Using the Children with Special Health Care Needs Screener with Immigrant Families: An Analysis of the National Survey of Children's Health

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Introduction/Background

The Children with Special Health Care Needs Screener© (CSHCN-S) is among the most widely used tools for assessing the prevalence of children with greater than typical need for healthcare due to chronic illness. Designed to operationalize the Maternal and Child Health Bureau's (MCHB) definition of children with special healthcare needs (Appendix Table A), children screen positive if they meet at least one of five criteria pertaining to any medical, behavioral, or other health condition lasting or expected to last 1 year: (1) needing or using a prescription medication; (2) needing or using more health or educational services than is usual for children of the same age; (3) being limited in their ability to do things most children of the same age can do; (4) needing or receiving special therapy (e.g., physical therapy); or (5) needing or receiving treatment or counseling for a chronic emotional, developmental, or behavioral problem[1]. Although the screener is not designed to identify all children with chronic conditions, 94.6% of children enrolled in Supplemental Security Income (SSI) and 65.8% of children with reported diagnoses of at least one of 18 chronic conditions screen positive with the English-language CSHCN-S[1, 2].

Researchers and policymakers have used the CSHCN-S to investigate health disparities and advocate for allocation of state and other resources[3]. However, parent-reported prevalence of children with special healthcare needs (CSHCN) is markedly lower among Latino children from Spanish-language households and among children in immigrant families relative to children with US-born parents[2, 4–7]. It is possible that chronic conditions are less prevalent among children in immigrant families, or chronically-ill children in these

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populations may have fewer functional impairments. Alternatively, the CSHCN-S may perform differently among immigrant populations. For example, immigrant parents who speak Spanish have reported reluctance to answer CSHCN-S questions via telephone, and refugee parents may have a higher threshold for concern about early childhood development[6, 8].

Using the 2011–2012 NSCH, we investigate the likelihood of children in immigrant and non-immigrant families screening positive with the CSHCN-S, with specific attention to children with an equivalent number of currently-diagnosed chronic conditions. By making comparisons between children with an equivalent number of currently-diagnosed chronic conditions—who likely have similar health service needs—we explore whether the CSHCN-S may under-count children from immigrant households.

METHODS

The 2011–2012 NSCH is a nationally representative telephone survey conducted by the National Center for Health Statistics in collaboration with and supported by the MCHB. Administrative procedures and data collection methods are detailed elsewhere[9]. Parents/guardians reported demographic and health information for one randomly-selected child per household.

Key Variables

We used the NSCH data file provided by the Data Resource Center for Children and Adolescent Health (DRC). This file includes indicator variables developed by the Child and Adolescent Health Measurements Initiative and State and Local Area Integrated Telephone Survey (SLAITS) team[10]. The primary outcome was whether a child screened positive on the CSHCN-S (Appendix Table A). Each child's household generational status was categorized using the NSCH-defined summary variable: First generation (child and parents born outside the US), second generation (child born in the US and at least one parent born outside the US; or child born outside the US and one parent born in the US), or third generation (both parents born in the US)[9]. A DRC summary variable was used to determine whether each child had 0, 1, or 2+ currently-diagnosed chronic conditions from a list of 18 possible conditions (Appendix Table D).

Analysis

All analyses were conducted in STATA 15.0[11] using svy estimation to account for weights and survey variances. Models were representative of non-institutionalized children aged 0–17 in the US[9]. Children with missing generational status were excluded (5.5%).

We used Pearson chi-squared tests to compare the likelihood of screening positive with the CSHCN-S for children from first, second, and third generation households with equivalent numbers of currently-diagnosed chronic conditions. We then used logistic regression to examine the relationship between CSHCN status, generational status, and number of chronic conditions, adjusting for characteristics previously shown to be associated with likelihood of screening positive for CSHCN that were also significant in our bivariate analysis: child age, sex, race/ethnicity and insurance status, and household language and educational

attainment[4–6]. Household income was examined but not included, as it was found to be non-significant in bivariate analysis. Additionally, we used bivariate and multivariate analyses to examine the relationship between generational status and each of the five CSHCN-S criteria[5]; children with missing data were excluded from these models (1.1%).

The analysis used a de-identified dataset; IRB review was not sought per institutional policy.

RESULTS

Our analysis included 90,417 children, comprising 94.5% of the total sample. The sociodemographic characteristics of the population were concordant with prior research[7] (Table I). Approximately 17% were children in first and second generation households, aka "children in immigrant families."

Regardless of the number of currently-diagnosed chronic conditions, children in third generation households were most likely to screen positive on the CSHCN-S (Table II). For example, among children with no reported chronic conditions, 6.3% of children in third generation households (95% CI 5.9–6.7), 4.2% of children in second generation households (95% CI 3.5–5.0), and 2.6% of children in first generation households (95% CI 1.3–4.8) screened positive. Among children with 2+ reported chronic conditions, the CSHCN-S was positive for 85.7% (95% CI 84.0–87.3) of third, 76.8% (95% CI 69.3–83.0) of second, and 75.0% (95% CI 49.8–90.1) of first generation household children (Table II). After adjusting for sociodemographic status, the effect of generational status was most marked when comparing children in first and third generation households (Table III). As generational status was also significantly associated with number of currently-diagnosed chronic conditions (F(8,90302) = 656.51, p <0.001), we considered a possible interaction effect, but none was detected (data not shown). Number of currently-diagnosed chronic conditions, child age, insurance status, household language, and household educational status were also associated with CSHCN-S results in the adjusted model (Appendix Table B).

Examining each the five CSHCN-S criteria individually revealed that adjusting for the number of currently-diagnosed chronic conditions and sociodemographic characteristics attenuated the differences between children in first, second, and third generation households for all but one criterion: use of or perceived need for a prescription medication (Appendix Table C).

DISCUSSION

We investigated the concordance between CSHCN-S results and relative chronic disease burden among children in first, second, and third generation households using the 2011–2012 NSCH. As previously reported, we found significantly fewer children in first and second generation households screened positive relative to children in third generation households[7]. Lower reported levels of currently-diagnosed chronic conditions among the children of immigrants paralleled this finding. However, when we examined the probability of screening positive with the CSHCN-S among children with the *same number of currently-diagnosed chronic conditions*, the association between generational status and CSHCN-S results remained significant. These findings may be largely attributable to differences in

responses to the CSHCN-S's prescription medication criterion, the most common qualifying criterion in this and other samples[2].

Our analysis suggests the CSHCN-S may perform differently for children in immigrant families. Read et al observed that immigrant parents interviewed in Spanish expressed reluctance to disclose the kind of health information solicited via the CSHCN-S to anonymous telephone interviewers[6]. Kroening et al found that parents in some refugee populations may be less likely to perceive young children as delayed or impaired relative to their peers[8]. Hence, parental reticence and differences in the perception of impairment/need for children in immigrant families may contribute to our findings.

Alternatively, our findings may reflect actual differences in the healthcare needs of chronically-ill children in immigrant and non-immigrant households. Chronically-ill children in non-immigrant households may have more severe chronic conditions with a greater need for services. However, this is unlikely to fully explain our results given that functional limitations were not reported more frequently among non-immigrant children (Appendix Table C), and this criterion is often endorsed by parents of children with more severe disabilities (e.g., those enrolled in SSI)[1]. Differences in the relative distribution of specific chronic conditions, e.g. ADD/ADHD and vision problems, among children from immigrant and non-immigrant families may also influence screener outcomes (Appendix Tables D, E).

This study has important limitations. Categorization of children as having 0, 1, or 2+ chronic conditions was based upon a list of 18 conditions. Children with conditions not on this list may be mis-categorized. However, the inventory includes the most commonly-diagnosed chronic childhood conditions (e.g., asthma and ADHD) and uses broad terms (e.g., "intellectual disability") pertinent to multiple diseases. Additionally, as subgroup analysis was not possible for specific languages, ethnicities, or immigrant subgroups (e.g., refugees), we were unable to describe CSHCN-S results for these subpopulations.

Prospective research is needed to confirm or refute our findings. Overall, our research suggests the CSHCN-S may undercount the prevalence of special healthcare needs among children in immigrant families. This has implications for resource allocation for programs at the local, state and national level that rely upon CSHCN prevalence estimates to determine whether efforts to ensure the quality and accessibility of care for CSHCN should target children in immigrant families[3].

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Acknowledgments

References

1. Bethell CD, et al. Identifying children with special health care needs: development and evaluation of a short screening instrument. Ambul Pediatr. 2002; 2(1):38–48. [PubMed: 11888437]

2. Bethell CD, et al. Taking stock of the CSHCN screener: a review of common questions and current reflections. Acad Pediatr. 2015; 15(2):165–76. [PubMed: 25486969]

3. Szilagyi PG, et al. Children with special health care needs enrolled in the State Children's Health Insurance Program (SCHIP): patient characteristics and health care needs. Pediatrics. 2003; 112(6, pt 2):e508. [PubMed: 14654673]

4. Bethell CD, et al. What is the prevalence of children with special health care needs? Toward an understanding of variations in findings and methods across three national surveys. Matern Child Health J. 2008; 12(1):1–14.

5. Blumberg SJ, et al. Hispanic children with special health care needs from Spanish-language households. Pediatrics. 2010; 126(Suppl 3):S120–8. [PubMed: 21123474]

6. Read D, et al. An evaluation of the linguistic and cultural validity of the Spanish language version of the children with special health care needs screener. Matern Child Health J. 2007; 11(6):568–85. [PubMed: 17562154]

7. Kan K, Choi H, Davis M. Immigrant Families, Children With Special Health Care Needs, and the Medical Home. Pediatrics. 2016; 137(1)

8. Kroening AL, et al. Developmental Screening of Refugees: A Qualitative Study. Pediatrics. 2016; 138(3)

9. Blumberg SJ, F E, Frasier AM, et al. Design and operation of the National Survey of Children's Health, 2007, National Center for Health Statistics. Vital and Health Statistics. 2012; 1(55)

10. 2011/12 National Survey of Children's Health. Child and Adolescent Health Measurement Initiative (CAHMI),"2011–2012 NSCH: Child Health Indicator and Subgroups SAS Codebook, Version 1.0" 2013. Data Resource Center for Child and Adolescent Health, sponsored by the Maternal and Child Health Bureau; www.childhealthdata.org

11. StataCorp.. Stata Statistical Software: Release 15. College Station: TSL; 2017.

Table I

Sociodemographic and Health Characteristics of Non-institutionalized Children Aged 0–17 in the United States from 1st, 2nd, and 3rd Generation Households using the 2011–2012 NSCH (N = 90,417)

	1st generation n = 1,731 % (SE)	2nd generation n = 14,095 % (SE)	3rd generation n = 74,591 % (SE)	Pearson X^2
Children with Special Health Care Needs	7.5 (1.5)	11.8 (0.6)	22.6 (0.3)	p < 0.0001
Number of Chronic Conditions				
None	88.5 (1.6)	84.8 (0.7)	73.7 (0.4)	
One	7.2 (1.0)	10.1 (0.6)	15.3 (0.3)	p < 0.0001
Two or more[b]	4.4 (1.3)	5.1 (0.4)	11.0 (0.2)	
Sex of child				
Female	45.2 (2.6)	49.0 (0.9)	49.1 (0.4)	
Male	54.8 (2.6)	52.0 (0.9)	50.9 (0.4)	p = 0.2214
Age of child (yrs)				
0 – 5	9.7 (1.2)	39.1 (0.9)	32.1 (0.4)	
6 – 11	34.3 (2.5)	33.1 (0.9)	33.1 (0.4)	p < 0.0001
12 – 17	56.1 (2.6)	27.8 (0.8)	34.8 (0.4)	
Child's Race/Ethnicity				
White, non-Latino	8.7 (1.0)	15.3 (0.5)	67.0 (0.4)	
Black, non-Latino	9.1 (1.2)	7.5 (0.4)	14.7 (0.3)	
Multi-racial/other, non-Latino	23.0 (2.3)	18.0 (0.7)	7.3 (0.2)	p < 0.0001
Latino	59.2 (2.5)	59.1 (0.9)	11.0 (0.3)	
Child's Insurance Status				
Insured	74.0 (2.2)	93.0 (0.5)	96.0 (0.2)	
Not Insured	26.0 (2.2)	7.0 (0.5)	4.0 (0.2)	p < 0.0001
Primary Household Language				
English	22.5 (2.1)	47.4 (0.9)	98.9 (0.1)	
Spanish or other	77.5 (2.1)	52.6 (0.9)	1.2 (0.1)	p < 0.0001
Highest Education in Child's Household				
Less than high school	32.7 (2.6)	26.3 (0.9)	11.3 (0.3)	
High school graduate or GED completed	20.7 (2.1)	21.7 (0.8)	19.8 (0.3)	p < 0.0001
Post-high school education	46.6 (2.6)	52.0 (1.0)	68.9 (0.4)	
Household Income Relative to Federal Poverty Level, %	a	a	a	
100	43.0 (2.6)	33.3 (0.9)	17.5 (0.3)	
101 – 200	25.9 (2.4)	24.4 (0.9)	20.3 (0.3)	
201 – 399	15.3 (1.8)	19.6 (0.7)	31.9 (0.4)	p < 0.0001
400	15.7 (1.8)	22.8 (0.7)	30.4 (0.3)	

[a] Percentiles were calculated using singly imputed income data and survey weights.

[b] Among children with 2+ chronic conditions, the average number of diagnosed conditions was comparable for children from 1st, 2nd, and 3rd generation households (3.45, 3.40, and 3.36, respectively).

NSCH = National Survey of Children's Health SE = Standard Error

Table II

Performance of the Children with Special Health Care Needs (CSHCN) Screener by Household Generational Status and Child's Number of Currently-diagnosed Chronic Conditions[a]

Of children with 0 chronic conditions, % with a + CSHCN screener	1st gen	2nd gen	3rd gen	Pearson X^2
	2.6 (1.3 – 4.8)	4.2 (3.5 – 5.0)	6.3 (5.9 – 6.7)	p < 0.0001
Of children with 1 chronic condition, % with a + CSHCN screener	1st gen	2nd gen	3rd gen	Pearson X^2
	27.3 (17.3 – 40.3)	43.1 (37.4 – 49.0)	55.3 (53.2 – 57.4)	p < 0.0001
Of children with 2+ chronic conditions, % with a + CSHCN screener	1st gen	2nd gen	3rd gen	Pearson X^2
	75.0 (49.8 – 90.1)	76.8 (69.3 – 83.0)	85.7 (84.0 – 87.3)	p = 0.01

[a]Weighted percentiles and 95% confidence intervals are shown for each cell.

CSHCN = Children with Special Health Care Needs

Table III

Predicted Prevalence of the Children with Special Health Care Needs (CSHCN) using the CSHCN Screener by Household Generational Status and Child's Number of Currently-diagnosed Chronic Conditions, Multivariate Logistic Regression Model[a]

Of children with 0 chronic conditions, predicted % with a + CSHCN screener[b]	1st gen	2nd gen	3rd gen
	3.6 (2.1 – 5.1)	4.9 (4.1 – 5.8)	6.0 (5.6 – 6.5)
Of children with 1 chronic condition, predicted % with a + CSHCN screener[b]	1st gen	2nd gen	3rd gen
	39.1 (28.9 – 49.4)	47.0 (42.7 – 51.3)	52.3 (49.9 – 54.6)
Of children with 2+ chronic conditions, predicted % with a + CSHCN screener[b]	1st gen	2nd gen	3rd gen
	75.0 (66.7 – 83.2)	80.5 (77.4 – 83.7)	83.8 (81.6 – 85.6)

[a] Predicted percentiles and 95% confidence intervals were derived from the multivariate model adjusted for child's sex, age, race/ethnicity, and insurance status and household language and educational attainment.

[b] Predicted prevalence of CSHCN is significantly higher for children from 3rd generation households than children from 1st or 2nd generation households.

CSHCN = Children with Special Health Care Needs