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ORIGINAL ARTICLE

Disparities in Health Care Quality Indicators among US Children with Special Health Care Needs According to Household Language Use

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ABSTRACT

Background: Lower health care utilization and less favorable health outcomes have been demonstrated in children from Non-English Primary Language households (NEPL) in previous studies. This study examines prevalence of health care quality indicators among US children with special health care needs (CSHCN) and their association with household language use.

Methods: We used data from the 2009-2010 National Survey of Children with Special Health Care Needs, restricted to an analytic sample of 40,242 children. Logistic regression models were used to examine the effects of primary household language on the attainment of the 6 health care quality indicators for CSHCN.

Results: Compared to CSHCN from English primary language households (EPL), CSHCN from NEPL households had 31% higher odds of not feeling like partners in health care decision-making. They had 67% higher odds of lacking care through a medical home and 42% higher odds of reporting inadequate health insurance. NEPL children had 32% higher odds of not receiving early and continuous screening for special health care needs. NEPL youths had 69% higher odds of not receiving services for transition to adulthood. Minority race/ethnicity, lower income and families other than two biological parents all conferred additional risks to not attaining quality indicators. Publicly insured or uninsured CSHCN were also at higher risk.

Conclusions and Global Health Implications: Our study provides compelling evidence that significant disparities exist for CSHCN by primary household language status across all health care quality indicators. Establishment of effective surveillance systems and targeting of outreach programs in both developed and developing countries may lead to improved understanding of health care needs and quality of services and reduction of health disparities for this underserved population.

Key words: Children with Special Health Care Needs • Household Language Use • Limited English Proficiency • Socioeconomic Status • Race/ethnicity • Health Care Quality

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Introduction

Children with Special Health Care Needs (CSHCN) are defined as those "who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally."[1] The estimated prevalence of CSHCN in the United States (US) has increased from 12.8% in 2001 to 13.9% in 2005 and 15.1% (11.2 million children) in 2010.[2] As the needs of CSHCN in the US evolved, the federal Maternal and Child Health Bureau (MCHB) worked with state Title V agencies, families, and other stakeholders to develop 6 key system building blocks, referred to as core outcomes or quality indicators, representing the essential elements needed for high-quality systems of health and medical services.[3]

In 2011, according to the American Community Survey, 25 million people in the US had limited English proficiency (LEP), with 34% of Hispanic/Latino and 36.2% of Asians reporting not speaking English very well.[4] Recognizing the important health care issues facing immigrant and LEP communities in the US, the Council on Community Pediatrics of the American Academy of Pediatrics recently released a policy statement on new insights and recommendations on providing health care for immigrant, migrant and border children.[5]

For parents with LEP, caring for CSHCN is particularly challenging. Parental LEP has been associated with risks of adverse outcomes in children's health and disparities in medical and oral health, access to care, and use of services.[6-8] Moreover, parents with LEP may be unable to read and comprehend important clinical evaluations, prescription instructions, follow-up appointments, referral to specialists and therapy-related documents. In fact, some parents with LEP may be unable to understand routinely dispensed written medication instructions.[9] The challenge faced by clinicians treating LEP populations remains high. Clinical providers and medical entities have reported using untrained interpreters to communicate with families as they lack the capacity or fail systematically to provide effective translation and interpretation services for families with LEP.[10-12]

Previous research has documented the lack of access to medical home, usual source of care, family-centered care and insurance coverage adequacy for CSHCNs from Non-English Primary Language (NEPL) households.[13-15] NEPL families have also been found to sacrifice more time and employment opportunities to care for their CSHCN.[16] With respect to health insurance, parental LEP has significantly impacted the enrollment of Medicaid-eligible children in publicly funded health insurance programs.[17] Moreover, language barriers in accessing health care have been associated with less patient education, worse interpersonal care, and lower patient satisfaction.[18]

To our knowledge, no previous study has focused on examining household language use and health care quality as measured by attainment of MCHB's six quality indicators of effective implementation of systems of services for CSHCN. Using data from the 2009-2010 National Survey of Children with Special Health Care Needs (NS-CSHCN), our study aims to describe the demographic characteristics of CSHCN and the prevalence of CSHCN meeting six quality indicators by the parent-reported primary household language, and to examine the independent effects of primary household language on the six quality indicators while controlling for confounding variables.

Methods

The federal MCHB within the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services funded the 2009-2010 NS-CSHCN. The National Center for Health Statistics (NCHS) of the Centers for Disease Control and Prevention (CDC) oversaw the sampling, data collection, and telephone interviews for the survey as a module of the State and Local Area Integrated Telephone Survey (SLAITS). The NS-CSHCN is a national telephone survey with independent random samples from 50 states and the District of Columbia. The 2009-2010 NS-CSHCN is the third administration of the NS-CSHCN as the previous surveys took place in 2000-2001 and 2005-2006. The final sample was comprised of 40,242 children. The available survey languages included the

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following: English, Spanish, Mandarin, Cantonese, Vietnamese and Korean. The topics covered by the NS-CSHCN included child health, insurance status, access to health care, preventive care, family-centered care, access to community-based services, impact of child's health on family, transition to adulthood, and child and family demographics. The respondent was the parent or guardian who knew most about the child's health status and health care.[19] The overall interview completion rate was 83.6% for the landline sample, 76.6% for the cell-phone sample, and 80.8% for the combined sample.[20] The NCHS Research Ethics Review Board approved all data collection procedures.

Variables

The definition of CSHCN is described earlier in the introduction section.[1] The major independent variable of our study was primary household language. Households were identified as speaking English as the primary language at home (EPL) or using another primary language (Non-English Primary Language (NEPL)). Covariates in the analyses included: child's age (0-5, 6-11, 12-17 years), gender, race/ethnicity (non-Hispanic white, non-Hispanic black, Hispanic, and other), household poverty status measured as a ratio of family income to federal poverty level (FPL) in four categories (<100%, 100-199%, 200-399%, ≥400%), parental education (less than high school, high school graduate, more than high school), family structure (in biological or adopted household, two-parent stepfamily household, mother only household, other), health insurance status (private only, public only, public and private, uninsured), qualification criteria for CHSCN (functional limitation only or with any other criterion, prescription medications only, service use only, both prescription medication and service use).[1]

The quality indicators describe what families should be able to expect from the service system: (1) family partnership in decision-making and satisfaction with care, (2) receipt of care through a medical home, (3) adequate health insurance, (4) early and continuous screening and surveillance, (5) services that are organized for ease of use, and (6) effective transition planning for adult health care. Together, these quality indicators represent the essential elements needed for high-quality systems of services. Details of the components of each quality indicator are described elsewhere.[3]

Statistical analyses

Chi-square statistics were used to test socioeconomic and demographic differences between EPL and NEPL households. Bivariate analyses were conducted to examine the association of household language with the six quality indicators. The independent effects of primary household language status were analyzed for all quality indicators in the multivariable logistic regression models while controlling for children's age, gender, race/ethnicity, family poverty level, and family structure. Educational level was not included as a covariate due to its collinearity with income. Income has been shown to be a better measure of socioeconomic status for immigrants, since education credentials from foreign countries often result in underemployment in the US.[21] Adjusted odds ratios (OR) and 95% confidence intervals (CI) were computed by using the beta coefficients and standard errors obtained from the multivariable logistic analyses. To account for the complex sample design involving stratification, clustering, and multistage sampling of the NS-CSHCN, SAS version 9.3 (survey procs) was used to conduct the statistical analyses.[22] The Taylor series (linearization) method was used to estimate the covariance matrix of the regression coefficients for complex survey data.

Results

The final analytic sample includes 1,896 CSHCN from NEPL households and 38,346 children from EPL households. Table 1 summarizes the socioeconomic and demographic characteristics of CSHCN from both household types. Children from EPL households were predominantly non-Hispanic white (63%), while those from NEPL households were primarily Hispanic (74%). Nearly half of NEPL children were from 'poor' households compared to one-fifth of EPL children. Nearly 40% of NEPL parents did not graduate from high school compared to <10% of EPL parents. Almost two-thirds of NEPL children came

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Table 1. Socioeconomic and Demographic Characteristics of US Children with Special Health Care Needs (CSHCN) by Primary Household Language use, Ages 0-17 years

Characteristics (weighted percents)	English		Other language		Chi-square p-value
	N=38,346		N=1,896		
	%	SE	%	SE	
Child's race/ethnicity					<0.0001
Hispanic	11.8	0.36	74.1	1.63	
Non-Hispanic White	63.3	0.47	12.8	1.07	
Non-Hispanic Black	17.2	0.40	4.0	0.67	
Non-Hispanic Multi-race/Other	7.7	0.25	9.0	1.21	
Child's age					<0.0001
0-5 years	20.2	0.38	27.9	1.82	
6-11 years	38.6	0.46	39.1	1.91	
12-17 years	41.2	0.45	33.0	1.97	
Gender					0.08
Male	59.0	0.46	62.6	1.96	
Female	41.0	0.46	37.4	1.96	
Household poverty level					<0.0001
<100%	20.1	0.39	47.7	2.01	
100-199%	21.4	0.40	26.9	1.79	
200-399%	29.5	0.42	16.4	1.57	
400+%	29.0	0.40	8.9	0.99	
Parental education					<0.0001
Less than high school	8.7	0.34	39.4	2.06	
High school grad	19.6	0.40	23.6	1.73	
More than high school	71.7	0.47	37.0	1.80	
Family structure					<0.0001
CSHCN in parent household biological or adopted	56.0	0.47	67.9	1.96	
CSHCN in 2 parent stepfamily household	9.8	0.29	6.2	0.90	
CSHCN in mother only household	26.1	0.45	20.9	1.60	
CSHCN in other family structure household	8.0	0.26	5.0	1.15	
Health insurance status					<0.0001
Private only	54.8	0.47	23.8	1.73	
Public only	34.5	0.47	51.7	2.05	
Both Public and Private	7.5	0.25	15.8	1.61	
Uninsured	3.1	0.19	8.7	1.25	
Qualification criteria for CSHCN					<0.0001
Functional limits (only or w/any other)	23.5	0.40	23.3	1.68	
Prescription medication use only	39.8	0.45	32.8	1.84	
Service use only	14.7	0.34	29.3	1.98	
Prescription medication and service use	22.0	0.38	14.6	1.25	

Source: 2009-20010 National Survey of Children with Special Health Care Needs

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from two-parent households, while only 56% of EPL children had both parents in their households. One quarter of NEPL children, compared to more than half of EPL children, had private health insurance. A higher proportion of NEPL children qualified for CSHCN classification by service use, whereas a higher percentage of EPL children qualified by prescription medication use. There was no significant gender difference between the two groups.

Table 2 displays differences in quality indicators attainment by household language type. Sixty percent of NEPL families, compared to 71% EPL families, believed they were partners in decision making for their children's health. Only 27% of NEPL children received care through a medical home, compared to 44% of EPL children. About 49% of NEPL families had adequate private and/or public insurance to pay for needed services, compared to 62% of EPL families. Two-thirds of NEPL children were screened early and continuously for special health care needs, in contrast with 80% of EPL children receiving early screening. Only 58% of NEPL children accessed community based services, compared to 66% of EPL children. More than 41% of EPL youths with special health care needs received the necessary services for transition to adulthood, compared with 22% of NEPL youths. All differences were statistically significant at p<0.0001.

Table 3 includes the results of the multivariable logistic regression analysis for adjusted odds ratios of not meeting each of the quality indicators, while controlling for child's age, race/ethnicity, gender, insurance and household poverty status, and family structure. NEPL families had 31% higher odds of not feeling like partners in decision making (OR=1.31, 95% CI=1.16, 1.48). They also had 67% higher odds of lacking care through a medical home (OR=1.67, 95% CI=1.46, 1.90) and 42% higher odds of reporting inadequate health insurance (OR=1.42, 95% CI=1.26, 1.59). NEPL children had 32% higher odds of not receiving early and continuous screening for special health care needs (OR=1.32, 95% CI=1.15, 1.51). In addition, NEPL youths were more likely to report not receiving necessary services for transition to adulthood (OR=1.69, 95% CI=1.3, 2.2). Access to community based services was not associated with household language use.

Minority race/ethnicity, lower incomes, and families other than two biological or adopted-parents households all conferred additional risks to not meeting quality indicators. Publicly insured or uninsured CSHCN were also at higher risk of not meeting quality indicators.

Discussion

Our study provides compelling evidence that significant disparities exist for CSHCN by primary household language status across all quality indicators examined. Results of multivariable analyses further substantiate the independent effects of language barriers on the overall wellbeing of CSHCN. Since the LEP population is a subset of NEPL households,

Table 2. Weighted Percentage of CSHCN Meeting Maternal and Children Health Bureau Quality Indicators by Primary Household Language Use

Quality indicators	English		Other language		Chi-square
	%	SE	%	SE	p-value
1. Families are partners in decision-making for child's optimal health	71.2	0.45	59.5	1.97	<0.0001
2. CSHCN received coordinated, ongoing, comprehensive care within a medical home	44.3	0.46	26.8	1.86	<0.0001
3. Families have adequate private and/or public insurance to pay for the services they need	61.5	0.46	48.6	2.07	<0.0001
4. CSHCN are screened early and continuously for special health care needs	79.6	0.38	66.3	1.99	<0.0001
5. CSHCN who can easily access community-based services	65.7	0.46	57.9	2.0	<0.0001
6. Youth with special health care needs who receive the necessary services for transition to adulthood	41.2	0.69	21.8	3.2	<0.0001

Source : The 2009-2010 National Survey of Children with Special Health Care Needs

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Table 3. Adjusted Odds of US Children with Special Health Care Needs (CSHCN) not Meeting Health Care Quality Indicators

Sociodemographic characteristics	Families are not partners in decision-making for child's optimal health			CSHCN did not received coordinated, ongoing, comprehensive care within a medical home			Families do not have adequate private and/or public insurance to pay for the services they need			CSHCN are not screened early and continuously for special health care needs			CSHCN who can not easily access community-based services			Youth who did not receive the necessary services for transition to adulthood		
	OR	95% CI		OR	95% CI		OR	95% CI		OR	95% CI		OR	95% CI		OR	95% CI	
Primary household language																		
English	ref																	
Other language	1.31	1.16	1.48	1.67	1.46	1.90	1.42	1.26	1.59	1.32	1.15	1.51	0.92	0.81	1.03	1.69	1.30	2.20
Gender																		
Male	1.07	1.02	1.12	1.07	1.03	1.12	1.01	0.97	1.05	1.02	0.96	1.07	1.03	0.98	1.07	1.30	1.22	1.39
Female	ref																	
Child race/ethnicity																		
Non-Hispanic White																		
Non-Hispanic Black	1.26	1.16	1.36	1.37	1.27	1.48	1.04	0.96	1.12	0.78	0.71	0.86	0.84	0.78	0.91	1.36	1.20	1.54
Hispanic	1.30	1.20	1.41	1.42	1.31	1.53	1.22	1.13	1.31	0.87	0.80	0.96	1.17	1.09	1.27	1.65	1.44	1.90
Non-Hispanic Multi-race/Other	1.28	1.19	1.39	1.30	1.21	1.40	1.05	0.98	1.13	0.98	0.89	1.07	1.18	1.09	1.27	1.25	1.10	1.42
Child's age																		
0-5 years	ref																	
6-11 years	1.04	0.97	1.11	1.06	1.00	1.12	1.16	1.09	1.23	0.45	0.42	0.48	0.92	0.87	0.98			
12-17 years	1.08	1.01	1.16	1.08	1.02	1.15	1.14	1.07	1.21	0.38	0.35	0.41	1.01	0.95	1.07			
Household poverty status (ratio of family income to poverty threshold)																		
<100%	1.45	1.32	1.59	1.42	1.30	1.54	1.34	1.25	1.43	2.24	2.02	2.49	1.30	1.19	1.41	1.32	1.15	1.52
100-199%	1.29	1.19	1.40	1.25	1.17	1.34	1.46	1.37	1.55	2.11	1.93	2.31	1.40	1.30	1.51	1.32	1.18	1.48
200-399%	1.15	1.08	1.23	1.14	1.08	1.20	1.37	1.30	1.45	1.61	1.50	1.72	1.27	1.20	1.34	1.20	1.11	1.30
400+%	ref																	
Health insurance status																		
Private only	ref																	
Both public and private	1.26	1.15	1.38	1.62	1.49	1.77				0.82	0.74	0.92	1.59	1.46	1.74	1.73	1.50	2.00
Public only	1.25	1.17	1.35	1.33	1.24	1.42				0.81	0.75	0.88	1.34	1.25	1.43	2.00	1.80	2.23
Uninsured	1.96	1.72	2.23	2.10	1.83	2.41				3.13	2.74	3.57	4.23	3.71	4.82	2.74	2.20	3.42
Family structure																		
CSHCN in parent household biological or adopted	ref																	

Cont...

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Table 3. *(Continued)*

Sociodemographic characteristics	Families are not partners in decision-making for child's optimal health			CSHCN did not received coordinated, ongoing, comprehensive care within a medical home			Families do not have adequate private and/or public insurance to pay for the services they need			CSHCN are not screened early and continuously for special health care needs			CSHCN who can not easily access community-based services			Youth who did not receive the necessary services for transition to adulthood		
	OR	95% CI		OR	95% CI		OR	95% CI		OR	95% CI		OR	95% CI		OR	95% CI	
CSHCN in 2 parent stepfamily household	1.18	1.08	1.28	1.23	1.14	1.33	1.00	0.93	1.08	1.06	0.96	1.17	1.16	1.07	1.25	1.15	1.03	1.27
CSHCN in mother only household	1.21	1.14	1.29	1.21	1.14	1.29	1.12	1.05	1.18	1.08	1.01	1.17	1.27	1.19	1.35	1.37	1.25	1.51
CSHCN in other family structure household	1.29	1.18	1.40	1.22	1.13	1.33	0.87	0.80	0.94	1.14	1.03	1.27	1.04	0.95	1.13	1.13	0.99	1.29

Source :The 2009-2010 National Survey of Children with Special Health Care Needs

the risks of not attaining quality indicators for care identified in our study are likely underestimated for the true LEP population. CSHCN may also be underdiagnosed in LEP populations because parts of the case definition such as prescription medication and services use are based on access to health care.

Compared to reports from the 2005-2006 National Survey for Children with Special Health Care Needs, NEPL families continue to report access barriers to medical home as well as insurance coverage adequacy.[16] More importantly, CSHCN from NEPL families are at an even greater disadvantage in receiving services for early and continuous screening for special health care needs and transition to adulthood services compared to the previous survey.

The surveillance and clinical evaluation provided through early and continuous screening are pivotal for clinicians and public health professionals to carry out early identification and detection of CSHCN for enrollment in Early Intervention (EI) Services who may be at risk for developmental delays.[23,24] EI services have a substantial, positive impact on the developmental trajectory and long-term outcomes for CSHCN with developmental delay and different types of disabilities.[25] During this critical, sensitive period in the life course, it is important that systems of care for CSHCN continue to extend outreach efforts to NEPL families. In particular, clinicians, allied health professionals, and other providers play critical roles in assisting children from culturally and linguistically diverse early intervention populations to reach developmental milestones and supporting their families in understanding public health system.[26]

Similarly, CSHCN from NEPL require improved access to transition services for successful entry into adulthood with respect to post-secondary education, employment, and independent living. Clinicians will need to work in collaboration with youth with special health care needs and their NEPL families for the development of a medical transition plan focused on seamless connection to clinical adult providers, especially to address needs of parents from immigrant households with regards to assistance with navigation through the often unfamiliar and complex health care delivery system in the US.[27]

The fact that CSHCN from both EPL and NEPL households reported comparable experiences on ease of access to community-based services is a reassuring finding. This may have resulted from the creation and expansion of ethnic community-based organizations (CBOs) serving specific

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immigrant populations that built stronger civic ethnic communities and engendered higher levels of political trust and social engagement among their members.[28] As the number of immigrant families in the US increases over time, strategic action plans must address the needs of CSHCN from these families, as well as clinicians, and public health professionals who serve them. Service providers will need to advance their understanding of the cultural context and life experiences of immigrant families, in particular to leverage CBOs that have become important cultural brokers for immigrant families as effective intermediaries to connect families to the complex system of service delivery in the US.[29]

The study has some limitations. First, the 2009-2010 NS-CSHCN is a cross-sectional survey conducted in English, Spanish, and four Asian languages, with the screener being in English or Spanish. This may bias the non-English respondents towards those who are more educated and fluent in English, resulting in a likely underestimate of risk for the actual US immigrant populations. Second, the cross-sectional nature of the survey data collections does not allow causal inferences. Thirdly, undocumented families (i.e., those living in the US without a legal status) would likely not have been included in the survey. Finally, in addition to identifying a language barrier, household language is also a proxy for immigrant household status and the length of stay of the family in the United States. While Asian ethnicity was not disclosed in this public-use dataset, we can infer that NEPL "others" are mostly Asians.

Future research will need to explore partnerships among CBOs, government agencies and immigrant communities with particular emphasis on evidence-based interventions that provide effective and optimal services for CSHCN from immigrant families. Finally, ongoing surveillance through MCHB's six quality indicators for CSHCN from immigrant families will provide the necessary monitoring and assurance for this underserved population.

Conclusion and Global Health Implications

Among the 25 Organisation for Economic Cooperation and Development (OECD) countries, the US ranks poorly in its social and economic inclusion of people with disabilities and in its disability benefit, compensation, and integration policies.[30] The worldwide immigration of children to the US has risen significantly from countries with diverse health systems and CSHCN. Our study has demonstrated that CSHCN including children with disabilities from immigrant families confront challenges regarding inadequate access to high-quality health care that warrants further policy solutions to improve their health care utilization and to reduce health disparities for CSHCN from immigrant populations both in the US and abroad.

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Key Messages

- With the continual increase in prevalence of CSHCN in the US and aboard, the global burden will likely rise.
- Significant health disparities exist in the timely receipt of early and continuous screening, comprehensive care within a medical home, and insurance adequacy for CSHCN from NEPL household.
- Strategic action plans must address the needs of CSHCN from NEPL families through the cultural context and life experiences of immigrant families, in particular to leverage ethnic community-based organizations (CBOs) that have become important cultural brokers for immigrant families as effective intermediaries in navigation of the complex health care system of service delivery in the US.

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