A National Profile of Caregiver Challenges Among More Medically Complex Children With Special Health Care Needs

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Objectives: To profile the national prevalence of more medically complex children with special health care needs (CSHCN) and the diversity of caregiver challenges that their families confront.


Setting: United States–based population.

Participants: National sample of CSHCN.

Main Exposure: More complex CSHCN were defined by incorporating components of child health and family need, including medical technology dependence and care by 2 or more subspecialists.

Main Outcome Measures: Caregiver challenges were defined by family-reported care burden (including hours providing care coordination and home care), medical care use (on the basis of health care encounters in the last 12 months), and unmet needs (defined by 15 individual medical care needs and a single nonmedical service need).

Results: Among CSHCN, 3.2% (weighted n=324,323) met criteria for more complex children, representing 0.4% of all children in the United States. Caregivers of more complex CSHCN reported a median of 2 (interquartile range, 1–6) hours per week on care coordination and 11 to 20 (interquartile range, 3–21) hours per week on direct home care. More than half (56.8%) reported financial problems, 54.1% reported that a family member stopped working because of the child's health, 48.8% reported at least 1 unmet medical service need, and 33.1% reported difficulty in accessing nonmedical services.

Conclusions: Extraordinary and diverse needs are common among family caregivers of more complex CSHCN. Enhanced care coordination support, respite care, and direct home care may begin to address the substantial economic burden and the multiple unmet needs that many of these families face.

versity of caregiver challenges. We hypothesized that family caregivers would report high levels of home care, unemployment, and unmet health care needs.

STUDY DESIGN

The study is a secondary analysis of the 2005-2006 National Survey of Children With Special Health Care Needs (NS-CSHCN). Funded by the Maternal and Child Health Bureau, the NS-CSHCN provides prevalence estimates of CSHCN and describes aspects of health care use, health status, and family burden. The NS-CSHCN is a module of the National Immunization Survey, conducted annually by the National Center for Health Statistics, with computer-assisted telephone interviews among a national random population sample. Participants for the NS-CSHCN were identified using the CSHCN screener, which asks whether the child had a chronic condition lasting at least 12 months that resulted in any of the following: (1) need for prescription medications; (2) need for more medical care than usual; (3) limited ability to do things; (4) need for occupational, physical, or speech therapy; or (5) emotional or behavioral problems. A positive response to any of the 5 questions enrolls a child in the NS-CSHCN. The sampling design specifies a goal of 750 CSHCN in each state, enabling a maximum standard error of 10% for all point estimates exceeding 15%. Because the data set is publicly available and deidentified, this study received exempt status from the institutional review board at the University of Arkansas for Medical Sciences.

STUDY POPULATION

The criteria for defining the study population were informed by enrollment criteria from geographically diverse clinical programs at tertiary care centers focused on comprehensive care for more complex CSHCN. Such criteria consider family-identified service need, medical equipment use for activities of daily living, the involvement of 2 or more subspecialists on an ongoing basis, and a history of elevated health service use, such as multiple hospitalizations. The criteria at such programs are typically not based on any specific diagnosis. Study participants in the NS-CSHCN were classified as more complex or less complex. Study participants who were more complex had to meet all 4 of the following criteria: (1) They had to have a positive response to the item on the CSHCN screener indicating “need for more medical care” than usual. This criterion addresses family-identified service need. (2) They had to have positive responses to at least 3 of 4 remaining items (listed in the “Study Design” subsection) on the CSHCN screener. We chose this criterion for several reasons. The number of positive responses on the CSHCN screener correlates with higher health care use. Furthermore, CSHCN with positive responses inclusive of different items have reported higher levels of complexity. We decided against requiring a positive response on all 4 items to avoid falsely excluding more complex CSHCN who were missing 1 component (eg, not all more complex CSHCN have family-identified emotional or behavioral problems). (3) The participants had to demonstrate use of medical equipment, defined as the need for a device to maintain activities of daily living. We operationalized equipment use as a positive response to the need for a mobility aid or device, communication aid or device, medical supplies, or durable medical equipment. This criterion was selected to approximate a comprehensive care program requirement of medical equipment use to address activities of daily living. (4) Finally, the participants had to have seen 2 or more subspecialists in the last 12 months. This criterion was selected to address the requirement of multiple subspecialist involvement.

OUTCOMES

The primary study outcome was family-reported care burden. This was assessed by weekly hours spent on care coordination and home care, financial burden out-of-pocket costs, and necessity for the family member to stop working, cut back on work to care for their child, or require additional income for medical expenses.

Secondary study outcomes were the following: (1) medical care use, including the use of outpatient, emergency department, early intervention, or special education services, and the stability of the child’s health care needs and family report of the number of school days missed and (2) unmet needs, assessed by specific questions relating to 15 identified medical care needs, including preventive, dental, and specialty care, and a single question on nonmedical service needs, such as early intervention services, child care, vocational education, rehabilitation, and related community programs.

We examined the demographic, health services, and clinical characteristics of the study cohort in relation to complexity and the study outcomes. Demographics included age, sex, race/ethnicity, census region, insurance type, poverty level, household educational level, and primary language of household. We examined the presence of a usual source of health care and a usual source of preventive care. The specific chronic medical condition of the child may account for some of the variation in health service use; accordingly, we examined whether the family member identified the child as having any of a list of 16 specific conditions.

STATISTICAL ANALYSIS

χ2 Test was used to compare demographic and diagnosis characteristics between more complex and less complex CSHCN. We identified diagnoses with the largest absolute prevalence differences (defined as being >15.0% between more complex and less complex CSHCN). Mann-Whitney test was used to compare medians or variables with nonnormal distributions (eg, school days missed and hours spent on care coordination). The skewed distribution of these variables led to a categorical large grouping of their highest values; results falling in such categories are reported as the numerical ranges.

The associations of more complex CSHCN with individual diagnoses were verified by logistic regression models that adjusted for significant (P < .05) demographics in bivariate analyses. The association of more complex CSHCN with individual diagnoses and unmet health care needs was examined using logistic regression analysis, adjusting for significant (P < .05) demographic and diagnosis characteristics in bivariate analyses. Multivariable analysis adjusted for demographic characteristics that were significant at P < .05 and the diagnoses with the largest absolute percentage difference. All the analyses were performed with commercially available software (STATA 10; StataCorp LP, College Station, Texas) using appropriate person-level weights provided in the NS-CSHCN to generate national estimates.

RESULTS

In 2006, there were 10,221,439 CSHCN aged 0 to 17 years (unweighted NS-CSHCN n=40,723) in the United States. Of children included in the survey, 38.8% required more medical care than usual according to the CSHCN screener, 12.9% had positive responses to 3 of 4 remaining screener items, 25.2% had use of medical equipment, and 23.7% saw

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2 or more subspecialists in the last year. Combining all the study criteria (Figure 1) resulted in a study sample of 324,323 (95% CI, 294,064-354,584) more complex CSHCN. This sample represents 3.2% (95% CI, 2.9%-3.5%) of all CSHCN or 0.4% of all children in the United States.

DEMOGRAPHIC AND DIAGNOSIS CHARACTERISTICS

Compared with less complex CSHCN, more complex CSHCN were more likely to be younger, have public insurance, and have lower family income (all P < .001) as well as have a usual source of health care (P < .05). No differences were found in sex, race/ethnicity, census region, household educational level, primary language of household, or usual source of preventive care (Table 1). Compared with less complex CSHCN, more complex CSHCN had more mean (SD) diagnoses (3.98 [0.13] vs 2.7%, autism (24.5% vs 4.0%), cerebral palsy (21.2% vs 9.8%), emotional problems (46.5% vs 20.3%), seizure disorder (26.6% vs 2.7%), autism (24.5% vs 4.0%), cerebral palsy (21.2% vs 1.2%), and joint problems (21.0% vs 3.7%) (P < .001 for all) (Figure 2).

CARE BURDEN

Caregivers of more complex CSHCN reported a median of 2 (interquartile range [IQR], 1-6) hours per week providing care coordination and 11 to 20 (IQR, 3-21) hours providing direct home care per week. Almost half (46.3% [weighted n = 150,021]) of families reported paying more than $1,000 in out-of-pocket health care costs in the prior year. Similar proportions reported that they had health care–related financial problems (36.8% [weighted n = 184,043]), that a family member stopped working because of the child’s health (54.1% [weighted n = 175,294]), that a family member cut back on working hours to care for the child (45.6% [weighted n = 147,753]), and that the family needed additional income for medical expenses (48.7% [weighted n = 157,798]) (Table 2).

MEDICAL CARE USE AND UNMET NEEDS

Families of more complex CSHCN reported medians of 11 to 15 (IQR, 6 to >21) physician visits and 10 (IQR, 5 to 16-20) school days missed in the last 12 months. Almost two-thirds (65.0% [weighted n = 210,810]) of families with more complex CSHCN reported variable health needs.
care service needs of the child (ie, needs change all the time or sometimes) (Table 3).

For individual unmet medical needs, families of more complex CSHCN reported an increased likelihood of receiving needed specialty care (adjusted odds ratio [aOR], 2.0; 95% CI, 1.3-3.1) compared with families of less complex CSHCN. Families of more complex CSHCN reported less likelihood of receiving needed prescription medications (weighted n=14 826; aOR, 0.5; 95% CI, 0.3-1.0). No differences were seen in the likelihood of receiving 13 other medical services (Table 4). Almost half (48.8% [weighted n=158 270]; aOR, 1.9; 95% CI, 1.4-2.5) of families with more complex CSHCN reported at least 1 unmet medical service need, and 5.4% (weighted n=17 513; aOR, 2.4; 95% CI, 1.3-4.3) reported 5 or more unmet medical service needs in the last 12 months. One-third (33.1% [weighted n=107 350]; aOR, 2.1; 95% CI, 1.6-2.8) of families with more complex CSHCN reported difficulties in accessing nonmedical services. Significantly fewer families (39.4% [weighted n=127 459]; aOR, 0.7; 95% CI, 0.5-0.9) of more complex CSHCN reported being very satisfied with medical services.

To our knowledge, this is the first study that describes demographics, family care burden, and service needs for the subset of more medically complex CSHCN in a large

Figure 2. Parent-reported diagnoses by complexity (weighted n=10 221 439). ADD indicates attention-deficit disorder; CSHCN, children with special health care needs.

Table 2. Family-Reported Care Burden of Children With Special Health Care Needs by Complexity

<table>
<thead>
<tr>
<th>Variable</th>
<th>Less Complex (n=9 897 116)</th>
<th>More Complexa (n=324 323)</th>
<th>Adjusted Odds Ratio (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Provision of, median (interquartile range), h/wk</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Care coordination</td>
<td>0 (0-2)</td>
<td>2 (1-6)</td>
<td>&lt;.001c</td>
</tr>
<tr>
<td>Home care</td>
<td>1 (0-4)</td>
<td>11-20 (3-21)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>In the last 12 mo, %</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family paid &gt;$1000 in out-of-pocket health care costs</td>
<td>19.1</td>
<td>46.3</td>
<td>3.0 (2.3-3.9)</td>
</tr>
<tr>
<td>Child’s health care caused financial problems</td>
<td>16.8</td>
<td>56.8</td>
<td>3.6 (2.7-4.7)</td>
</tr>
<tr>
<td>Family member stopped working because of child’s health</td>
<td>12.0</td>
<td>54.1</td>
<td>2.9 (2.2-3.9)</td>
</tr>
<tr>
<td>Family member cut work to care for the child</td>
<td>15.4</td>
<td>46.6</td>
<td>2.2 (1.7-2.8)</td>
</tr>
<tr>
<td>Needed additional income for medical expense</td>
<td>15.2</td>
<td>48.7</td>
<td>3.0 (2.3-3.9)</td>
</tr>
</tbody>
</table>

aAll data are weighted. P <.001 for all variables (χ² test for proportions and Mann-Whitney test for nonparametric variables). Logistic regression analyses are adjusted for age, insurance type, family income, usual source of health care, mental retardation, emotional problems, seizure disorder, autism, cerebral palsy, and joint problems.

bMore complex is defined as positive response to “need for more medical care” than usual item and 3 of the remaining 4 items on the complex children with special health care needs screener; medical equipment use; and seeing 2 or more specialists in the last 12 months.

cP <.001 for comparison of medians by Mann-Whitney test.

Table 3. Medical Care Use of Children With Special Health Care Needs by Complexity

<table>
<thead>
<tr>
<th>Variable</th>
<th>Less Complex (n=9 897 116)</th>
<th>More Complexa (n=324 323)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child’s health care needs, %</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Change all the time</td>
<td>5.4</td>
<td>32.0</td>
</tr>
<tr>
<td>Change sometimes</td>
<td>27.9</td>
<td>33.0</td>
</tr>
<tr>
<td>Are usually stable</td>
<td>66.9</td>
<td>35.0</td>
</tr>
<tr>
<td>No. in the last 12 mo, median (interquartile range)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>School days missed</td>
<td>3 (1-8)</td>
<td>10 (5 to 16-20)</td>
</tr>
<tr>
<td>Physician visits</td>
<td>4 (2-7)</td>
<td>11-15 (6-21)</td>
</tr>
<tr>
<td>Emergency department visits</td>
<td>0 (0-1)</td>
<td>1 (0-3)</td>
</tr>
<tr>
<td>Receipt of, %</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Early intervention services at age &lt;3 y</td>
<td>19.0</td>
<td>82.2</td>
</tr>
<tr>
<td>Special education services at age range 3-17 y</td>
<td>27.0</td>
<td>76.9</td>
</tr>
</tbody>
</table>

aAll data are weighted. P <.001 for all variables (χ² test for proportions and Mann-Whitney test for nonparametric variables).

bMore complex is defined as positive response to “need for more medical care” than usual item and 3 of the remaining 4 items on the complex children with special health care needs screener; medical equipment use; and seeing 2 or more specialists in the last 12 months.
complexity.” The absence of a definitional gold standard makes it difficult to judge the accuracy of our methods. A nationally representative population. Our findings suggest that families of more complex CSHCN face exceptionally high care demands, increased unemployment and underemployment, and large financial burden and that many more complex CSHCN have unmet medical needs. Our study criteria were specifically designed to select children with complex medical care needs, and it is not surprising to find a high care burden. However, quantifying this burden is revealing: most families with more complex CSHCN in our study reported at least 10 physician visits in the last 12 months, more than 11 missed school days in the past year, and out-of-pocket health care costs exceeding $1000 annually. More than 175 000 parents terminated employment to stay at home and care for a child with high medical complexity. Our method is novel in describing a population that Our criteria captured children with a high prevalence of neurodevelopmental conditions, particularly mental retardation, emotional problems, seizure disorder, autism, cerebral palsy, and joint problems. More complex is defined as positive response to “need for more medical care” than usual item and 3 of the remaining 4 items on the complex children with special health care needs screener; medical equipment use; and seeing 2 or more specialists in the last 12 months. Our method is adapted from clinical services dedicated to more complex CSHCN and ascertaining such children via family responses as opposed to administrative data focused on diagnostic lists, we focus on attributes that coexist in a distinct population of children within population-level surveys. These attributes are similar to a recently developed definitional framework of more complex CSHCN, termed “children with medical complexity.” The absence of a definitional gold standard makes it difficult to judge the accuracy of our methods to study these children. However, our population estimate (0.4%) is similar to prior prevalence estimates of 0.2% to 0.4% of more complex CSHCN in the United States using case ascertainment from health administrative data.

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lihood of any individual unmet medical service need. Access to medical services generally may not be an issue for more complex CSHCN, possibly because their fragile health results in ongoing frequent contact with the medical system. More notable is our finding that families of more complex CSHCN were more likely to have multiple unmet medical service needs; 5.4% reported at least 5 separate unmet medical service needs. This illustrates the difficulty in navigating services and the essential role of care coordination among this subset of CSHCN.

We also found that community-based nonmedical services for more complex CSHCN were lacking. Care models that incorporate improved access to and coordination of community-based services are critical for optimal medical, developmental, and service outcomes, yet these are the services that families of more complex CSHCN frequently regard as deficient.34,35

More than half of the families among more complex CSHCN in our study reported financial difficulties and employment loss. There is a critical need to help such families overcome these life-disruptive problems. Existing policies can help families sustain employment (eg, the Family Medical Leave Act), but evidence shows that these policies remain underused.36 Enhanced home caregiving support may help families maintain their employment status and financial stability.35 There is a perceived home nursing shortage throughout the United States for more complex CSHCN. Other jurisdictions have adopted cost-effective alternative strategies to mitigate this shortage (eg, in Victoria, Australia, a workforce of trained regulated personal care attendants has been created to care for children with tracheostomy who require home mechanical ventilation).37

Our study has several limitations. We recognize that there is tautology between the methods used to extract more complex CSHCN (ie, having multiple special needs) and our outcomes (eg, medical care use and unmet needs). Our main intent was to quantify these outcomes rather than highlight the relationship between them and our selected cohort of patients. We had no a priori hypothesis about the magnitude or proportion of health service use in multiple domains that families of more complex CSHCN would report. Specific inclusion criteria, such as having an emotional problem on the CSHCN screener, may be associated with a specific study outcome, such as a parent reporting the presence of an emotional diagnosis or condition. However, of the more complex CSHCN who did not report an emotional problem on the CSHCN screener, 41.6% identified an emotional condition or problem on high medical complexity. It lacks related clinical information (eg, illness severity and duration of functional impairment) and health care use information (eg, hospitalizations) that may help capture more complex CSHCN. Some study criteria, such as the need for supplies, may have increased sensitivity and decreased specificity; not all medical supplies have direct relationships to activities of daily living. However, the prevalence of more complex CSHCN in our study is similar to that in prior studies examining the highest resource users.25,29

The less complex CSHCN group in our study likely varies in the level of complexity, and some children in the comparison group likely require a high level of services. However, inclusion of higher levels of complexity in the comparison group would likely lead to a bias toward the null hypothesis, which may strengthen our findings. The survey is cross-sectional and does not permit the determination of causality. Nonmedical service need was characterized as a single question, which did not enable us to specify specific community-based services that may be particularly lacking. Finally, there is no external validation of study responses, although our findings are consistent with clinical experience and prior qualitative literature documenting the pervasive effects of caregiving on the family unit.20,38

Given the rising number of more complex CSHCN and their substantial influence on health care costs, an important target for the health care system is to maximize health, development, and function among this subset of CSHCN. Hospital-based programmatic models of care for more complex CSHCN may deliver enhanced care coordination and technical expertise that is necessary to improve care, health outcomes, and family satisfaction.39 Comprehensive medical care and care coordination for more complex CSHCN in a hospital-based clinic may reduce hospitalizations and overall costs.40 Family training during transition from hospital to home may decrease morbidity and mortality for children who are dependent on respiratory support.37 A challenge is to bring these clinical initiatives to the primary care setting, including the training of personnel to manage chronic illnesses and changes to reimbursement patterns that de-incentivize comprehensive care.6

In conclusion, more complex CSHCN can be distinguished by exceptionally high demands placed on their families and the health care system. Families of more complex CSHCN report multiple unmet needs and many hours devoted to care coordination and home care. Enhanced care coordination support, respite care, and direct home care may begin to address the substantial economic burden and the multiple unmet needs that many of these families face.

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Author Contributions: Dr Kuo had full access to all the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis. Study concept and design: Kuo, Agrawal, Berry, and Casey. Acquisition of data: Kuo, Cohen, and Berry. Analysis and interpretation of data: Kuo, Cohen, and Berry. Drafting of the manuscript: Kuo, Berry, and Casey. Critical revision of the manuscript for important intellectual content: Kuo, Cohen, Agrawal, Berry, and Casey. Statistical analysis: Kuo, Cohen, and Berry. Obtained funding: Kuo.

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