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# A National Profile of Health Care and Family Impacts of Children With Muscular Dystrophy and Special Health Care Needs in the United States

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## Abstract

We used the 2005–2006 National Survey of Children with Special Health Care Needs to compare 3 types of outcomes between children with and those without parental reported muscular dystrophy: (1) functional limitations; (2) health care experiences in terms of the 5 components of a medical home; and (3) family impacts, including financial or out-of-pocket costs and parental employment and time use. We used weighted logistic regression to examine their associations with muscular dystrophy after adjustment for socio-demographic characteristics. Among children with special health care needs, children with reported muscular dystrophy were much more likely to have difficulties with ambulation and self-care. They were more likely to have family members who reported financial problems, reduced or stopped employment, and spent more than 10 hours weekly providing or coordinating care. Muscular dystrophy was not associated with the likelihood of having a medical home after adjustment for socioeconomic status and other socio-demographic characteristics.

### Keywords

muscular dystrophy; National Survey of Children with Special Health Care Needs; medical home; family impact; Duchenne; Emery-Dreifuss

The muscular dystrophies are a diverse group of genetic disorders characterized by progressive muscle wasting and weakness. They vary with regard to the gene involved,



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**Authors' Contributions**

Lijing Ouyang, Scott Grosse, Michael Fox, and Julie Bolen contributed to the study design, interpretation of the data and the results, and critical review and revision of the manuscript. Lijing Ouyang analyzed the data. All authors contributed to and have approved the final manuscript.

**Declaration of Conflicting Interests**

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

**Ethical Approval**

Not applicable, analysis of public use data.

mode of inheritance, age of onset, distribution of muscle involvement, and severity.[1,2] Some major forms of muscular dystrophies are childhood onset, including Congenital, Duchenne/Becker, limb girdle, and Emery-Dreifuss.[3] Most types of muscular dystrophies are not simply muscle disorders, but rather multisystem disorders with manifestations in a variety of body systems, including the heart, gastrointestinal system, endocrine glands, skin, eyes, brain, and other organ systems.[3]

Children with muscular dystrophy require complex and long-term health services in multiple settings by a variety of professionals. To protect and promote the well-being of this population, it is important to assess and monitor their receipt of care. In this study, we characterized the health care experiences and family impacts of children with muscular dystrophy using data from the 2005–2006 National Survey of Children with Special Health Care Needs. Three questions were addressed. First, how did functional and emotional difficulties and health care needs of children with muscular dystrophy compare with other special needs children without muscular dystrophy? We hypothesize that children with muscular dystrophy experience more functional and emotional difficulties and have greater health care needs. Second, how did services suggesting the presence of a medical home[4] for children with muscular dystrophy compare with children with special healthcare needs without muscular dystrophy? American Academy of Pediatrics' medical home model of primary care includes 5 components: a usual place for sick and preventive care; a personal doctor or nurse; no problems obtaining referrals when needed; effective care coordination; and family-centered, compassionate, and culturally appropriate care. We hypothesize that children with muscular dystrophy are less likely to have a medical home. Third, how were families affected by muscular dystrophy in terms of employment, time use, and payment for medical care? We hypothesize that children with muscular dystrophy are more likely to have family members who reduce employment and that their families pay more for their medical care.

## Methods

### Data Source

This study was a secondary analysis of cross-sectional data from the 2005–2006 National Survey of Children with Special Health Care Needs. The National Survey of Children with Special Health Care Needs was a complex random digit-dial telephone survey using independent random household samples for all 50 states and the District of Columbia. During April 2005 to February 2007, Children with special health care needs screening was completed for 192 083 households with children, defined as persons living in the household under the age of 18. One child with special health care needs was randomly selected from each household with children with special health care needs for a detailed proxy interview. A parent or guardian knowledgeable about the child's health and health care served as the survey respondent. Surveys were conducted in other languages (mainly Spanish) when the household was identified as needing a language other than English. A total of 40 840 interviews were completed for children with special health care needs. An interview weight has been associated with all children with special health care needs from the main sample. Estimates based on the interview weights generalize to the US noninstitutionalized

population of children with special health care needs 0–17 years of age. Screener weight is on the screener file and is used to produce estimates that are representative of children nationally. The weighted overall response rate for special needs interviews was 56.1%. Details of the survey methods are described elsewhere.[5]

## Description of Variables

Children with special health care needs with muscular dystrophy were identified on the basis of the question, "To the best of your knowledge, does your child currently have muscular dystrophy?" Possible answers include yes, no, don't know, or refused. No questions about the specific form of muscular dystrophy were included in the survey. We use 3 variables to measure functional ability, including whether the surveyed child, relative to other children of their age, experienced any difficulty with coordination or moving around, whether he or she needed durable medical equipment (such as wheelchairs, hospital beds, oxygen tanks, pressure machine, and orthotics.), and whether he or she needed mobility aids or devices such as canes, crutches, wheelchairs, or scooters in the past 12 months.

We assess health care experiences based on the 5 components of the American Academy of Pediatrics' medical home model of primary care.[4] We follow the algorithm provided by the National Center for Health Statistics to create these variables for the 2005–2006 National Survey of Children with Special Health Care Needs.[6] Care coordination was considered effective if the family respondent was very satisfied with doctors' communications with each other and with other programs and the family respondent reported usually getting sufficient help coordinating care if needed. Care was regarded as family centered if doctors were reported to usually spend enough time, listen carefully, be sensitive to values and customs, provide needed information, make the family feel like a partner, and have an interpreter usually available when needed.

Family impact was assessed based on parent-reported out-of-pocket expenditures and time use.[7] We included measures of whether the family paid US$1000 or more during the previous 12 months for the child's medical care (excluding health insurance premiums and costs reimbursed by insurance or other payment sources), which was more than 3 times the mean out-of-pocket annual health care expense per person with expenses (US$319) in 2006.[8] Other measures of financial burden were dichotomous measures of whether the child's health care caused financial problems for the family or whether the family needed additional income to cover the child's medical expenses; whether the family spent ≥ 10 hours per week providing, arranging, or coordinating the child's health care; and whether any family members stopped working or cut down on work hours because of the child's health conditions.[9]

Socio-demographic covariates included the child's age in years (0 to 5, 6 to 11, and 12 to 17), sex, race/ethnicity (non-Hispanic white, non-Hispanic black, Hispanic, and other), family structure (2-parent biologic/adoptive family versus other), household poverty level (<100%, 100% to <200%, 200% to <400%, ≥ 400% federal poverty level), primary language spoken in the household language (English versus other),the highest education level in the household (below high school versus high school or above). We used the imputed household poverty level using multiple imputation methods by National Center for

Health Statistics. Type of health insurance was reported as private (offered through employer or union or self-purchase), public (Medicaid or State Children's Health Insurance Program), private and public, insured with unknown type, and uninsured. Socioeconomic status was proxied by household poverty level, household education, and public insurance.

### Statistical Analysis

We performed bivariate analyses to examine the relationship of muscular dystrophy to socio-demographic characteristics and variables measuring health care experiences and family impact. The Pearson's $\chi^2$ test was used to examine the association between categorical variables. We then examined the relationship between having muscular dystrophy and dependent variables (health care experiences and family impact) in multivariate logistic regressions with socio-demographic variables as covariates. For regression analyses, interview weights were used to produce weighted estimates that are representative of children with special health care needs nationally. Multiple imputation estimation was used. Statistical estimates were calculated using Stata 11.[10]

In our preliminary analyses, respondents who answered the survey in a language other than English were 7 times more likely to report a child with muscular dystrophy. We restricted our final sample to those whose surveys were administered in English. In total, 997 children (3.7% of the weighted full sample) were excluded. Our results are representative of children with special health care needs in households where English was spoken.

## Results

### Children With Special Health Care Needs With Muscular Dystrophy

In this nationally representative sample of children with special health care needs for whom the survey was conducted in English, we identified 112 children with parent-reported muscular dystrophy, who represented an estimated 27 479 children with both special health care needs and muscular dystrophy among children under age 18 in the United States. This translated into a weighted prevalence of 39 per 100 000 children under age 18 in the United States. Children with muscular dystrophy were more likely to be male (69%) and aged between 12 and 17 years (50%) (Table 1).

The majority of those with muscular dystrophy had difficulties with coordination or moving around (67%), difficulties with self-care such as eating, dressing, and bathing (48%), and difficulty using hands or fingers (51%). In comparison, only 10% to 15% of children with special health care needs without muscular dystrophy had these problems. Approximately one-fourth of the children with muscular dystrophy needed mobility aids or durable medical equipment, compared with 5% to 10% among children with special health care needs without muscular dystrophy. Children with muscular dystrophy in this sample were also more likely to have emotional or behavioral difficulties. Children with muscular dystrophy had significantly elevated frequencies of most other conditions named in the survey compared with children without muscular dystrophy, including attention deficit disorder (40% vs 30%), autism (12% vs 5%), Down syndrome (3.7% versus 0.9%), intellectual disability (35% vs 11%), emotional problems (30% versus 21%), cystic fibrosis (5.4% vs

0.25%), cerebral palsy (20% vs 1.8%), seizure (14% vs 3.3%), migraine (48% vs 15%), and joint problems (38% vs 4.2%).

Children with muscular dystrophy had family members who significantly more frequently reported enrollment in public health insurance, family incomes below the poverty threshold, and low education. Children with muscular dystrophy were less likely to live in 2-parent biological/adoptive households and more likely to be black non-Hispanic (Table 1).

## Health Care Experiences and Family Impacts

In bivariate analyses (Table 1), smaller percentages of children with special health care needs with muscular dystrophy had a medical home compared with other children in the survey (28% vs 46%, $P < .05$). Among the 5 components of a medical home, children with special healthcare needs with muscular dystrophy were significantly less likely to have a usual source of sick and preventive care, to have personal doctor or nurse, and to receive family-centered care relative to children with special healthcare needs without muscular dystrophy. Children with muscular dystrophy were also significantly more likely to have parents who reported financial problems, reduced or stopped employment, or spent more than 10 hours per week providing or coordinating care.

After adjusting for socio-demographic factors, there were no significant differences between children with special healthcare needs with muscular dystrophy and those without muscular dystrophy in the odds of having a medical home (Table 2). In contrast, being male, older age, other than white non-Hispanic, language other than English spoken at home, household education below high school, household income below poverty line, living in a single parent household, and having no insurance or public insurance were associated with an elevated risk of not having a medical home.

Family measures of impact were greater for a child with muscular dystrophy relative to other children with special health care needs after controlling for socio-demographic characteristics (Table 3). Children with muscular dystrophy were significantly more likely to have family members who reported that they had financial problems, stopped or cut back on work due to muscular dystrophy, provided more than 10 hours of care per week, and paid $1000 or more out of pocket during the previous 12 months for the child's medical care after controlling for confounding. The magnitudes of these associations were large; in multivariate analyses, children with muscular dystrophy were approximately 5 times as likely to have family members who reported that they spent more than 10 hours per week providing or coordinating care compared with other children with special health care needs. Children with muscular dystrophy were more than 3 times as likely to have family members who reduced or stopped employment or had financial problems, and more than twice as likely to have family members who paid more than $1000 for their child's medical care during the previous year.

Most socio-demographic characteristics had associations in opposite directions with the dichotomous care hours and out-of-pocket medical payment variables (Table 3). Being Hispanic, household income below poverty line, household education being high school or

below were associated with a higher probability of spending more than 10 hours per week to care for a child and a lower probability of spending $1000 or more for child's medical care.

## Discussion

The 2005–2006 National Survey of Children With Special Health Care represents an opportunity to examine the characteristics of children with muscular dystrophy, their health care experiences, and impacts on their families. Although prevalence data of muscular dystrophy in the United States is lacking, the prevalence of 39 per 100 000 agree in broad terms with the recent findings of 37 per 100 000 in Northern England.[11]

Compared with other children with special healthcare needs, our study showed that children with parent- or guardian-reported muscular dystrophy were more likely to be Black non-Hispanic and to live in single-parent households with low education and in poverty. Prevalence data for different race groups in the United States are lacking and future research is needed on whether and how race plays a role in the occurrence of muscular dystrophy. The relationship of low social economic status with the occurrence of muscular dystrophy is consistent with a study which reported that a higher than expected proportion of families of patients with Duchenne muscular dystrophy seemed to be from a socioeconomically disadvantaged background, even at the time of first diagnosis.[12] Although having a child with a disability might contribute to lower income, it is unclear how or whether these lower social economic status characteristics might lead to a higher incidence of muscular dystrophy.

We identified children with muscular dystrophy based on parent or guardian response to a survey question of whether the child had muscular dystrophy. There was no ability to confirm these reports through linkage to medical records. It is likely that there was some degree of misclassification because of potential confusion of the term "muscular dystrophy" with other conditions. In particular, children with parental reported muscular dystrophy were far more likely to also have parental reported cystic fibrosis or cerebral palsy than children without reported muscular dystrophy. It is unlikely that a child would have both muscular dystrophy and cerebral palsy, but it is impossible to know on which of the 2 conditions the respondent was mistaken. Similarly because muscular dystrophy and cystic fibrosis are unrelated genetic disorders the true prevalence of cystic fibrosis should be the same as for any other child, which suggests that most children who were reported to have both cystic fibrosis and muscular dystrophy (n = 7) were misreported. However, when we redid the analysis restricting the sample to those without reported cystic fibrosis or cerebral palsy, the results were very similar to the results reported here (available upon request to the authors).

Research is needed to both further assess and improve the ability of surveys to obtain accurate information on rare disorders. The National Center for Health Statistics has linked records for some of its surveys to public health insurance claims and national mortality data. The survey we used in this article, National Survey of Children with Special Health Care Needs 2005–2006, cannot be linked to health records because no information on Social Security numbers was collected from respondents.

After controlling for socio-demographic factors, children with muscular dystrophy were neither more nor less likely to have a medical home than other children with special healthcare needs. Socio-demographic characteristics accounted for the gross differences in health care experiences between the 2 groups. In contrast, controlling for covariates, children with muscular dystrophy were considerably more likely to have family members who experienced financial and employment problems and spent 10 or more hours per week providing or coordinating care. Parents of more than half of children with muscular dystrophy reported that they had to either reduce hours or stop working to care for their child. More than half of respondents said that they spent more than 10 hours weekly providing or coordinating care because of their child's condition. Children with muscular dystrophy had family members who experienced much greater time demands and restrictions on parental employment than did other children with special healthcare needs without muscular dystrophy. This is consistent with a finding from the same survey that health conditions with the most severe functional limitations were associated with the greatest impacts on family employment.[13]

The finding that lower socio-economic status was associated with more hours spent by family members providing care and a lower likelihood of spending more than $1000 out-of-pocket could reflect that children living in higher socio-economic status families were able to have family care replaced by professional care which those children in lower socio-economic status families were unable to have. It is also consistent with the finding that lower-income families spend less in absolute terms but a greater percentage of their income, which is a more meaningful indicator of financial burden.[8,14] Also, lower-socioeconomic status families perceive a greater financial burden for the same level of out-of-pocket expenditures.[15]

The large self-reported financial and caregiving impacts in families with muscular dystrophy suggest a need to identify effective strategies to help families and caregivers cope with muscular dystrophy. These strategies can be based on identified factors that influence family impacts. A previous study using health insurance claims data for a privately insured US sample has shown that average medical care expenditures for children and young adults with muscular dystrophy are 10 to 20 times higher than individuals without muscular dystrophy.[16] Economic pressure has been shown to be a significant predictor of quality of life in caregivers for people with a progressive neurological condition.[17] Interventions focused on resiliency and social support are likely to improve the quality of life of muscular dystrophy caregivers.[18] It has also been reported that children with special health care needs experienced significantly fewer adverse family financial and economic impacts if the affected child has a medical home or a family-centered system of health care.[13,19] Similarly, children with special health care needs who had access to family-centered care in a medical home and had adequate health insurance scored higher on a latent-variable well-being construct that was strongly predictive of family financial problems and negative financial impact.[20]

This study has limitations. First, muscular dystrophy is a rare disorder, and we only have information in this survey for a little over 100 children with muscular dystrophy. Future research is needed on how to sample rare conditions to increase sample size in nationally

representative samples. Second, because this is a cross-sectional study, causality cannot be established for associations between muscular dystrophy and socio-demographic characteristics such as family income and family structure. Longitudinal studies that follow children with muscular dystrophy and their families over time can provide insight into these questions. Third, it is important to note that this is a study of muscular dystrophy among children identified as having a special healthcare need. Estimates for the prevalence and characteristics of children with muscular dystrophy in the general population of all children can differ. Fourth, the group of children with special health care needs with or without muscular dystrophy is a diverse group of children with varying health condition complexity.[7,21] Future research differentiating subgroups of children with special health care needs can shed light on the features of muscular dystrophy that drive the impacts.

In conclusion, among children with special health care needs, those children having muscular dystrophy had lower family socioeconomic status than children without muscular dystrophy and also had more negative health care experiences. The negative healthcare experiences appear to be explained by the association with lower socioeconomic status. Adjusting for multiple factors, muscular dystrophy was not associated with lower likelihood of a medical home. Children with muscular dystrophy incurred substantially more negative financial and employment impacts on family members than did other children in the survey, independent of household socio-demographic characteristics. There is a need to identify effective strategies to help families and caregivers cope with muscular dystrophy.

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## Table 1

Comparison of Characteristics of Children with Special Health Care Needs in the United States 2005–2006, by Parent-Reported Muscular Dystrophy

| | CSHCN without muscular dystrophy %(SE) Weighted N=9 786 392 | CSHCN with muscular dystrophy %(SE) Weighted N=27 479 | *P* value |
|---|---|---|---|
| Age | | | .70 |
| 0 to 5 | 20.5(0.4) | 12.5(4.6) | |
| 6 to 11 | 37.2(0.4) | 37.5(8.7) | |
| 12 to 17 | 42.2(0.4) | 50.0(9.8) | |
| Male | 59.2(0.4) | 68.9(7.7) | .88 |
| Hispanic origin and race | | | .1 |
| White, non-Hispanic | 67.2(0.4) | 47.8(9.5) | |
| Black, non-Hispanic | 16.6(0.4) | 33.8(11.4) | |
| Hispanic | 8.7(0.3) | 9.6(4.6) | |
| Other | 7.5(0.2) | 8.8(3.9) | |
| Functional difficulty | | | |
| Experience any difficulty with coordination or moving around | 13.7(0.3) | 67.1(11.4) | < .001 |
| Difficulty with self-care such as eating, dressing, and bathing | 10.6(0.2) | 48.3(9.6) | < .001 |
| Difficulty using hands or fingers | 10.6(0.3) | 50.9(9.8) | < .001 |
| Emotional or behavioral difficulty | | | |
| Feeling anxious or depressed | 27.7(0.4) | 33.7(7.9) | < .001 |
| Behavior problems such as acting-out, fighting, bullying, or arguing | 27.3(0.4) | 48.4(10) | < .001 |
| Health care needs | | | |
| Needed mobility aids or devices such as canes, crutches, wheelchairs, or scooters | 4.1(0.2) | 24.4(5.9) | < .001 |
| Needed durable medical equipment during the past 12 months | 11.4(0.3) | 28.1(6.7) | < .001 |
| Family income, % of federal poverty level | | | < .001 |
| <100 | 18.1(0.3) | 47.8(10) | |
| 100 to <200 | 21.5(0.4) | 21.8(6.2) | |
| 200 to <400 | 30.6(0.4) | 17.8(4.9) | |
| ≥400 | 29.8(0.4) | 12.6(4.3) | |
| Highest education level of anyone in household | | | < .001 |
| Less than high school | 5.5(0.2) | 27.7(12.3) | |
| High school diploma or General Educational | 22.6(0.4) | 27.4(7.1) | |
| Development | | | |
| > High school | 71.6(0.4) | 44.9(9.1) | |
| Primary language in home | | | .10 |
| English | 98.3(0.1) | 92.9(3.3) | |
| Other | 1.7(0.1) | 7.1(3.3) | |
| Missing | | | |
| Type of insurance | | | < .001 |
| Public | 26.8(0.4) | 48.0(10.0) | |

| | CSHCN without muscular dystrophy %(SE) Weighted N=9 786 392 | CSHCN with muscular dystrophy %(SE) Weighted N=27 479 | *P* value |
|---|---|---|---|
| Both private and public | 7.2(0.2) | 19.2(5.9) | |
| Insured (type unknown) | 1.9(0.1) | 5.1(3.5) | |
| Uninsured | 3.1(0.1) | 2.4(1.2) | |
| Missing | 0.2(0) | 0.3(0.3) | |
| Family structure | | | .02 |
| 2 parent (biological or adoptive) | 53.4(0.4) | 33.4(7.5) | |
| Health care experiences : had a medical home | 46(0.4) | 28.1(6.9) | .02 |
| Has usual source of sick and preventive care | 93(0.2) | 86.6(6.2) | < .001 |
| Has personal doctor or nurse | 93.7(0.2) | 78.3(12.9) | .05 |
| No referral problems when needed | 79.5(0.6) | 67.8(11.9) | .16 |
| Receives effective care coordination | 59.8(0.5) | 48.4(7.4) | .1 |
| Receives family-centered care | 67(0.4) | 49.7(7.5) | < .001 |
| Family impact | | | |
| Financial problems | 23.3(0.4) | 52.8(9.5) | < .001 |
| Reduce or stop employment | 22.9(0.4) | 53.1(9.5) | < .001 |
| Paid $1000 or more for child’s medical care in previous year | 20(0.3) | 23(5.7) | .35 |

Abbreviations: N, number of subjects. SE, standard error. CSHCN: Children with Special Health Care Needs.

**Table 2**

The Association Between Muscular Dystrophy and Measures of Health Care Experiences Among Children With Special Health Care Needs in the United States: Adjusted Odds Ratios

| | Medical home | Usual source of care | Has personal doctor | No referral problem when needed | Receives family centered care | Received effective care coordination |
|---|---|---|---|---|---|---|
| Muscular dystrophy | 0.69 | 1.26 | 0.44 | 1.01 | 0.73 | 0.77 |
| Race/ethnicity | | | | | | |
| Black, non-Hispanic | 0.71[a] | 0.65[a] | 0.60[a] | 1.23 | 0.58[a] | 0.94 |
| Hispanic | 0.62[a] | 0.79 | 0.59[a] | 0.73[a] | 0.55[a] | 0.74[a] |
| Other | 0.74[a] | 0.81 | 0.8 | 0.92 | 0.68[a] | 0.75[a] |
| Female | 1.07 | 0.99 | 1.19 | 1.28 | 1.12 | 1.07 |
| Age group | | | | | | |
| 6 to 11 | 0.84[a] | 0.9 | 1.18 | 0.94 | 0.87[a] | 0.82[a] |
| 12 to 17 | 0.76[a] | 0.72[a] | 1.08 | 0.82 | 0.76[a] | 0.75[a] |
| 2 parent, biological or adoptive | 1.34[a] | 1.50[a] | 1.47[a] | 1.22[a] | 1.35[a] | 1.24[a] |
| Family income >100% of federal poverty level | 1.31[a] | 1.48[a] | 1.17 | 1.06 | 1.44[a] | 1.12 |
| Household education above high school | 1.05 | 1.45[a] | 1.76[a] | 0.80[a] | 1.19[a] | 0.79[a] |
| Language other than-English spoken at home | 0.52[a] | 0.39[a] | 0.69 | 0.63 | 0.50[a] | 0.93 |
| Type of insurance | | | | | | |
| Public | 0.83[a] | 1.04 | 0.93 | 0.80[a] | 0.88[a] | 0.81[a] |
| Both private and public | 0.66[a] | 0.9 | 0.81 | 0.72[a] | 0.81[a] | 0.68[a] |
| Insured, type unknown | 1.01 | 0.79 | 0.81 | 0.94 | 1.06 | 0.88 |
| Uninsured | 0.44[a] | 0.26[a] | 0.33[a] | 0.43[a] | 0.49[a] | 0.40[a] |

Note: The baseline is children with special health care needs without muscular dystrophy, being non-Hispanic white, male, aged 0 to 5 years, single parent household, household income below federal poverty level, household education is high school or below, English spoken at home, and private insurance.

[a] $P < .05$.

## Table 3

The Association Between Muscular Dystrophy and Measures of Family Impact Among Children With Special Health Care Needs in the United States: Adjusted Odds Ratios

| | Financial problem | Reduce or stop employment | Spend ≥10 hours week per for care | Paid ≥$1000 for medical care in previous year |
|---|---|---|---|---|
| Muscular dystrophy | 3.21[a] | 3.83[a] | 5.09[a] | 2.22[a] |
| Race/ethnicity | | | | |
| Black non-Hispanic | 0.93 | 0.9 | 1.1 | 0.46[a] |
| Hispanic | 0.96 | 1.12 | 1.36[a] | 0.80[a] |
| Other | 1.17[a] | 0.99 | 1.05 | 0.89 |
| Female | 0.89[a] | 0.95 | 0.90[a] | 1.08 |
| Age group | | | | |
| 6 to 11 | 1.03 | 0.82[a] | 0.80[a] | 1.07 |
| 12 to 17 | 1.13[a] | 0.72[a] | 0.70[a] | 1.30[a] |
| 2 parent, biological or adoptive | 0.81[a] | 0.93 | 1 | 1.06 |
| Family income ≥100% of federal poverty level | 0.91 | 0.89 | 0.70[a] | 1.73[a] |
| Household education above high school | 1 | 1.07 | 0.75[a] | 1.48[a] |
| Language other than-English spoken at home | 1.37 | 1.46[a] | 1.01 | 1.43[a] |
| Type of insurance | | | | |
| Public | 1.38[a] | 2.12[a] | 2.12[a] | 0.27[a] |
| Both private and public | 1.93[a] | 2.84[a] | 2.77[a] | 0.75[a] |
| Insured (type unknown) | 2.05[a] | 1.23 | 1.86[a] | 1.61[a] |
| Uninsured | 5.23[a] | 2.09[a] | 1.86[a] | 1.90[a] |

Note: The baseline is children with special health care needs without muscular dystrophy, being non-Hispanic white, male, aged 0 to 5 years, single parent household, household income below federal poverty level, household education is high school or below, English spoken at home, and private insurance.

[a] $P < .05$.