

Unmet Health Care Needs Among CSHCN With Neurologic Conditions

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KEY WORDS

health care needs, attention-deficit/hyperactivity disorder, autism, emotional conditions, behavioral conditions, intellectual disability, Down syndrome, epilepsy, muscular dystrophy, cerebral palsy, hearing problems, vision problems

ABBREVIATIONS

CSHCN—children with special health care needs
NS-CSHCN—National Survey of Children With Special Health Care Needs
ADHD—attention-deficit/hyperactivity disorder
DSM—*Diagnostic and Statistical Manual of Mental Disorders*
CI—confidence interval
OR—odds ratio

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abstract

OBJECTIVE: Children with neurologic conditions require a variety of services. With this study we examined health care needs and unmet needs among children with neurologic conditions.

METHODS: Cross-sectional data reported by parents of 3- to 17-year-olds in the 2005–2006 National Survey of Children With Special Health Care Needs were analyzed. Demographic characteristics, health care needs, and unmet needs of children with special health care needs (CSHCN) and neurologic conditions were descriptively compared with an independent referent group of children without special health care needs; statistical contrasts were performed as a function of the type (conditions included in the *Diagnostic and Statistical Manual of Mental Disorders* [DSM] or not) and number of reported neurologic conditions.

RESULTS: Compared with the parents of children without special health care needs, parents of CSHCN with neurologic conditions were more likely to report unmet health care needs for their child. After adjustment for demographic factors and severity of functional limitation, CSHCN with at least 2 conditions had more visits to a health care provider, needed more services, and reported more unmet needs than CSHCN with a single DSM condition. The magnitude of need among CSHCN was greatest among those with at least 1 of each type of neurologic condition.

CONCLUSIONS: Unmet health care needs exist among CSHCN with neurologic conditions and are particularly pronounced among children with a combination of both DSM and non-DSM disorders. The health care needs among CSHCN with multiple neurologic conditions may be better served by targeted efforts to improve care coordination. *Pediatrics* 2009;124:S343–S351

Childhood neurologic conditions encompass a heterogeneous group of diagnoses including epilepsy and neurodevelopmental and sensorimotor conditions. A variety of medical needs have been identified among children with neurologic conditions.^{1–8} Thus, most children with neurologic conditions are children with special health care needs (CSHCN) who, by definition, “require health and related services of a type or amount beyond that required by children generally.”⁹ The health care needs of CSHCN with neurologic conditions have not been well examined.¹⁰ The limited literature provides evidence that specific health care needs and unmet needs among children with neurologic conditions can vary according to the type of condition. For example, CSHCN with emotional, developmental, or behavioral problems are more likely to need mental health care, and to have unmet needs for health care services, compared with other CSHCN.^{1,11}

The fact that neurologic and other medical conditions often co-occur complicates the provision of needed services to children with neurologic conditions; children with such conditions often need to access multiple services including primary care, mental health care, education, and specialized medical services.^{2–4,12–20} Recent population-based estimates of co-occurring developmental disorders exceeded 90% among children with autism, 80% among children with an intellectual disability, and 50% among children with cerebral palsy.⁴ Other studies have reported that one third of young children with hearing loss have another neurodevelopmental condition,¹³ and more than 60% of children with vision loss have at least 1 other condition.^{14,15}

Beyond what is found in the diagnostic profile of a child, additional factors associated with health care needs and

unmet needs among CSHCN include demographic characteristics and the presence and severity of a functional limitation.^{1,21–27} Unmet needs are associated with insurance status,^{1,21,27} poverty,^{1,21,27} and race.^{2,28} In addition, parents of CSHCN with severe limitations have reported increased health care needs in most domains, more unmet needs, and less satisfaction with care.^{1,25–27}

Conditions that result in similar functional impairment, such as different mental disorders, can result in similar challenges in the provision of services in the face of high service needs, barriers to access to care, and complicated treatment plans. Identifying similarities and differences in the health care needs among groups of CSHCN can help identify opportunities for service optimization at national and local levels that will affect a larger number of families. The extent to which service need and acquisition are similar among samples of children with various neurologic conditions has not been examined. The purpose of this study was to describe patterns of health care needs and unmet needs among CSHCN with neurologic conditions, including mental disorders, by using data from the 2005–2006 National Survey of Children With Special Health Care Needs (NS-CSHCN). We hypothesized that the frequency and types of health care needs, and unmet needs, would be similar among CSHCN with mental disorders and differ markedly from CSHCN with other types of neurologic conditions.

METHODS

Sample

Data from the 2005–2006 NS-CSHCN were analyzed; the general methodology for this survey is described in this supplemental issue²⁹ and elsewhere.³⁰ CSHCN aged 3 to 17 years with neurologic conditions ($N = 19\,112$) were in-

cluded for the current analyses. Neurologic conditions reported by parents included attention-deficit/hyperactivity disorder (ADHD), autism, emotional disorders (depression, anxiety, eating disorders, or other emotional disorders), mental retardation or other developmental delay, Down syndrome, epilepsy or seizure disorder, cerebral palsy, muscular dystrophy, and vision or hearing loss not correctable with lenses or aids. Although the current accepted terminology for mental retardation is “intellectual disability,”³¹ and “epilepsy” is usually preferred over the term “seizure disorder,” these were the terms used in the NS-CSHCN.

For all conditions except vision and hearing, parents were asked, “To the best of your knowledge, does [child] currently have [condition]?” For vision and hearing, parents were asked if “Without (glasses, contact lenses/hearing aids), would you say (he/she) experiences any difficulty (seeing/hearing)?” If parents answered yes, they were asked whether the child used an aid, and if again they answered yes, they were asked whether the child had “any difficulty (seeing/hearing) even when (wearing glasses or contact lenses/using a hearing aid)?” Only children whose parents answered yes to the third question were considered to have significant hearing or vision problems. Because of the large overlap in this survey in reporting of intellectual disability among children with Down syndrome (89.4%), a single-condition variable, “intellectual disability, including Down syndrome,” was derived.

Neurologic conditions were divided into 2 groups on the basis of their inclusion in the fourth edition of the *Diagnostic and Statistical Manual of Mental Disorders*³² (DSM): (1) conditions referenced by the DSM, including ADHD, autism, emotional disorders, and intellectual disability or

TABLE 1 Prevalence and Characteristics of CSHCN Aged 3 to 17 Years With Neurologic Conditions, Compared With a Referent Sample: NS-CSHCN, United States, 2005–2006

Characteristic	Children Without Special Health Care Needs, % (95% CI)	CSHCN With Any Neurologic Condition, % (95% CI) ^a	CSHCN With 1 DSM ^b Condition Only, % (95% CI) (Referent)	CSHCN With ≥2 DSM ^b Conditions, % (95% CI)	CSHCN With ≥1 Non-DSM ^c Conditions, % (95% CI)	CSHCN With At Least 1 DSM ^b and 1 Non-DSM ^c Condition, % (95% CI)
<i>n</i>	4181	19 112	10 242	5639	1227	2004
Weighted <i>n</i>	51 449 950	4 756 629	2 469 755	1 450 551	307 300	529 023
Weighted % (prevalence)	100	49.9	51.9	30.5	6.5	11.1
ADHD	2.0 (1.6–2.6)	63.7 (62.5–64.5)	61.3 (60.0–63.0)	84.9 (83.2–86.5)	0.0	53.1 (49.4–56.7)
Autism	0.09 (0.04–0.2) ^d	11.5 (10.8–12.3)	3.7 (3.2–4.3)	25.0 (23.1–26.9)	0.0	18.6 (15.7–21.5)
Intellectual disability ^e	0.7 (0.5–1.2)	22.6 (21.6–23.7)	8.4 (7.5–9.4)	38.6 (36.5–40.8)	0.0	58.7 (55.2–62.2)
Emotional problems ^f	1.6 (1.2–2.0)	45.1 (43.9–46.3)	28.5 (26.9–30.0)	82.0 (80.2–83.7)	0.0	47.3 (43.7–50.9)
Cerebral palsy	0.04 (0.01–0.2) ^d	3.8 (3.3–4.3)	0.0	0.0	13.0 (9.9–16.8)	26.7 (23.6–30.1)
Muscular dystrophy	0.04 (0–0.3) ^d	0.7 (0.5–1.0)	0.0	0.0	3.6 (2.4–5.5)	4.2 (2.6–6.5)
Epilepsy	0.13 (0.1–0.4) ^d	6.9 (6.4–7.5)	0.0	0.0	34.0 (30.1–38.2)	42.6 (39.1–46.2)
Vision problems	0.9 (0.6–1.4)	7.6 (7.0–8.3)	0.0	0.0	47.1 (42.6–51.7)	41.3 (37.8–44.9)
Hearing problems	0.0 (0.0)	1.2 (0.9–1.4)	0.0	0.0	8.4 (6.2–11.2)	5.6 (4.2–7.5)
Mean No. of conditions	NC	1.6 (1.6–1.6)	1.0 (1.0–1.0)	2.3 (2.3–2.3)	1.1 (1.0–1.1)	3.0 (2.9–3.0)
Percent male	49.9 (48.0–51.8)	63.7 (62.5–64.8)	63.7 (62.0–65.3)	69.3 (67.2–71.3) ^g	50.6 (46.1–55.2)	56.1 (52.5–59.7) ^g
Race						
White only (referent)	66.3 (64.4–68.2)	71.4 (70.2–72.5)	73.2 (71.5–74.8)	69.5 (67.4–71.6)	69.1 (64.5–73.3)	69.4 (65.9–72.7)
Black only	14.8 (13.3–16.3)	17.1 (16.1–18.1)	15.8 (14.5–17.3)	18.6 (16.8–20.5) ^g	18.0 (14.5–22.1)	18.3 (15.5–21.5)
Multiple race	2.8 (2.2–3.5)	3.9 (3.5–4.4)	3.7 (3.2–4.3)	4.5 (3.7–5.4)	4.1 (2.7–6.3)	3.2 (2.3–4.5)
Other race	16.2 (14.8–17.7)	7.6 (6.95–8.34)	7.2 (6.3–8.3)	7.5 (6.4–8.8)	8.8 (6.4–12.1)	9.1 (7.2–11.4)
Hispanic	21.0 (19.4–22.7)	11.6 (10.8–12.5)	11.1 (9.9–12.3)	11.8 (10.3–13.4)	12.5 (9.5–16.2)	13.1 (10.7–16.0)
Age, y						
3–5	23.5 (21.9–25.3)	8.8 (8.1–9.6)	8.2 (7.3–9.2)	8.5 (7.3–10.0)	16.2 (13.0–20.0) ^g	8.1 (6.5–10.1)
6–12	44.5 (42.6–46.4)	48.9 (47.7–50.1)	50.0 (48.3–51.6)	46.7 (44.6–48.9)	47.8 (43.3–52.3)	50.5 (46.9–54.1)
13–17 (referent)	31.9 (30.3–33.7)	42.3 (41.1–43.5)	41.9 (40.2–43.5)	44.7 (42.6–46.9)	36.0 (31.8–40.5)	41.4 (37.9–45.0)
Inadequate insurance ^h	13.6 (12.2–15.1)	23.9 (22.8–25.0)	20.6 (19.3–22.1)	29.0 (26.9–31.1) ^g	22.7 (18.9–27.0)	25.8 (22.5–29.3) ^g
Type of insurance						
Private (referent)	66.9 (65.0–68.7)	50.2 (49.0–51.4)	58.8 (57.1–60.5)	40.0 (37.9–42.1)	55.0 (50.3–59.5)	35.1 (31.8–38.6)
Public	18.7 (17.1–20.3)	34.2 (33.0–35.3)	28.5 (27.0–30.1)	42.4 (40.2–44.6) ^g	30.5 (26.2–35.2)	40.1 (36.6–43.8) ^g
Private and public	4.4 (3.7–5.4)	9.6 (8.9–10.3)	7.0 (6.2–7.9)	11.6 (10.3–13.0) ^g	8.6 (6.4–11.5)	16.4 (14.0–19.2) ^g
Other ⁱ	2.7 (2.2–3.3)	2.0 (1.7–2.4)	1.9 (1.5–2.5)	1.9 (1.5–2.5)	2.0 (1.1–3.5)	2.7 (1.8–4.1) ^g
Uninsured	7.3 (6.41–8.41)	4.1 (3.6–4.6)	3.8 (3.2–4.4)	4.1 (3.4–5.0) ^g	4.0 (2.4–6.7)	5.6 (4.0–7.9) ^g
Household income at <200% federal poverty level	35.5 (33.7–37.4)	48.3 (47.1–49.5)	42.2 (40.5–43.9)	55.5 (53.4–57.7) ^g	43.9 (39.2–48.5)	59.8 (56.3–63.3) ^g
Severity of limitation						
None (referent)	NA	23.4 (22.4–24.5)	32.8 (31.2–34.3)	12.1 (10.7–13.6)	30.0 (26.0–34.4)	7.6 (5.9–9.6)
Some	NA	37.6 (36.4–38.7)	41.0 (39.4–42.6)	34.5 (32.5–36.6) ^g	39.6 (35.3–44.0)	28.9 (25.7–32.4) ^g
Severe	NA	39.0 (37.8–40.2)	26.3 (24.8–27.9)	53.4 (51.3–55.6) ^g	30.4 (26.2–34.9)	63.5 (59.9–67.0) ^g

NC indicates not calculated; NA, not asked.

^a Of CSHCN. Neurologic conditions include all DSM and non-DSM conditions listed below.

^b DSM conditions include conditions listed in the fourth edition of the DSM,³² including ADHD, autism, intellectual disability or developmental delay including Down syndrome, and emotional problems including depression, anxiety, eating disorder, or other emotional problems.

^c Non-DSM conditions include neurologic conditions not listed in the DSM,³² including cerebral palsy, muscular dystrophy, epilepsy, and hearing or vision problems not correctable with aids.

^d RSE > 30%.

^e Intellectual disability or developmental delay, including Down syndrome.

^f Depression, anxiety, eating disorder, or other emotional problems.

^g Unadjusted OR (not shown) significantly different from those with a single DSM condition.

^h Summary score based on 3 questions that assessed whether health insurance covered needs, whether the costs associated with the insurance were reasonable, and whether the insurance allowed the child to see the health care providers needed.

ⁱ Other comprehensive insurance.

other developmental delays; and (2) conditions not included in the DSM, including epilepsy, cerebral palsy, muscular dystrophy, and vision or hearing problems.

Statistical Analyses

Given the variation and significant degree of co-occurrence among the neurologic conditions both within and between the 2 groups, analyses were conducted to test whether there were differences in health care needs among mutually exclusive subgroups

of CSHCN with (1) a single DSM condition, (2) more than 1 DSM condition, (3) a single non-DSM condition, (4) more than 1 non-DSM condition, or (5) at least 1 DSM and 1 non-DSM condition. Because of limited sample size, subgroups 3 and 4 were combined, which resulted in 4 independent subgroups.

Variables that assess demographics, health care needs, and unmet needs were compared among subgroups (Tables 1–3). Variables of satisfaction

with family-centered care and care coordination that were developed by the Maternal and Child Health Bureau and the National Center for Health Statistics were included.^{33,34} Satisfaction with family-centered care was based on whether doctors spent enough time, listened carefully, were sensitive to values and customs, provided needed information, made the family feel like a partner, and an interpreter was available when needed. Satisfaction with care coordination was based

TABLE 2 Prevalence of Health Care Needs Among CSHCN Aged 3 to 17 Years With a Neurologic Condition, Compared With a Referent Sample: NS-CSHCN, United States, 2005–2006

Health Care Needs	Children Without Special Health Care Needs, % (95% CI)	CSHCN With Any Neurologic Condition ^a , % (95% CI)	CSHCN With 1 DSM ^b Condition Only, % (95% CI) (Referent)	CSHCN With ≥2 DSM ^b Conditions, % (95% CI) or OR (95% CI) ^c	CSHCN With ≥1 Non-DSM ^d Conditions, % (95% CI) or OR (95% CI) ^c	CSHCN With At Least 1 DSM ^b and 1 Non-DSM ^d Condition, % (95% CI) or OR (95% CI) ^c
At least 1 emergency department visit in previous year	17.6 (16.2–19.0) NC	36.9 (35.7–38.0) NC	32.3 (30.7–33.9) Referent	38.9 (36.8–41.0) 1.1 (1.0–1.3)	44.1 (39.6–48.6) 1.5 (1.2–1.9) ^e	48.6 (45.0–52.2) 1.5 (1.3–1.8) ^e
Visits to doctor or other health care provider in previous year						
None	20.4 (18.8–22.0) NC	5.9 (5.3–6.6) NC	6.4 (5.5–7.3) Referent	5.4 (4.4–6.5) 0.9 (0.7–1.2)	4.3 (2.6–7.2) 0.5 (0.3–1.0)	6.3 (4.4–9.1) 1.2 (0.7–1.9)
1–8 visits	77.8 (76.2–79.4) NC	67.3 (66.2–68.4) NC	72.3 (70.7–73.9) Referent	62.1 (60.0–64.1) NA ^f	72.7 (68.3–76.7) NA ^f	55.0 (51.3–58.6) NA ^f
≥9 visits	1.8 (1.4–2.4) NC	26.8 (25.7–27.8) NC	21.3 (19.9–22.8) Referent	32.6 (30.7–34.6) 1.5 (1.3–1.7) ^e	23.0 (19.3–27.1) 1.1 (0.8–1.3)	38.7 (35.2–42.3) 1.9 (1.5–2.2) ^e
Needed a referral	11.5 (10.4–12.7) NC	36.7 (35.6–37.9) NC	31.5 (30.0–33.1) Referent	40.9 (38.7–43.1) 1.3 (1.2–1.5) ^e	40.9 (36.5–45.4) 1.5 (1.2–1.8) ^e	47.3 (43.7–50.9) 1.6 (1.4–2.0) ^e
Services needed						
Routine preventive care	64.8 (63.0–66.6) NC	76.0 (74.9–77) NC	75.6 (74.1–76.9) Referent	76.8 (74.9–78.6) 1.2 (1.0–1.4)	75.4 (71.0–79.3) 1 (0.8–1.2)	76.0 (72.5–79.1) 1.2 (1.0–1.5)
Specialty doctor	15.0 (13.7–16.3) NC	54.5 (53.3–55.7) NC	46.2 (44.6–47.9) Referent	58.3 (56.1–60.4) 1.5 (1.3–1.7) ^e	73.0 (68.5–77.0) 3.2 (2.5–4.0) ^e	72.1 (68.6–75.4) 2.8 (2.3–3.4) ^e
Preventive dental care	79.5 (77.9–81.1) NC	84.9 (84.0–85.8) NC	85.4 (84.2–86.6) Referent	83.5 (81.8–85.2) 1.0 (0.9–1.3)	85.0 (80.9–88.1) 1.2 (0.8–1.7)	86.5 (84.1–88.6) 1.3 (1.0–1.7)
Other dental care	19.6 (18.2–21.2) NC	26.4 (25.4–27.5) NC	27.2 (25.7–28.7) Referent	25.9 (24.0–27.9) 1.0 (0.9–1.2)	25.9 (22.3–30.0) 1.0 (0.8–1.3)	24.6 (21.8–27.6) 1.0 (0.8–1.1)
Prescription medications	37.3 (35.5–9.1) NC	84.6 (83.7–85.5) NC	84.7 (83.5–85.9) Referent	84.8 (83.2–86.3) 1.2 (1.0–1.5)	82.6 (78.9–85.8) 1.0 (0.7–1.3)	84.6 (81.4–87.4) 1.2 (0.9–1.6)
Physical, occupational, or speech therapy	4.4 (3.7–5.2) NC	32.6 (31.5–33.7) NC	22.2 (20.9–23.6) Referent	40.7 (38.5–42.9) 2.0 (1.7–2.3) ^e	29.0 (25.1–33.3) 1.4 (1.1–1.8) ^e	60.9 (57.3–64.4) 4.8 (4.0–5.7) ^e
Mental health care or counseling	3.0 (2.5–3.7) NC	47.4 (46.2–48.6) NC	40.7 (39.1–42.4) Referent	68.6 (66.5–70.7) 3.1 (2.7–3.5) ^e	8.1 (5.9–11.0) 0.1 (0.1–0.2) ^e	43.3 (39.7–46.9) 0.9 (0.8–1.1)
Home health care	1.3 (0.8–1.9) NC	5.4 (4.9–6.0) NC	3.1 (2.6–3.7) Referent	7.3 (6.1–8.7) 2.0 (1.5–2.6) ^e	3.3 (2.2–5.0) 1.1 (0.7–1.7)	12.5 (10.3–15.0) 3.0 (2.2–3.9) ^e
Eyeglasses or vision care	23.2 (21.7–24.8) NC	40.1 (38.9–41.3) NC	33.9 (32.4–35.4) Referent	37.6 (35.5–39.8) 1.2 (1.1–1.4) ^e	63.7 (59.3–67.8) 3.9 (3.2–4.9) ^e	62.0 (58.5–65.4) 3.3 (2.7–3.9) ^e
Hearing aids or hearing care	0.9 (0.6–1.3) NC	5.7 (5.1–6.3) NC	3.6 (3.0–4.2) Referent	5.0 (4.0–6.1) 1.2 (0.9–1.6)	11.2 (8.6–14.5) 3.3 (2.3–4.8) ^e	14.4 (11.7–17.7) 3.7 (2.7–5.1) ^e
Mobility aids or devices	1.5 (1.1–2.0) NC	5.5 (5.0–6.1) NC	3.3 (2.8–3.8) Referent	2.8 (2.3–3.5) 0.6 (0.5–0.8) ^e	8.8 (6.6–11.6) 2.7 (1.9–3.9) ^e	21.6 (18.8–24.6) 5.8 (4.5–7.5) ^e
Communication aids or devices	0.02 (0–0.1) ^g NC	4.0 (3.6–4.5) NC	1.4 (1.1–1.7) Referent	5.1 (4.2–6.2) 2.4 (1.7–3.3) ^e	2.1 (1.1–3.8) 1.5 (0.7–3.0)	14.6 (12.3–17.1) 7.7 (5.5–10.7) ^e
Medical supplies	6.0 (5.2–6.9) NC	16.5 (15.6–17.4) NC	13.8 (12.7–15.0) Referent	15.0 (13.6–16.6) 0.9 (0.8–1.1)	22.4 (18.8–26.5) 1.7 (1.4–2.2) ^e	29.8 (26.6–33.2) 2.2 (1.8–2.6) ^e
Durable medical equipment	1.1 (0.8–1.6) NC	8.4 (7.7–9.1) NC	5.8 (5.1–6.7) Referent	6.1 (5.2–7.2) 0.8 (0.6–1.0)	13.6 (10.6–17.3) 2.5 (1.8–3.5) ^e	23.7 (20.6–27.1) 3.5 (2.8–4.5) ^e

NC indicates not calculated; NA, not appropriate.

^a Of CSHCN. Neurologic conditions include all DSM and non-DSM conditions listed below.

^b DSM conditions include conditions listed in the fourth edition of the DSM,³² including ADHD, autism, intellectual disability or developmental delay including Down Syndrome, and emotional problems including depression, anxiety, eating disorder, or other emotional problems.

^c Adjusted OR and 95% CI, compared to referent, controlling for gender, race, Hispanic ethnicity, age, adequacy of insurance, poverty, and severity of limitation. ORs were not calculated to compare children without special health care needs.

^d Non-DSM conditions include neurologic conditions not listed in the DSM,³² including cerebral palsy, muscular dystrophy, epilepsy, and hearing or vision problems not correctable with aids.

^e Adjusted OR significantly different from those with a single DSM condition.

^f For number of health care visits, there were 3 levels, and the referent group chosen was those with 1 to 8 visits. Therefore, ORs were not calculated for the 1- to 8-visit category.

^g RSE > 30%.

on satisfaction with communication among doctors and between doctors and other programs and whether the family received sufficient help coordinating care, if needed. A principal com-

ponents analysis was used to reduce 3 health insurance items assessing coverage, cost, and allowance to see needed providers into a single “adequacy-of-health-insurance” factor

($\alpha = .70$), which was included as a covariate. Although most outcome measures correlated significantly with one another, most correlation coefficients were <.4, and all were <.7.

TABLE 3 Prevalence of Unmet Health Care Needs Among CSHCN Aged 3 to 17 Years With a Neurologic Condition, Compared With a Referent Sample: NS-CSHCN, United States, 2005–2006

Unmet Health Care Needs	Children Without Special Health Care Needs, % (95% CI)	CSHCN With Any Neurologic Condition ^a , % (95% CI)	CSHCN With 1 DSM Condition Only ^b , % (95% CI) (Referent)	CSHCN With ≥2 DSM Conditions ^b , % (95% CI) or OR (95% CI) ^c	CSHCN With ≥1 Non-DSM Conditions ^d , % (95% CI) or OR (95% CI) ^c	CSHCN With At Least 1 DSM ^b and 1 Non-DSM Condition ^d , % (95% CI) or OR (95% CI) ^c
Delayed or lack of access to care	5.3 (4.5–6.3) NC	11.5 (10.7–12.3) NC	9.4 (8.4–10.4) Referent	14.3 (12.7–16.0) 1.3 (1.1–1.6) ^e	8.2 (6.1–10.9) 0.8 (0.6–1.2)	15.4 (13.0–18.2) 1.3 (1.0–1.7)
Not satisfied with family-centered care	33.8 (31.8–35.9) NC	40.9 (39.7–42.1) NC	36.5 (34.8–38.2) Referent	47.5 (45.3–49.7) 1.3 (1.1–1.5) ^e	36.0 (31.5–40.8) 0.9 (0.8–1.2)	45.9 (42.3–49.6) 1.2 (1.0–1.4)
Not satisfied with care coordination	23.2 (20.8–25.8) NC	50.9 (49.6–52.2) NC	44.7 (42.8–46.6) Referent	60.0 (57.7–62.2) 1.5 (1.3–1.7) ^e	38.8 (34.2–43.6) 0.8 (0.6–0.9) ^e	57.5 (53.8–61.1) 1.3 (1.1–1.6) ^e
Problem getting a referral	1.3 (1.0–1.7) NC	9.4 (8.7–10.2) NC	6.9 (6.0–7.8) Referent	12.3 (10.7–14.0) 1.5 (1.2–1.9) ^e	6.8 (5.0–9.1) 1.0 (0.7–1.4)	15.2 (12.8–17.9) 1.9 (1.5–2.6) ^e
Difficulties using other services ^f	2.5 (2.0–3.2) NC	17.3 (16.4–18.2) NC	12.2 (11.2–13.3) Referent	24.5 (22.7–26.4) 1.8 (1.5–2.1) ^e	10.9 (8.1–14.4) 0.8 (0.5–1.1)	25.4 (22.4–28.6) 1.8 (1.4–2.2) ^e
Dissatisfaction using services	4.3 (3.5–5.3) NC	13.1 (12.3–13.9) NC	9.4 (8.5–10.4) Referent	17.8 (16.2–19.5) 1.6 (1.3–1.9) ^e	8.5 (5.9–12.2) 0.8 (0.5–1.3)	19.7 (16.9–22.7) 1.8 (1.4–2.3) ^e
Have an unmet need	6.0 (5.2–7.1) NC	22.8 (21.8–23.8) NC	17.5 (16.3–18.9) Referent	29.4 (27.4–31.4) 1.5 (1.3–1.7) ^e	16.6 (13.3–20.6) 0.8 (0.6–1.1)	32.9 (29.6–36.4) 1.7 (1.3–2.0) ^e
Did not receive all needed care						
Routine preventive care	2.0 (1.3–3.1) NC	3.6 (3.1–4.1) NC	2.5 (2.0–3.2) Referent	4.5 (3.5–5.8) 1.7 (1.1–2.7) ^e	3.1 (1.4–6.5) [§] 1.0 (0.4–2.3)	6.1 (4.3–8.7) 2.0 (1.0–3.7)
Specialty doctor	5.0 (3.3–7.4) NC	8.1 (7.2–9.1) NC	6.5 (5.4–7.8) Referent	10.9 (8.9–13.2) 1.6 (1.1–2.2) ^e	3.6 (2.2–5.8) 0.5 (0.3–0.9) ^e	9.3 (7.0–2.4) 1.1 (0.7–1.8)
Preventive dental care	4.5 (3.7–5.4) NC	10.1 (9.3–10.9) NC	8.8 (7.7–10.0) Referent	11.6 (10.2–13.1) 1.0 (0.8–1.3)	7.4 (5.0–10.7) 0.7 (0.4–1.1)	13.6 (11.2–16.5) 1.2 (0.9–1.7)
Other dental care	5.3 (3.8–7.4) NC	14.3 (12.8–16.0) NC	11.7 (9.7–14.0) Referent	17.3 (14.4–20.7) 1.1 (0.8–1.6)	13.1 (8.3–20.1) 1.0 (0.5–1.8)	19.8 (15.0–25.7) 1.3 (0.8–2.0)
Prescription medications	0.56 (0.3–1.1) [§] NC	2.6 (2.2–3.1) NC	1.6 (1.1–2.1) Referent	4.2 (3.3–5.4) 2.7 (1.7–4.5) ^e	2.4 (1.0–6.1) [§] 1.5 (0.4–5.5)	3.5 (2.4–5.1) 2.1 (1.2–3.7) ^e
Physical, occupational, or speech therapy	5.6 (2.7–11.3) [§] NC	15.0 (13.7–16.5) NC	12.4 (10.4–14.7) Referent	16.6 (14.3–19.2) 1.3 (1.0–1.7)	9.1 (5.8–14.0) 0.6 (0.3–1.1)	18.3 (15.1–21.9) 1.5 (1.1–2.0) ^e
Mental health care or counseling	11.7 (6.8–19.4) NC	15.4 (14.2–16.8) NC	13.7 (12.0–15.6) Referent	16.8 (14.8–19.0) 1.1 (0.9–1.4)	16.5 (5.5–39.9) [§] 0.6 (0.2–2.2)	17.2 (13.5–21.6) 1.0 (0.7–1.5)
Home health care	1.8 (0.4–7.3) [§] NC	15.2 (11.8–19.4) NC	12.6 (7.1–21.3) Referent	17.5 (12.0–25.0) 2.2 (0.9–5.4)	10.1 (3.5–25.9) [§] 1.1 (0.2–5.0)	15.4 (9.8–23.5) 1.9 (0.7–5.0)
Eyeglasses or vision care	3.0 (1.8–5.0) NC	5.4 (4.5–6.3) NC	3.6 (2.7–4.7) Referent	6.7 (4.9–8.9) 1.4 (0.9–2.3)	7.2 (4.6–11.1) 1.9 (1.0–3.6)	6.7 (4.5–9.8) 1.4 (0.8–2.6)
Hearing aids or hearing care	0.0 NC	9.3 (6.6–13.0) NC	4.3 (2.4–7.5) Referent	16.3 (10.3–24.8) 9.4 (3.1–29.0) ^e	3.1 (1.1–8.2) [§] 1.0 (0.2–4.6)	11.5 (5.4–22.5) [§] 4.0 (0.9–18.9)
Communication aids or devices	0.0 NC	25.9 (21.2–31.3) NC	16.0 (9.8–25.0) Referent	24.4 (17.3–33.1) 1.2 (0.5–2.9)	16.6 (5.2–41.7) [§] 0.7 (0.1–4.3)	32.3 (24.3–41.5) 2.0 (0.8–4.8)
Medical supplies	1.1 (0.22–5.21) [§] NC	4.4 (3.3–5.8) NC	3.8 (2.4–6.1) Referent	3.4 (1.9–6.0) 0.7 (0.3–1.6)	2.1 (0.9–4.7) [§] 0.4 (0.1–1.2)	7.9 (4.7–12.9) 1.7 (0.7–3.9)
Durable medical equipment	1.2 (0.2–7.9) [§] NC	6.7 (4.8–9.2) NC	6.2 (3.2–11.4) Referent	6.9 (4.0–11.6) 1.3 (0.5–3.3)	5.1 (1.5–16.1) [§] 0.8 (0.2–2.9)	7.7 (4.5–12.9) 1.7 (0.6–4.4)

NC indicates not calculated.

^a Of CSHCN. Neurologic conditions include all DSM and non-DSM conditions listed below.

^b DSM conditions include conditions listed in the fourth edition of the DSM,³² including ADHD, autism, intellectual disability or developmental delay including Down Syndrome, and emotional problems including depression, anxiety, eating disorder, or other emotional problems.

^c Adjusted OR and 95% CI, compared to referent, controlling for gender, race, Hispanic ethnicity, age, adequacy of insurance, poverty, and severity of limitation. ORs were not calculated to compare children without special health care needs.

^d Non-DSM conditions include neurologic conditions not listed in the DSM,³² including cerebral palsy, muscular dystrophy, epilepsy, and hearing or vision problems not correctable with aids.

^e Adjusted OR significantly different from those with a single DSM condition.

^f Other services included nonmedical services such as early intervention programs, child care facilities, vocational education and rehabilitation programs, and other community programs.

[§] RSE > 30%.

Data management was conducted by using SAS (SAS Institute Inc, Cary, NC), and weighted statistical analyses were conducted by using SUDAAN software (Research Triangle Institute, Research Tri-

angle Park, NC) to account for the complex sampling design of the NS-CSHCN. Prevalence and 95% confidence intervals (CIs) were calculated, followed by multivariable regression analyses

that controlled for race (white or other), Hispanic ethnicity, age (3–5, 6–12, or 13–17 years), gender, adequacy of health insurance (adequate or not), household income of <200% of the fed-

eral poverty level, and severity of limitation (none, some, or severe).²⁵ The referent group for the multivariable analyses comprised CSHCN with a single DSM condition. Imputed income values were provided by the National Center for Health Statistics and incorporated statistically by using a single-imputation approach as described in the survey documentation.³⁵ Adjusted odds ratios (ORs) and 95% CIs were calculated for categorical outcomes and linear regression β coefficients for the number of services needed.

Descriptive statistics were also calculated for an independent sample of 4181 US children aged 3 to 17 years without special health care needs. These families were sampled by the NS-CSHCN as a baseline for expected health care needs among US children of the same age without special health care needs, and they completed the special health care needs screener and most of the NS-CSHCN. Evaluating the estimates and the overlap of the 95% CIs for each estimate allows for descriptive comparisons with the CSHCN.

Posthoc analyses were conducted to account for the large number of statistical comparisons. The data set was restructured and logistic regression models were run to collectively determine if there were overall differences in needs (all variables in Table 2) or unmet needs (all variables in Table 3) while controlling for the type of service (each variable) and all covariates previously included in the model.

RESULTS

Characteristics of CSHCN With Neurologic Conditions

Of all CSHCN aged 3 to 17 years, 50% had 1 of the reported neurologic conditions, representing 4.8 million US children. Children with neurologic conditions most often were included in the CSHCN sample, but some children without special health care needs nonetheless were reported to have a neurologic condition,

most commonly ADHD or emotional problems (Table 1). Among CSHCN with neurologic conditions, DSM conditions were more common than non-DSM conditions. Only 54 (4%) of the 1227 in the non-DSM-disorder group had more than 1 condition.

Compared with children without special health care needs, a greater percentage of CSHCN with neurologic conditions were male, white, non-Hispanic, and aged 6 to 17 years. They also were more likely to have inadequate insurance, public health insurance only, or a combination of private and public health insurance and to be living in poverty (Table 1). Among CSHCN with neurologic conditions, those with 2 or more neurologic conditions (either at least 2 DSM conditions or 1 of each type) were more likely than CSHCN with a single DSM condition to have inadequate insurance, be uninsured, have public health insurance, and be living in poverty (Table 1).

Descriptive Comparison of Health Care Needs Between CSHCN With Neurologic Conditions and Children Without Special Health Care Needs

As expected, on the basis of the definition of CSHCN, CSHCN with neurologic conditions had more health care needs than children without special health care needs (Table 2). CSHCN with neurologic conditions were more likely than children without special health care needs to have had a lack of or delayed access to care, a problem getting a referral, a specific unmet need, problems using other services, and dissatisfaction with the degree of care coordination and family-centered care (Table 3).

Health Care Needs Among CSHCN With Neurologic Conditions

Among CSHCN with neurologic conditions, those with a single DSM con-

dition needed the least number of distinct services (mean: 4.5 [95% CI: 4.4–4.5]), compared with the other subgroups (2 or more DSM conditions, mean: 5.2 [95% CI: 5.1–5.3]; a non-DSM condition, mean: 5.0 [95% CI: 4.9–5.2]; at least 1 of each type of condition, mean: 6.3 [95% CI: 6.1–6.4]). The number of services required by the 3 subgroups was significantly greater than that required by the single-DSM-disorder subgroup after controlling for covariates ($P < .001$ for each contrast).

After adjustment for sociodemographic factors and severity of limitation, CSHCN with 2 or more DSM conditions had threefold increased odds of needing mental health care and were more likely to have had more health care visits and to have needed more home health care and communication aids, compared with CSHCN with a single DSM condition. In contrast, CSHCN with 2 or more DSM conditions were less likely to have needed mobility devices than CSHCN with a single DSM condition.

Compared with CSHCN with a single DSM condition, CSHCN with non-DSM conditions had greater odds of having had a recent emergency department visit and having needed a referral, therapy, or medical supplies. This subgroup also had a twofold to threefold increase in odds of needing a specialty doctor, vision care, hearing care, mobility aids, and durable medical equipment. CSHCN with non-DSM conditions had 10% of the odds of needing mental health care compared with CSHCN with a single DSM condition.

CSHCN with at least 1 DSM and 1 non-DSM condition had the highest mean number of conditions (3.0) and generally had the greatest magnitude of need. CSHCN with both DSM and non-DSM conditions had a nearly twofold increase in reporting 9 or more health care visits and at least 3 times greater

odds of needing communication aids, physical, occupational, or speech therapy, and home health care compared with CSHCN with a single DSM condition (Table 2).

The posthoc analyses that collectively tested for all needs listed in Table 2 showed that compared with CSHCN with a single DSM condition, those with 2 or more DSM conditions needed more services (OR: 1.3 [95% CI: 1.3–1.4]), as did those with at least 1 non-DSM condition (OR: 1.4 [95% CI: 1.3–1.5]) and those with at least 1 of each type of condition (OR: 2.1 [95% CI: 1.9–2.3]).

Unmet Needs Among CSHCN With Neurologic Conditions

Unmet health care needs were generally greatest for CSHCN with 2 or more DSM conditions or at least 1 of each type of condition. These 2 groups had increased odds for dissatisfaction with care coordination and difficulty using “other” (non–health care) services. These subgroups were also at increased odds for having any unmet need, including not receiving all prescriptions, as compared with CSHCN with a single DSM condition (Table 3). The increased odds of having an unmet need remained significant for the subgroup of those with 2 or more DSM conditions (OR: 1.3 [95% CI: 1.1–1.6]), with a statistical trend for the DSM and non-DSM subgroups (OR: 1.2 [95% CI: 1.0–1.5]), after controlling for number of services needed. In addition, parents of CSHCN with 2 or more DSM conditions had increased odds of reporting delayed or lack of access to care, dissatisfaction with family-centered care, and not receiving all needed routine care or care from a specialty doctor. CSHCN with only non-DSM conditions were less likely to report dissatisfaction with care coordination and were less likely to have not received all needed care from special-

ists, compared with CSHCN with a single DSM condition.

The posthoc analyses that collectively tested for all unmet needs listed in Table 3 showed that compared with CSHCN with a single DSM condition, those with 2 or more DSM conditions had more unmet needs overall (OR: 1.2 [95% CI: 1.1–1.2]), as did those with at least 1 of each type of condition (OR: 1.1 [95% CI: 1.1–1.2]). There was no difference in the collective measure of unmet needs among CSHCN with at least 1 non-DSM condition (OR: 0.9 [95% CI: 0.9–1.0]; $P = .09$) compared with CSHCN with a single DSM condition.

DISCUSSION

Several significant differences were noted between subgroups of CSHCN with neurologic conditions. CSHCN with a single DSM condition generally had fewer health care needs than CSHCN in the other subgroups. CSHCN with at least 1 DSM and 1 non-DSM condition had the greatest magnitude of health care needs.

The findings associated with the subgroup of CSHCN with non-DSM conditions are somewhat challenging to interpret, because this subgroup included CSHCN with single or multiple conditions. However, because few children in the group had multiple conditions (4%), the estimates largely represent those with a single non-DSM condition.

Having multiple neurologic conditions seemed to be more important in defining unmet needs than the specific type of neurologic condition. CSHCN in the multiple-neurologic-condition subgroups (at least 2 DSM conditions or at least 1 DSM and 1 non-DSM disorder) had more unmet needs and reported greater dissatisfaction with care, care coordination, ability to get a referral, and ability to use other services. Having an unmet need did not seem to be a direct consequence of having more needs, because adjusting for the num-

ber of needs did not completely explain the differences in unmet needs between the subgroups. In addition, unmet needs did not seem to be the result of increased severity of conditions among CSHCN with multiple conditions, because all findings were adjusted for severity of limitation.

Notably, the non-DSM-disorder subgroup was least likely to have unmet needs or to be dissatisfied with care coordination, whereas the 2 subgroups of CSHCN with multiple conditions had the greatest unmet needs and dissatisfaction with care coordination. Care coordination may be more challenging for children with multiple conditions, which could result in more unmet needs among this subgroup of CSHCN.

The findings presented here should be interpreted in the context of several limitations. The study was limited to neurologic conditions and did not assess other co-occurring conditions (eg, diabetes, asthma, or heart conditions). In addition to being at greater risk for co-occurring neurologic conditions, CSHCN with neurologic conditions are also at greater risk for other health conditions; therefore, unmet needs associated with neurologic conditions may have been overestimated.^{12,36} Moreover, analyses were limited to those conditions included in the survey, and therefore the findings may not generalize to children with other neurologic conditions. Furthermore, results were influenced by the most prevalent conditions (eg, ADHD) and can only be generalized to noninstitutionalized CSHCN. Because of the relatively small numbers of children in the non-DSM-disorder group, it was not possible to draw conclusions about health care needs specific to CSHCN with single versus multiple non-DSM conditions. Finally, this study focused on health care needs, not services provided by social welfare and educa-

tional systems that are relevant to children with neurologic conditions.^{3,16,37,38}

Despite these limitations, several major strengths of the NS-CSHCN contributed to this study. These strengths included the large sample of CSHCN, the assessment of multiple conditions that allowed comparisons between several distinct subgroups of CSHCN based on the type and number of neurologic conditions, the assessment of many

health care issues specific to CSHCN, and the representativeness of the sample to the noninstitutionalized population of US CSHCN.

CONCLUSIONS

These findings highlight the importance of identifying and addressing the needs of subpopulations of CSHCN with neurologic conditions who are most in need, including children with multiple condi-

tions. CSHCN who require different types of services not only need more resources in terms of service but also may require coordination of care. These results support previous recommendations for educating pediatricians about care coordination, providing reimbursement for coordination, and finding creative strategies to improve care coordination for CSHCN with multiple neurologic conditions.^{39–43}

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