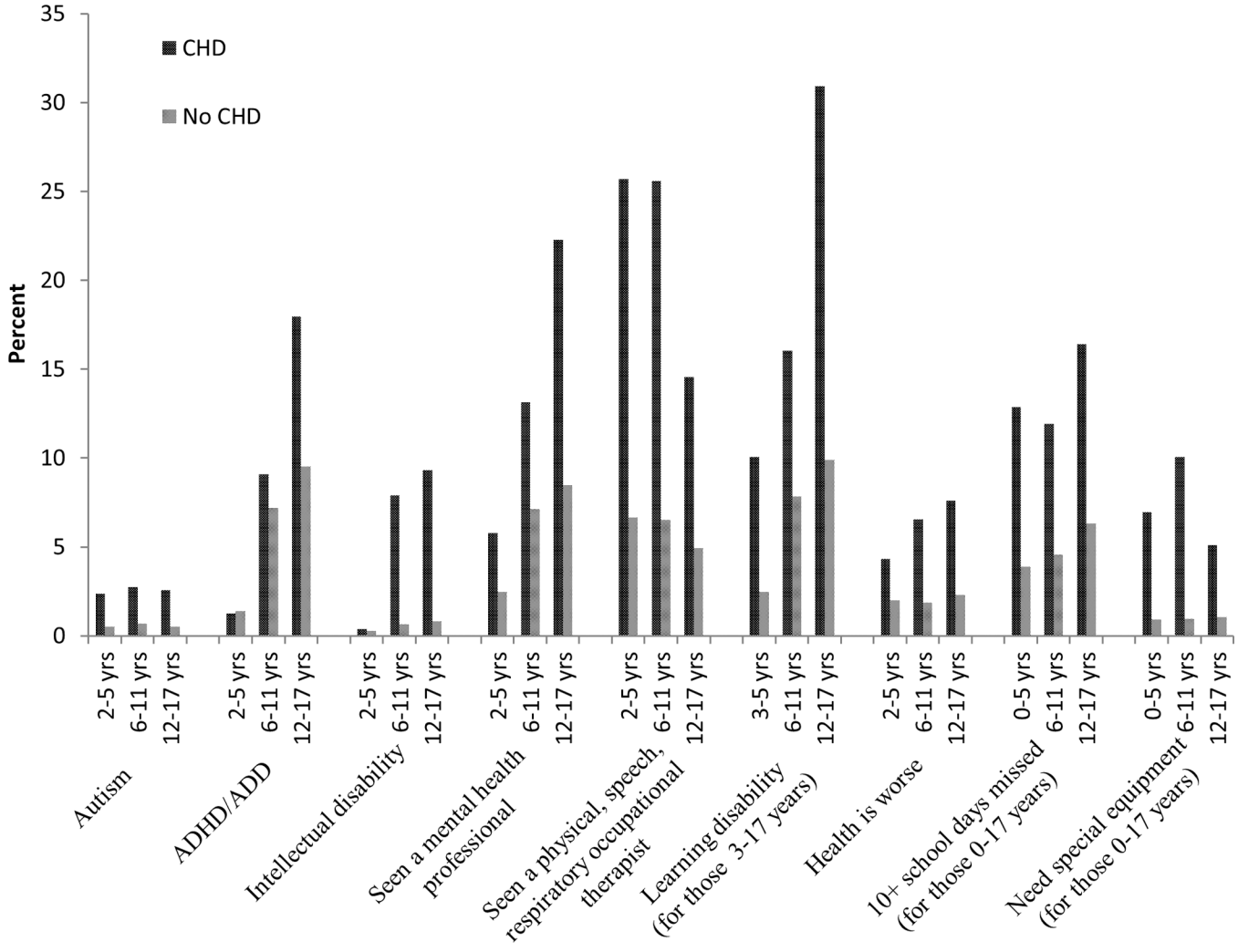

Figure 1.

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Table 1

Characteristics of children 0–17 years of age with and without congenital heart disease in the Unites States, 1997–2011*

Variable	CHD 420 (%)	No CHD 180,048 (%)
Age		
0–5 years	144 (33.4)	61,916 (33.2)
6–11 years	127 (33.1)	55,487 (33.3)
12–17 years	149 (33.4)	62,645 (33.5)
	P^{**}=0.99	
Sex		
Male	216 (49.4)	92,518 (51.1)
Female	204 (50.6)	87,530 (48.9)
	P^{**}=0.54	
Race/Ethnicity		
NH White	252 (68.1)	87,993 (59.8)
NH Black	42 (10.4)	28,055 (14.5)
Hispanic	97 (15.1)	51,601 (19.1)
Other	27 (6.3)	11,792 (6.4)
	P^{**}=0.05	

* Data source: CDC/NCHS, National Health Interview Survey

** p-values for χ^2 test

CHD: congenital heart disease; NH: non-Hispanic; CDC: Center for Disease Control and Prevention; NCHS: National Center for Health Statistics

Percentages do not correspond with raw numbers because of the weighting used in the National Health Interview Survey (NHIS)

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Table 2

Crude associations for comorbidities and daily life and impairment factors in children 0–17 years for children with and without congenital heart disease diagnoses in the Unites States, 1997–2011*

Variable	CHD 420 (%)	No CHD 180,048 (%)	Odds Ratio (95% CI)
Health in the last 12 months (children aged 2–17 years)			
About the same	237 (93.4)	120,890 (97.9)	3.3 (1.8–6.0)
Worse	16 (6.6)	2,680 (2.1)	
Days of school/day care missed among those who attended school/day care			
≤10 days	240 (85.9)	117,427 (94.7)	2.9 (2.1–4.1)
>10 days	47 (14.1)	6,953 (5.3)	
Special equipment need due to health problem			
No	386 (92.6)	178,247 (99.0)	8.2 (5.5–12.1)
Yes	34 (7.4)	1,752 (1.0)	
Impairment limits crawl/walk/run			
No	334 (78.7)	176,542 (98.0)	14.1 (10.2–19.4)
Yes	86 (21.3)	3,431 (1.9)	
Cerebral Palsy			
No	411 (98.2)	178,423 (99.0)	1.9 (0.9–4.1)
Yes	9 (1.8)	1,625 (1.0)	
Sickle Cell Anemia			
No	417 (99.4)	179,711 (99.8)	3.7 (0.7–18.8)
Yes	3 (0.6)	337 (0.2)	
Asthma			
No	329 (79.4)	156,820 (87.3)	1.8 (1.3–2.4)
Yes	90 (20.6)	22,934 (12.7)	
Had an episode in last 12 months	48 (53.0)	9,725 (43.1)	1.5 (0.9–2.5)
Regular intake of prescription medication for over 3 months due to medical problem			
No	283 (67.5)	158,930 (87.8)	3.5 (2.7–4.6)
Yes	136 (32.5)	20,974 (12.2)	
Questions pertaining to children two years of age and younger			
	72 (%)	32,384 (%)	
Allergy (respiratory, food, skin) in last 12 months			
No	45 (76.6)	26,276 (81.8)	1.4 (0.8–2.7)
Yes	23 (23.4)	5,362 (18.2)	
Three or more ear infections in the last 12 months			
No	53 (73.5)	27,739 (87.5)	2.4 (1.2–5.2)
Yes	15 (26.5)	3,890 (12.5)	

* Data source: CDC/NCHS, National Health Interview Survey

CHD: congenital heart disease; CI: confidence interval; CDC: Center for Disease Control and Prevention; NCHS: National Center for Health Statistics

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Table 3

Crude associations between congenital heart disease, neurodevelopmental outcomes, and healthcare utilization children 0–17 years in the Unites States, 1997–2011*

Variable	CHD 374 (%)	No CHD 158,243(%)	Odds Ratio (95% CI)
Neurodevelopmental Outcomes and Healthcare Utilization in children 2–17 years			
Autism/ASD			
No	368 (97.4)	157,360 (99.4)	4.6 (1.9–11.0)
Yes	6 (2.6)	883 (0.6)	
ADHD or ADD			
No	329 (89.7)	147,983 (93.4)	1.6 (1.1–2.4)
Yes	44 (10.3)	9,942 (6.6)	
Been told SC had intellectual disability			
No	351 (94.7)	157,146 (99.4)	9.1 (5.4–15.4)
Yes	23 (5.3)	981 (0.6)	
Seen or talked to a mental health professional in last 12 months			
No	317 (85.5)	147,749 (93.5)	2.5 (1.6–3.7)
Yes	54 (14.5)	9,834 (6.5)	
Seen a physical, speech, respiratory, occupational therapist or audiologist in last 12 months			
No	292 (78.4)	148,907 (94.0)	4.3 (3.2–5.9)
Yes	79 (21.6)	8,657 (6.0)	
Learning disability**			
No	271 (79.1)	136,579 (92.4)	3.8 (2.9–5.2)
Yes	77 (20.9)	10,875 (7.6)	
Healthcare Utilization for Children 0–17			
	CHD 420 (%)	**No CHD 158,243(%)**	**Odds Ratio (95% CI)**
There is a usual place you go to when child is sick			
Yes	400 (96.0)	167,946 (94.3)	0.7 (0.4–1.2)
No	20 (4.0)	11,777 (5.7)	
Has healthcare provider changed in last 12 months			
No	374 (92.0)	154,255 (91.6)	0.9 (0.6–1.4)
Yes	31 (8.0)	14,203 (8.4)	
Not due to changes in health insurance	23 (82.0)	9,788 (70.6)	0.5 (0.2–1.2)
Due to changes in health insurance	8 (18.0)	4,401 (29.4)	
Has child seen a medical doctor who treats a variety of illnesses^ in last 12 months			
No	52 (12.0)	38,203 (20.2)	1.9 (1.3–2.7)
Yes	364 (88.0)	140,922 (79.8)	
Has child received a well-child checkup in last 12 months			
No	75 (22.6)	36,363 (25.7)	1.2 (0.9–1.6)
Yes	245 (77.4)	101,699 (74.3)	
Has child gone to an ER in last 12 months			

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Variable	CHD 374 (%)	No CHD 158,243(%)	Odds Ratio (95% CI)
No	277 (68.4)	141,329 (79.5)	1.8 (1.4–2.4)
Yes	136 (31.6)	37,762 (20.5)	
1–5 time	122 (90.6)	36,909 (97.8)	4.7 (2.1–10.4)
>5 times	14 (9.4)	854 (2.2)	
Did child receive care at home in last 12 months			
No	397 (95.1)	177,823 (99.1)	5.7 (3.3–9.7)
Yes	20 (4.9)	1,588 (0.9)	
1–5 times	3 (20.6)	690 (58.1)	5.3 (1.3–22.6)
>5 times	12 (79.4)	473 (41.9)	
Has child seen a health care professional in doctor's office or clinic in last 12 months			
No	18 (4.0)	21,744 (11.6)	3.2 (1.7–6.0)
Yes	398 (96.0)	156,057 (88.4)	
1–5 times	253 (64.8)	130,971 (83.9)	2.8 (2.2–3.7)
>5 times	145 (35.2)	25,086 (16.1)	
Time since child last saw or talked to a doctor or other healthcare provider			
≥6 months	56 (10.9)	43,407 (24.4)	2.6 (1.8–3.8)
<6 months	360 (89.1)	134,800 (75.6)	

* Data source: CDC/NCHS, National Health Interview Survey

** only asked of those 3–17 years of age

^ Pediatrics, family or internal medicine physicians

CHD: congenital heart disease; ASD: autism spectrum disorders; ADHD: attention-deficit/hyperactivity disorder; ADD: attention-deficit disorder; SC: sample child; ER: emergency room; CI: confidence interval; CDC: Center for Disease Control and Prevention; NCHS: National Center for Health Statistics