Children with Heart Conditions and Their Special Health Care Needs — United States, 2016

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Children with heart conditions often use more health care services and specialized care than children without a heart condition (1); however, little is known about the number of U.S. children with heart conditions and their special health care needs. CDC used data from the 2016 National Survey of Children's Health (NSCH) to estimate the prevalence of heart conditions among U.S. children aged 0–17 years, which indicated that 1.3% had a current heart condition and 1.1% had a past heart condition (representing approximately 900,000 and 755,000 children, respectively). Sixty percent and 40% of children with current and past heart conditions, respectively, had one or more special health care needs, compared with 18.7% of children without a heart condition (adjusted prevalence ratios [aPRs] = 3.1 and 2.1, respectively). Functional limitations were 6.3 times more common in children with current heart conditions (30.7%) than in those without heart conditions (4.6%). Among children with current heart conditions, males, children with lower family income, and children living in other than a two-parent household had an increased prevalence of special health care needs. These findings highlight the importance of developmental surveillance and screening for children with heart conditions and might inform public health resource planning.

Heart conditions in children can be congenital or acquired and range from asymptomatic to life-threatening. Congenital heart defects (CHDs) are the most common type of birth defect in the United States, affecting approximately 1% of live births (2). Children with CHDs often use more health care or educational services than do children without CHDs and might require specialized care (1,3,4). Less is known about the prevalence or needs of children with acquired heart conditions. Previously, there have been no known U.S. population-based estimates of the number of children with heart conditions or their special health care needs.

NSCH is a population-based, nationally representative survey of parents or primary caregivers (parents) of noninstitutionalized U.S. children aged 0–17 years.* NSCH asks parents about a selected child’s health, health care access, and family characteristics. In 2016, a total of 364,150 households were

*https://mchb.hrsa.gov/data/national-surveys.
sampled; 138,009 (37.9%) parents completed screener surveys, and 50,212 (36.4%) of those completed topical surveys. The overall weighted response rate was 40.7%.

Parents were asked if they had ever been told by a health care provider that their child had a heart condition. Those who responded affirmatively were asked if their child currently had a heart condition. Children’s heart condition status was categorized as “current,” “past,” or “none.” Parents were also asked about their child’s special health care needs using a standardized five-item screener that included 1) need for or use of medications (other than vitamins) prescribed by a doctor; 2) need for or use of medical care, mental health, or educational services beyond those of a similarly aged child (referred to as “average use”); 3) limitation in the child’s ability to do things most children of the same age can do; 4) need for or receipt of treatment or counseling for an emotional, behavioral, or developmental problem. If any special health care need was attributable to a medical, behavioral, or other health condition that had lasted, or was expected to last, 12 months or longer, the child was considered to have a special health care need. The questionnaire also inquired about 26 other health conditions.§

The numbers and percentages of children with current, past, and no heart conditions were calculated. Chi-square tests were used to examine the differences in demographic characteristics (sex, age, race/ethnicity, family income as a percentage of the federal poverty level [FPL], highest parental education level achieved, health insurance type, and household structure); other health conditions; and special health care needs, by heart condition status. Marginal prediction approach to logistic regression was used to assess the association between heart condition status and one or more special health care needs, adjusted for demographic characteristics. Among children with a current heart condition, characteristics associated with having one or more special health care needs also were examined. All analyses were repeated excluding children with Down syndrome or other genetic conditions because these children’s heart conditions might be related to the syndromes. All analyses included design parameters to account for complex sampling.

§Allergies, anxiety problems, arthritis, asthma, attention deficit disorder/attention deficit hyperactivity disorder, autism spectrum disorder, behavioral/conduct problems, blood disorders, brain injury, cerebral palsy, cystic fibrosis, depression, developmental delay, diabetes, Down syndrome, epilepsy/seizure disorder, headaches/migraines, hearing impairment, learning disability, mental retardation/intellectual disability, other genetic/inherited conditions, other mental health conditions, speech/language disorder, substance abuse, Tourette syndrome, and vision impairment.
TABLE 1. Characteristics of children aged 0–17 years, by parent-reported heart condition status — National Survey of Children’s Health, United States, 2016

| Characteristic                  | Current          | Past             | None             | Chi-square | p value |
|--------------------------------|------------------|------------------|------------------|------------|---------|
|                                | Unweighted no.   | Weighted % (95% CI) | Unweighted no.   | Weighted % (95% CI) | Unweighted no. | Weighted % (95% CI) |               |
| Total                          | 634              | —                | 498              | —          | 47,347  | —                |               |
| Sex                            |                  |                  |                  |            |         |                  |               |
| Male                           | 356              | 58.3 (50.0–66.1) | 267              | 53.5 (42.6–64.1) | 24,189  | 50.8 (49.8–51.8) | 0.17          |
| Female                         | 278              | 41.7 (33.9–50.0) | 231              | 46.5 (35.9–57.4) | 23,158  | 49.2 (48.2–50.2) |               |
| Age group (yrs)                |                  |                  |                  |            |         |                  |               |
| 0–5                            | 185              | 28.9 (22.9–35.7) | 136              | 27.9 (20.5–36.7) | 13,717  | 32.4 (31.5–33.4) | 0.16          |
| 6–11                           | 194              | 44.0 (35.9–52.4) | 144              | 32.7 (23.2–43.7) | 14,139  | 33.9 (32.9–34.9) |               |
| 12–17                          | 255              | 27.1 (21.6–33.5) | 218              | 39.5 (29.1–50.9) | 19,491  | 33.7 (32.8–34.6) |               |
| Race/Ethnicity                 |                  |                  |                  |            |         |                  |               |
| White, non-Hispanic            | 455              | 55.7 (47.3–63.8) | 356              | 52.0 (41.0–62.8) | 33,510  | 52.5 (51.5–53.6) | 0.75          |
| Other*                         | 179              | 44.3 (36.2–52.7) | 142              | 48.0 (37.2–59.0) | 13,837  | 47.5 (46.4–48.5) |               |
| Family income as a percentage of federal poverty level† |                  |                  |                  |            |         |                  |               |
| <100%                          | 72               | 21.5 (15.5–28.9) | 58               | 28.7 (17.6–43.3) | 4,309   | 20.5 (19.5–21.5) | 0.28          |
| 100%–199%                      | 112              | 27.4 (19.6–36.8) | 81               | 19.4 (13.2–27.6) | 7,375   | 21.9 (21.0–22.9) |               |
| 200%–399%                      | 208              | 27.4 (21.8–33.9) | 169              | 27.6 (20.6–36.0) | 14,693  | 27.2 (26.3–28.0) |               |
| ≥400%                          | 242              | 23.7 (18.7–29.7) | 190              | 24.2 (17.6–32.3) | 20,970  | 30.4 (29.6–31.2) |               |
| Parental education level§      |                  |                  |                  |            |         |                  |               |
| High school graduate or less   | 107              | 35.2 (26.9–44.6) | 77               | 29.3 (19.9–40.9) | 6,772   | 28.4 (27.3–29.6) | 0.38          |
| More than high school          | 527              | 64.8 (55.4–73.1) | 421              | 70.7 (59.1–80.1) | 40,575  | 71.6 (70.4–72.7) |               |
| Household structure            |                  |                  |                  |            |         |                  |               |
| Two parents                    | 503              | 72.3 (65.1–78.5) | 393              | 77.6 (69.6–83.9) | 38,606  | 75.8 (74.9–76.7) | 0.54          |
| Other                          | 131              | 27.7 (21.5–34.9) | 105              | 22.4 (16.1–30.4) | 8,741   | 24.2 (23.3–25.1) |               |
| Insurance type‡                |                  |                  |                  |            |         |                  |               |
| Any private, unspecified, or uninsured | 459          | 55.4 (47.0–63.5) | 354              | 50.7 (39.9–61.5) | 36,679  | 61.6 (60.5–62.6) | 0.10          |
| Public, unspecified, or uninsured | 173             | 44.6 (36.5–53.0) | 141              | 49.3 (38.5–60.1) | 10,544  | 38.4 (37.4–39.5) |               |

Abbreviation: CI = confidence interval.
* Includes Hispanic, non-Hispanic black, American Indian/Alaska Native, Native Hawaiian or Other Pacific Islander, and Asian.
† Based on the U.S. Department of Health and Human Services Poverty Guidelines.
§ Highest education level among two parents or child’s primary caregivers.
‡ 129 had missing information on insurance type.
TABLE 2. Percentage and adjusted prevalence ratio* of special health care needs† among children aged 0–17 years, by parent-reported heart condition status — National Survey of Children’s Health, United States, 2016

| Special health care needs                                                                 | Current     | Current aPR* (95% CI) | Past        | Past aPR* (95% CI) | None        | None aPR* (95% CI) |
|----------------------------------------------------------------------------------------|-------------|-----------------------|-------------|-------------------|-------------|-------------------|
| Has one or more special health care needs                                              | 60.0 (51.6–67.8) | 3.1 (2.7–3.6)         | 40.0 (29.9–50.9) | 2.1 (1.6–2.7)    | 18.7 (18.0–19.5) |
| Needs or uses prescription medicines                                                   | 42.8 (35.3–50.7) | 3.0 (2.5–3.6)         | 26.6 (17.5–38.1) | 1.9 (1.3–2.8)    | 13.8 (13.2–14.5) |
| Above average use of health care or educational services‡                            | 41.8 (34.5–49.4) | 4.2 (3.5–5.1)         | 23.9 (17.2–32.2) | 2.4 (1.8–3.3)    |
| Has functional limitations                                                             | 30.7 (24.3–38.0) | 6.3 (5.0–8.1)         | 17.4 (11.5–25.5) | 3.7 (2.4–5.6)    | 4.6 (4.1–5.0)   |
| Needs or uses physical, occupational, or speech therapies                             | 22.4 (16.9–29.0) | 4.3 (3.2–5.7)         | 14.4 (9.2–21.8) | 2.9 (1.8–4.6)    | 4.7 (4.3–5.2)   |
| Needs or receives treatment or counseling for emotional, developmental or behavioral conditions | 23.4 (17.8–30.0) | 2.7 (2.1–3.5)         | 22.5 (15.9–30.9) | 2.7 (1.9–3.8)    |

Abbreviations: aPR = adjusted prevalence ratio; CI = confidence interval.
* Prevalence ratio of special health care needs for current and past heart conditions versus no heart condition, adjusted for sex, age group, race/ethnicity, family income as a percentage of the federal poverty level, parental education level, and household structure.
† Based on having one or more of the following five conditions: needing or using prescription medicine; needing or using more medical care, mental health, or educational services than other children their age; having limitations in doing things, compared with other children their age; needing special therapy (e.g., physical, occupational, or speech therapy); or having an emotional, developmental, or behavioral problem in need of counseling or treatment. These conditions must be related to a medical, behavioral, or other health condition that has lasted or is expected to last 12 months or longer.
‡ Beyond those of a similarly aged child.
§ Highest relative differences observed for functional limitations (current aPR = 6.3; 95% CI = 5.0–8.1) (past aPR = 3.7; 95% CI = 2.4–5.6).

Among children with current heart conditions, an increased prevalence of special health care needs was observed among males (aPR = 1.3; 95% CI = 1.1–1.7), children with family income <100% of FPL (aPR = 1.4; 95% CI = 1.0–2.0), and children living in other than a two-parent household (aPR = 1.3; 95% CI = 1.0–1.6) (Table 3). Findings did not change substantially after excluding 1,650 children with Down syndrome or other genetic conditions, 181 (11%) of whom had a heart condition.

**Discussion**

According to the 2016 NSCH, 1.3% and 1.1% of U.S. children had a current or past heart condition, respectively. Because the specific types of heart conditions were unknown (i.e., congenital versus acquired), comparing current findings with published estimates of CHDs or acquired heart conditions is difficult. The birth prevalence of CHDs is nearly 1%, and approximately 1 million U.S. children have CHDs (2). Although U.S. estimates of some acquired heart diseases such as those resulting from Kawasaki disease (5) and rheumatic heart disease (6) exist, the prevalence of other acquired heart conditions in children is unknown.

Children with CHDs are at increased risk for developmental disabilities and speech, motor, behavior, or learning problems (7), whereas the risk for children with acquired heart conditions has not been quantified. The higher prevalence of special health care needs among children with heart conditions, particularly

TABLE 3. Associations between selected demographic characteristics and special health care needs among children aged 0–17 years who have a current heart condition — National Survey of Children’s Health, United States, 2016

| Characteristic                                | One or more special health care needs | Weighted % (95% CI) | aPR* (95% CI) |
|-----------------------------------------------|--------------------------------------|---------------------|--------------|
| Sex                                           |                                       |                     |              |
| Male                                          | 68.9 (60.5–76.3)                     | 1.3 (1.1–1.7)       |
| Female                                        | 47.4 (34.5–60.7)                     | Referent            |
| Age group (yrs)                               |                                       |                     |              |
| 0–5                                          | 57.8 (45.9–68.9)                     | Referent            |
| 6–11                                         | 58.5 (42.7–72.7)                     | 1.0 (0.7–1.2)       |
| 12–17                                        | 64.4 (53.4–74.4)                     | 1.1 (0.9–1.3)       |
| Race/Ethnicity                                |                                       |                     |              |
| White, non-Hispanic                           | 62.4 (54.6–69.7)                     | Referent            |
| Other                                         | 56.8 (41.3–71.1)                     | 0.9 (0.7–1.1)       |
| Family income as a percentage of federal poverty level§ | |                     |              |
| <100%                                         | 80.5 (67.3–89.3)                     | 1.4 (1.0–2.0)       |
| 100%–199%                                     | 52.8 (32.6–72.2)                     | 1.0 (0.7–1.5)       |
| 200%–399%                                     | 59.5 (47.8–70.2)                     | 1.1 (0.9–1.5)       |
| ≥400%                                         | 50.1 (38.5–61.7)                     | Referent            |
| Parental education level†                     |                                       |                     |              |
| High school graduate or less                  | 62.0 (41.6–78.9)                     | 1.0 (0.8–1.3)       |
| More than high school                         | 58.8 (51.6–65.7)                     | Referent            |
| Household structure                           |                                       |                     |              |
| Two parents                                   | 54.2 (44.2–63.8)                     | Referent            |
| Other                                         | 75.1 (63.3–84.0)                     | 1.3 (1.0–1.6)       |

Abbreviations: aPR = adjusted prevalence ratio; CI = confidence interval.
* Prevalence ratios adjusted for sex, age group, race/ethnicity, family income, parental education level, and household structure.
† Includes Hispanic, non-Hispanic black, American Indian/Alaska Native, Native Hawaiian or Other Pacific Islander, and Asian.
‡ Based on the U.S. Department of Health and Human Services Poverty Guidelines.
§ Highest education level among two parents or child’s primary caregivers.
functional limitations identified in this study, supports the American Academy of Pediatrics’ guidance on developmental surveillance and screening for early identification and intervention (7), particularly for children with complex CHDs (e.g., single ventricle defects) (7).

Similar to the present findings among children with CHDs, male sex, lower family income, and other than two-parent household structure have been associated with special health care needs in the general pediatric population (8). The differences in the prevalence of special health care needs by sex, family income, and household structure could reflect a difference in health status or differential ascertainment. Associations between special health care needs and family income and household structure might be attributable to stress and financial issues associated with the child’s health and treatment (9). More information is needed to know what resources might support families and benefit children.

The findings in this report are subject to at least five limitations. First, data are parent-reported and unconfirmed by medical records; however, according to findings from a study that used medical records to verify parental report of a diagnosis of autism (10), parental report of their child’s medical history might be valid. Second, separate analyses for congenital, acquired, or other heart conditions could not be conducted because information on the type of heart condition was not available. Third, the composition of heart conditions relies on what the responding parent considered a “heart condition” or a “current heart condition,” which might underestimate or overestimate the prevalence of heart conditions. Fourth, although the data were weighted for nonresponse, bias might remain. Finally, the temporality of special health care needs and family income or household structure is unknown.

These first population-based prevalence estimates of children with heart conditions and their special health care needs highlight the importance of guidelines for developmental surveillance and screening for early identification and intervention (4,7). These estimates could inform national and state child health programs to ensure that children with heart conditions receive necessary services.

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