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Original Research

Access to Health Care for Children and Youth with Special Health Care Needs in Kansas: A Retrospective Analysis

Trinity Bogle, MS-4, Dulcinea Rakestraw, Ph.D., MPH, Hayrettin Okut, Ph.D., Kari Nilsen, Ph.D.

ABSTRACT

Introduction. Despite the high prevalence of Children and Youth with Special Health Care Needs (CYSHCN) in the United States, health care services for this population remain insufficient. Prior studies have documented disparities in both access to and quality of care. We aimed to evaluate health care access and barriers among CYSHCN in Kansas.

Methods. Using data from the 2021 National Survey of Children's Health (NSCH), we conducted a retrospective, quasi-experimental analysis of health care access and barriers among 1,696 Kansas households. Children were classified as having special health care needs based on diagnoses across 24 specified conditions.

Results. Although most CYSHCN in Kansas reported adequate access to health care (97.2%), significant barriers persist, particularly among those with lifelong conditions. These children were more likely to report needing care but not receiving it ($\chi^2_{\text{Rao-Scott}}$ (1, n = 1696) = 11.64; p <0.001; OR 0.29; 95% CI, 0.14-0.61), primarily due to appointment or service unavailability and cost. They also were more likely to report difficulty paying medical bills ($\chi^2_{\text{Rao-Scott}}$ (1, n = 1291) = 10.21; p <0.001; OR 0.49; 95% CI, 0.31-0.77), and a greater proportion lived in poverty ($\chi^2_{\text{Rao-Scott}}$ (1, n = 1696) = 5.29; p = 0.021; OR 0.74; 95% CI, 0.57-0.96).

Conclusions. While CYSHCN in Kansas generally reports adequate health care access, important barriers remain. Efforts to improve access to specialty care, reduce costs, and enhance insurance coverage are essential to improving care for this vulnerable population.

INTRODUCTION

According to the National Survey of Children's Health (NSCH), nearly 14 million children in the United States were living with special health care needs as of 2019, representing 18.8% of the pediatric population.[1] Given this high prevalence, ensuring access to high-quality care for Children and Youth with Special Health Care Needs (CYSHCN) is important.

Despite their prevalence, research consistently demonstrates that health care for CYSHCN remains inadequate. In the 2019 NSCH, 30.9% of families of CYSHCN reported unmet health care needs, and 8.3% reported frustration in obtaining services, compared with 11.0% and 1.3% of families of children without special health care needs, respectively.[2] CYSHCN often require more complex and resource-intensive care, including interdisciplinary coordination, more frequent clinical visits, and higher out-of-pocket costs. As a result, access to care is critical for both affected children and their families.

Access to and quality of care for CYSHCN vary based on functional status and specific health care needs and are strongly influenced by factors such as insurance coverage, socioeconomic status, and geographic location.[3] Additional barriers include a nationwide shortage of pediatric subspecialists and insufficient training and support for primary care professionals managing these patients in the absence of specialty care.[2] Structural and societal factors, including racial and ethnic disparities and ableism, further contribute to inequities in care.[2,4]

Disparities particularly are pronounced in rural areas, where CYSHCN face greater challenges in accessing high-quality care compared with their urban counterparts. Contributing factors include higher rates of poverty and uninsurance, as well as limited availability of trained health care professionals, including pediatric specialists and general pediatricians.[5] However, the expanding use of telemedicine offers a potential solution by improving access to care and reducing barriers related to travel time and cost.[6]

Although numerous studies have documented disparities in access and quality of care for CYSHCN, meaningful improvements remain limited, as caregivers continue to report unmet needs at disproportionately higher rates compared with families of children without special health care needs. Addressing these disparities is critical to improving health outcomes and quality of life for this vulnerable population. Therefore, the purpose of this study was to evaluate access to patient-centered health care and identify barriers among CYSHCN in Kansas.

METHODS

Study Design and Data Source. This study was a retrospective, quasi-experimental analysis of data from the 2021 NSCH.[7] Approval to access the dataset was obtained from the Child & Adolescent Health Measurement Initiative (CAHMI) Data Resource Center for Child and Adolescent Health. The NSCH provides national- and state-level estimates on children's health and well-being, including the prevalence and impact of special health care needs. The survey is funded and directed by the Health Resources and Services Administration's Maternal and Child Health Bureau (HRSA MCHB) within the U.S. Department of Health and Human Services and is administered by the U.S. Census Bureau on behalf of HRSA MCHB. This analysis adhered to the STROBE (Strengthening the Reporting of Observational Studies in Epidemiology) guidelines[8] and PRICSSA (Preferred Reporting Items for Complex Sample Survey Analysis) guidelines.[9]

Participants. The 2021 NSCH was administered from June 25, 2021, to January 14, 2022, using a national sample of approximately 300,000 addresses.[10] The overall response rate was 40.3%.[10] A total of 106,000 screener questionnaires were completed, of which 62,010 households were eligible for the topical questionnaire.[10] Among these, 50,892 completed the topical survey.[10] Weighted estimates from the topical dataset are generalizable to state and na-

tional populations of children.[10] For this study, all 1,696 responses from Kansas households were included.

Procedure. The NSCH collects data on children's physical and mental health, special health care needs, health care access and utilization, insurance coverage, family and caregiver well-being, social determinants of health, and the child's home, school, and community environment.[10] The survey was administered online and by mail using a state-representative, address-based probability sample drawn from the U.S. Census Bureau's Master Address File. Addresses were stratified by the likelihood of containing children, with oversampling of households with young children. One child per eligible household was randomly selected for the topical survey, with additional oversampling of children aged 0-5 years and CYSHCN to ensure reliable estimates.[10]

Households received reminder letters and postcards to complete the survey, followed by a mailed paper screener questionnaire for nonrespondents.[10] The screener identified households with children and determined CYSHCN status. One child from each eligible household was then selected for a detailed topical questionnaire. Deidentified data were provided to the study team by the CAHMI Data Resource Center. The survey instrument is publicly available at: https://mchb.hrsa.gov/national-survey-childrens-health-questionnaires-datasets-supporting-documents.

Statistical Analysis. This was a primarily descriptive analysis of CYSHCN in Kansas. A two-stage, survey-weighted analytic approach was used to account for the complex sampling design, including clustering and unequal selection probabilities. First, survey-weighted univariate analyses were conducted to describe study variables, using frequencies and percentages for categorical variables. Standard errors were estimated using the Taylor series linearization method.

Second, survey-weighted bivariate analyses were performed using the Rao–Scott likelihood ratio chi-square test to assess associations. Missing data were assumed to be missing at random and were imputed as appropriate, an approach that yields valid estimates when missingness depends on observed characteristics rather than unobserved outcomes. All analyses incorporated survey weights and cluster adjustments and were conducted using SAS® version 9.4 (SAS Institute Inc., Cary, NC). This study was reviewed by the University of Kansas Medical Center Institutional Review Board and determined to be non-human subjects research.

RESULTS

Participants. Table 1 summarizes participant characteristics. Children evenly were distributed across age groups, and 51.7% were male. Most identified as White alone (82.3%), followed by two or more races (10.4%). About half (52.0%) lived in core-based statistical areas (CBSAs) with populations >10,000. Regarding income, 38.4% reported ≥400% and 10.9% reported <100% of the Federal Poverty Guidelines. Most children (95.6%) had health insurance.

Table 1. Identified child demographics and health care needs (N = 1696).

Measure	n	Weighted %
Age		
0 to 2	256	15.3
3 to 5	357	20.7
6 to 8	245	13.9
9 to 11	247	15.7
12 to 14	369	14.6
15 to 17	222	19.8
Gender		
Male	885	51.7
Female	811	48.3
Race		
White alone	1408	82.3
Black or African American alone	55	3.2
American Indian or Alaska Native alone	13	0.9
Asian alone	55	3.1
Native Hawaiian and Other Pacific Islander alone	5	0.2
Two or More Races	160	10.4
Location of Home Address		
Lives in area with >10,000 people	843	52.0
Lives in area with <10,000 people	118	6.7
Suppressed for confidentiality	735	41.3
Family Poverty Status		
<100% of Federal Poverty Guidelines	197	10.9
100 to 199% of Federal Poverty Guidelines	292	16.6
200 to 299% of Federal Poverty Guidelines	305	18.1
300 to 399% of Federal Poverty Guidelines	265	16
400% or more of Federal Poverty Guidelines	637	38.4
Health Insurance (Currently Covered)		
Yes	1615	95.6
No	77	4.4
Number of lifelong health conditions		
None	975	58.2
1 health condition	360	23.9
2 or more health conditions	361	23.9
Number of functional difficulties		
None	1304	74.8
1 functional difficulty	252	15.5
2 or more functional difficulties	140	9.7
Special Health Care Needs Status		
Yes	397	26.4
No	1299	73.6

Health Care Needs. Over half (58.2%) of children did not have a lifelong health condition.[11] Similarly, 74.8% had no functional difficulties, and 73.6% did not meet criteria for special health care needs.[11]

Health Care Access. Only 2.8% of respondents reported unmet health care needs in the past 12 months. Among these, 15.4% reported difficulty paying medical bills, 6.6% reduced work hours, and 8.9% avoided job changes due to insurance concerns (Table 2).

Children with lifelong conditions were more likely to report unmet care ($\chi^2_{Rao\text{-}Scott}$ (1, n = 1696) = 11.64; p <0.001; OR 0.29; 95% CI, 0.14-0.61), difficulty paying bills ($\chi^2_{Rao\text{-}Scott}$ (1, n = 1291) = 10.21; p <0.001; OR 0.49; 95% CI, 0.31-0.77), reduced work hours ($\chi^2_{Rao\text{-}Scott}$ (1, n = 1681) = 15.98; p <0.001; OR 0.29; 95% CI, 0.15-0.55), and avoiding job changes ($\chi^2_{Rao\text{-}Scott}$ (1, n = 1683) = 16.72; p <0.001; OR 0.36; 95% CI, 0.22-0.61). Effect sizes were small (≤0.15).

Table 2. Health care access.

During the past 12 months…	Yes (Weighted %)	No (Weighted %)
…was there any time when this child needed health care, but it was not received?	**48 (2.8%)**	**1648 (97.2%)**
No health condition	12 (30.0%)	
1 or more	36 (70.0%)	
…did your family have problems paying for any of this child's medical or health care bills?	**173 (15.4%)**	**1118 (84.6%)**
No health condition	74 (41.1%)	
1 or more	99 (56.9%)	
…did you cut down on the hours you work because of this child's health or health conditions?	**90 (6.6%)**	**1591 (93.4%)**
No health condition	24 (30.4%)	
1 or more	66 (69.6%)	
…did you avoid changing jobs due to concerns about maintaining health insurance for this child?	**124 (8.9%)**	**1559 (91.1%)**
No health condition	47 (35.7%)	
1 or more	77 (64.3%)	

Barriers to Care. Among those with unmet needs, the most common barriers were difficulty obtaining appointments (72.4%), cost (53.0%), and service unavailability (40.8%); transportation was least reported (15.8%; Table 3). Subgroup sample sizes limited further statistical testing.

Relationship with Providers. Most respondents reported positive health care professional interactions, including sufficient time (66.4%), careful listening (74.8%), cultural sensitivity (79.8%), ease of communication (70.0%), and shared decision-making (75.1%; Table 4). Fewer than 1.5% reported these behaviors never occurred.

Health Insurance Coverage. As shown in Table 5, most reported that insurance "always" covered needed services (62.4%) and allowed access to health care professionals (76.4%). Coverage and access were lower among children with lifelong conditions; however, dichotomized analyses showed no significant associations (p = 0.060 and p = 0.665, respectively).

Demographic Differences. Lower household income (≤299% of the Federal Poverty Guidelines) was associated with having a lifelong condition ($\chi^2_{Rao\text{-}Scott}$ (1, n = 1696) = 5.29; p = 0.021; OR 0.74; 95% CI, 0.57-0.96), though the effect size was small. No significant associations were observed for race, gender, or urban versus rural residence.

Table 3. Barriers to receiving care.

Barriers	Yes (Weighted %)	No (Weighted %)
Not Eligible	**9 (27.9%)**	**40 (72.1%)**
No health condition	3 (32.3%)	
1 or more	6 (67.7%)	
Not Available	**20 (38.3%)**	**29 (61.7%)**
No health condition	2 (8.6%)	
1 or more	18 (91.4%)	
Getting an Appointment	**36 (72.4%)**	**13 (27.6%)**
No health condition	7 (23.3%)	
1 or more	29 (76.7%)	
Getting Transportation	**7 (15.8%)**	**42 (84.2%)**
No health condition	1 (25.5%)	
1 or more	6 (74.5%)	
Office not Open	**15 (31.8%)**	**34 (68.2%)**
No health condition	6 (46.0%)	
1 or more	9 (54.0%)	
Cost	**25 (53.0%)**	**24 (47.0%)**
No health condition	8 (39.0%)	
1 or more	17 (61.0%)	

DISCUSSION

This study provides important insights into health care access and barriers among CYSHCN in Kansas. Despite a diverse and generally representative sample, characterized by balanced age distribution, slight male predominance, and high insurance coverage, notable disparities persist. The predominance of White participants likely reflects the underlying demographics of Kansas, and the high rate of insurance coverage may partially explain the overall favorable access reported.[12,13] These contextual factors are critical when interpreting the findings.

Encouragingly, only a small proportion of children (2.8%) reported unmet health care needs, suggesting that pediatric health care access in Kansas broadly is adequate. However, this aggregate finding obscures meaningful disparities. CYSHCN were significantly more likely to experience unmet health care needs, despite their greater reliance on health services and increased vulnerability to adverse outcomes.[1-3,14] This discrepancy highlights a persistent gap between overall access and equitable access for high-need populations.

Barriers to care were consistent with prior literature, with appointment availability, cost, and service unavailability identified as the most significant challenges. These barriers disproportionately affected CYSHCN, who often require more frequent care, multidisciplinary coordination, and subspecialty services.[2,3] Structural limitations, particularly shortages of pediatric subspecialists and higher out-of-pocket costs for specialized services, likely contribute to these disparities.[15] Addressing these system-level constraints will be needed to improving care delivery for this population.

Patient-reported experiences with health care professionals were largely positive, with most respondents indicating effective communication, sufficient time spent, and shared decision-making. While these findings suggest generally high-quality care, even small proportions of dissatisfaction clinically are meaningful,

Table 4. Relationship with provider.

During the past 12-months, how often did this child's doctors or other health care providers...	Always (Weighted %)	Usually (Weighted %)	Sometimes (Weighted %)	Never (Weighted %)
... spend enough time with this child?	957 (66.4%)	372 (27.3%)	74 (4.8%)	20 (1.5%)
	563 (70.6%) None	*171 (23.7%) None*	*39 (4.3%) None*	*10 (1.3%) None*
	394 (61.2%) 1+	*201 (31.7%) 1+*	*35 (5.4%) 1+*	*10 (1.6%) 1+*
...listen carefully to you?	1062 (74.8%)	308 (21.2%)	44 (3.5%)	6 (0.6%)
	618 (80.0%) None	*145 (17.6%) None*	*17 (2.2%) None*	*1 (0.1%) None*
	444 (68.4%) 1+	*163 (25.5%) 1+*	*27 (5.0%) 1+*	*5 (1.1%) 1+*
...show sensitivity to your family's values and customs?	1117 (79.8%)	251 (16.9%)	39 (2.4%)	14 (0.9%)
	633 (81.4%) None	*127 (15.9%) None*	*17 (1.9%) None*	*4 (0.8%) None*
	484 (77.7%) 1+	*124 (18.0%) 1+*	*22 (3.0%) 1+*	*10 (1.2%) 1+*
...make it easy for you to raise concerns or disagree with recommendations for this child's health care?	307 (70.0%)	87 (21.1%)	28 (7.4%)	4 (1.5%)
	128 (75.7%) None	*25 (15.1%) None*	*9 (7.3%) None*	*3 (1.9%) None*
	179 (66.8%) 1+	*62 (24.6%) 1+*	*19 (7.4%) 1+*	*1 (1.2%) 1+*
...work with you to decide together which health care and treatment choices would be best for this child?	314 (75.1%)	83 (19.3%)	26 (8.3%)	3 (0.9%)
	131 (77.9%) None	*23 (12.1%) None*	*11 (8.7%) None*	*1 (1.3%) None*
	183 (67.7%) 1+	*60 (23.6%) 1+*	*15 (8.0%) 1+*	*2 (0.7%) 1+*

Note: "None" indicates the number/percent children without a reported lifelong health condition.
"1+" indicates the number/percent children with one or more lifelong health conditions.

Table 5. Health insurance coverage.

How often does this child's health insurance…	Always (Weighted %)	Usually (Weighted %)	Sometimes (Weighted %)	Never (Weighted %)
...offer benefits or cover services that meet this child's needs?	*1019 (62.4%)*	*473 (29.9%)*	*108 (7.0%)*	*10 (0.7%)*
	621 (70.2%) None	*237 (23.7%) None*	*44 (5.0%) None*	*8 (1.1%)*
	398 (52.0%) 1+	*236 (38.2%) 1+*	*64 (9.7%) 1+*	*2 (0.2%) 1+*
... allow them to see the health care providers they need?	*1239 (76.4%)*	*295 (18.9%)*	*70 (4.5%)*	*2 (0.2%)*
	723 (80.1%) None	*158 (15.5%) None*	*26 (4.0%) None*	*2 (0.4%) None*
	516 (71.4%) 1+	*110 (23.5%) 1+*	*44 (5.0%) 1+*	*0 (0.0%) 1+*

Note: "None" indicates the number/percent children without a reported lifelong health condition.
"1+" indicates the number/percent children with one or more lifelong health conditions.

as negative experiences may erode trust, reduce adherence, and exacerbate disparities in outcomes.[16-18]

Contrary to expectations, no significant differences were observed between rural and urban populations. This finding should be interpreted with caution due to suppressed geographic data and limited subgroup power. Additionally, the increasing adoption of telemedicine may be mitigating traditional geographic barriers to care, though this was not directly measured.[6]

The modest effect sizes observed likely reflect high baseline levels of access and insurance coverage, which reduce variability across groups.[13] Methodological factors, including reliance on caregiver self-report, broad survey measures, and the heterogeneity of CYSHCN, may further attenuate observed associations.[19-21] These limitations underscore the need for more granular, longitudinal data to better capture disparities in access and outcomes.

Several study limitations warrant consideration. The voluntary, mail-based survey design may introduce selection bias, potentially underrepresenting families with lower socioeconomic status or greater caregiving burden. Additionally, self-reported data are subject to recall bias and variable interpretation. Despite these limitations, the findings provide valuable population-level insights into pediatric health care access in Kansas.

CONCLUSIONS

While pediatric health care access in Kansas appears generally adequate, important disparities persist for CYSHCN, particularly in access to timely and affordable care. These findings underscore the need for targeted interventions to improve specialty access, reduce financial barriers, and strengthen care coordination. Advancing equitable, patient-centered care for CYSHCN will require coordinated efforts across clinical, policy, and health system levels to ensure that access translates into meaningful, high-quality care for all children.

ARTICLE INFORMATION

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Corresponding Author: Dulcinea Rakestraw, The University of Kansas School of Medicine-Wichita, Wichita, Kansas, 1010 N. Kansas St., Wichita, KS, 67214, drakestraw@kumc.edu.

Author Affiliations: The University of Kansas School of Medicine-Wichita, Wichita, Kansas (Bogle, Rakestraw, Nilsen); Department of Family and Community Medicine, The University of Kansas School of Medicine-Wichita, Wichita, Kansas (Rakestraw, Nilsen).

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