Immigrant Families, Children With Special Health Care Needs, and the Medical Home

Kristin Kan, MD, MPH,a,b Hwajung Choi, PhD,a,f Matthew Davis, MD, MAPPa,b,c,d,e,f

**Abstract**

**Objective:** Immigrant children in the United States historically experience lower-quality health care. Such disparities are concerning for immigrant children with special health care needs (CSHCNs). Our study assesses the medical home presence for CSHCN by immigrant family type and evaluates which medical home components are associated with disparities.

**Methods:** We used the 2011 National Survey of Children’s Health, comparing the prevalence and odds of a parent-reported medical home and 5 specific medical home components by immigrant family types using bivariate and multivariate logistic regression.

**Results:** Foreign-born CSHCNs were less likely than CSHCNs with US-born parents to have a medical home (adjusted odds ratio = 0.40, 95% confidence interval 0.19–0.85). The adjusted prevalence of having a medical home was 28% among foreign-born CSHCNs (P < .05) and 37% among CSHCNs with a foreign-born parent (P < .001), compared with 49% among CSHCNs with US-born parents. Foreign-born children without special needs also had a lower odds of a medical home, compared with children with US-born parents (adjusted odds ratio = 0.62, 0.46–0.83). The medical home component most frequently absent for immigrant children without special needs and CSHCNs with a foreign-born parent was family-centered care. In contrast, foreign-born CSHCNs most often lacked care coordination (adjusted prevalence = 37% versus 56% for CSHCNs with US-born parents; P < .05).

**Conclusions:** Disparities in medical home presence for CSHCNs appear to be exacerbated by immigrant family type. Efforts focused on improving family-centered care and care coordination may provide the greatest benefit for immigrant CSHCNs.

**WHAT’S KNOWN ON THIS SUBJECT:** Immigrant children experience disparities in health, including having a medical home, but evidence is limited about the medical home for immigrant children with special health care needs (CSHCNs) and which medical home domains are associated with these differences in primary care.

**WHAT THIS STUDY ADDS:** CSHCNs in immigrant families were less likely to have a medical home than CSHCNs with US-born parents. Improving the medical home for immigrant CSHCNs and their peers without special needs might depend on enhancing family-centered care and care coordination.

One-quarter of US children live in immigrant families,\(^1\) and they historically experience less health care access and lower-quality health care compared with children in nonimmigrant families.\(^2\)–\(^5\) These disparities are particularly concerning for immigrant children with special health care needs (CSHCNs), whose health conditions require greater interaction with the health care system. The medical home is integral to primary care delivery for CSHCN, as they need primary care coordinated with other services to support their health and well-being.\(^6\) Examining medical home presence is one way to gauge how well the primary care system is working for CSHCNs from immigrant and nonimmigrant families.

The American Academy of Pediatrics (AAP) defines medical homes as coordinated, continuous, accessible, family-centered, culturally competent, and compassionate models of primary care delivery.\(^6\),\(^7\) Improved health status, lower family burden, and equitable care for children from racial minority groups are a few of the studied benefits associated with medical home access.\(^8\)–\(^10\) The medical home also has been associated with less work loss for parents of CSHCNs and higher satisfaction with care among non–English-speaking parents.\(^11,12\)

Evidence is limited, however, regarding the health of CSHCNs living in immigrant families, and their receipt of quality primary care on a national level. Previous studies highlighting the variation in child health outcomes and health care access and utilization by immigrant family type have not focused on CSHCNs.\(^3,13\) A California study described that CSHCNs in immigrant families were more likely to lack a usual source of care, to report a delay in care, and to report fair or poor health compared with nonimmigrant CSHCNs.\(^14\) Disparities in health care access and quality by primary household language have also been shown among CSHCNs, although children have not been distinguished by their immigrant status per se.\(^15\)–\(^17\) Although existing studies illuminate aspects of the health of children living in immigrant families, language barriers do not fully capture the inequities of immigrant CSHCN’s experiences, and studies limited to California may not be nationally representative.

The purpose of this study was to assess how different immigrant family types affect having a medical home by comparing children who are foreign-born and children with \(\geq 1\) foreign-born parents with nonimmigrant children, especially among CSHCNs. The components of the medical home, 5 domains that reflect the AAP-defined comprehensive medical home, are also examined to describe which care domains may be associated with identified disparities. Based on existing evidence, we hypothesize that having a medical home among CSHCNs will vary by immigrant family type; specifically, that foreign-born CSHCNs will be least likely to report having a medical home and that the lack of family-centered care will be associated with disparities in medical home presence. We also examined the association of immigrant family type with medical home overall and with specific medical home components for children without special health care needs.

**METHODS**

**Data Source**

We used data from the 2011 National Survey of Children’s Health (NSCH), a nationally representative telephone survey of households with children 0 to 17 years old conducted by the National Center for Health Statistics under the sponsorship of the Maternal and Child Health Bureau. The NSCH is fielded every 4 years, and the 2011 version is the most recent edition available. The 2011 NSCH dataset includes 95,677 children (overall response rate 38.2\%), for all 50 states and the District of Columbia. Surveying and methodology are extensively documented elsewhere.\(^18\) The University of Michigan Medical School Institutional Review Board deemed the study not regulated because the dataset is publicly available and deidentified.

**Measures**

Our primary outcome variable is the medical home measure implemented in the NSCH to approximate the characteristics of the AAP medical home definition, which has been used in many previous studies to examine the presence of a medical home.\(^8,19,20\) Using the NSCH codebook, we defined a dichotomous, composite variable indicative of having a medical home, based on parents’ responses to 17 questions.\(^21\) These questions cover 5 medical home components: (1) having a usual source of care for well and sick visits that is not an emergency department, (2) having a personal doctor or nurse, (3) family-centered care, (4) getting needed referrals to other doctors or services, if needed, and (5) receiving effective care coordination, if needed. Children must at least have the first 3 components to qualify for having a medical home; if any component is missing, the child is considered not to have a medical home. The last 2 components of the medical home are considered only if the child needs the services. Our secondary outcomes of interest were the 5 individual components of the medical home, analyzed separately.

The primary independent variable is the immigrant family type. The categories for immigrant family type are based on a combination of the birthplace of the child and parents and have also been used.
in previous studies of the health of children living in immigrant families.\textsuperscript{3,13,22} The categories are as follows: foreign-born child with foreign-born parents (foreign-born child), US-born child with at least one foreign-born parent and foreign-born child with 2 parents of mixed nativity (child with a foreign-born parent), and US-born child with only US-born parents (child with US-born parents).

A child with special health care needs in the NSCH is determined by the Children with Special Health Care Needs Screener that examines the medical, behavioral, or other needs of children with chronic conditions and has been applied in many studies of CSHCNs.\textsuperscript{14,23,24} The information is coded into a dichotomous variable available in the dataset for whether the child in the household has special health care needs or not and is assessed by 5 stem items: (1) need or use of prescription medications; (2) above-routine use of medical, mental health, or education services; (3) daily activity limitations; (4) need or use of specialized therapies; and (5) need or use of treatment or counseling for emotional, behavioral, or developmental conditions.

Parents must report if the child experiences ≥ 1 of the 5 needs to qualify as a child with special health care needs.

Covariates of interest included child’s age, child’s gender, race/ethnicity (non-Hispanic white, non-Hispanic black, Hispanic and other), household income-to-poverty ratio (<100%, 101%–133%, 134%–200%, >200% of the federal poverty level), highest education attained among parents (less than high school, high school graduate, or more than high school), primary language at home (English or other), and insurance type (public, private, or uninsured).

**Analysis**

Our analysis sample was based on 87,762 children from the 2011 NSCH for those who have no missing data in the measures of immigrant family type and the composite medical home variable (92% of the overall sample).

We assessed bivariate relationships between each of the sociodemographic characteristics and immigrant family type, by using the $\chi^2$ test. To examine the extent to which the medical home and its 5 components are associated with immigrant family type, we conducted bivariate and multivariate logistic regressions, stratified by CSHCN status. Covariates in the multivariate models included the child’s age, gender, race/ethnicity, insurance, parent’s education, household income-to-poverty ratio, and household primary language. We obtained adjusted prevalence estimates of having a medical home or component of the medical home by each immigrant family type after holding covariates at each child’s own values and using predicted marginals derived from the fitted logistic models.

As a supplementary analysis, we also tested if the differences in having a medical home by immigrant type were associated with CSHCN status by checking for interaction between CSHCN status and immigrant family type in an unstratified analysis.

There were 9% missing data in the ratio of household income-to-poverty in the NSCH. We addressed the missing data by using multiple imputations with 5 replications for household income-to-poverty ratio that were provided by the State and Local Area Integrated Telephone Survey and incorporated them into our analysis.\textsuperscript{25} All analyses were conducted with Stata (Version 13; Stata Corp, College Station, TX), accounting for survey sampling weights and multiple imputation to permit nationally representative references.

**RESULTS**

The sample included 2% foreign-born children, 15% children with a foreign-born parent, and 83% children with US-born parents. Over the full analytic sample, 55% of children had a parent-reported medical home and 20% of children were identified as CSHCN. Demographic characteristics differed by immigrant family type, except for child’s gender (Table 1). Foreign-born children were on average older, more likely to be uninsured, to have parents with less than a high school education, and to live in poorer families. Foreign-born children and children with a foreign-born parent were more likely to be Hispanic. In addition, a smaller proportion of foreign-born children were reported as CSHCN compared with children with a foreign-born parent and children with US-born parents.

**Children With Special Health Care Needs**

Among CSHCNs, the parent-reported prevalence of having a medical home was lower for foreign-born children and children with a foreign-born parent compared with children with US-born parents (Table 2). In unadjusted analyses, foreign-born CSHCNs had significantly lower odds of having a personal doctor, having a usual source of care, and receiving effective care coordination. CSHCNs with a foreign-born parent experienced significantly less family-centered care, in addition to less frequent usual source of care and care coordination.

Based on models for CSHCNs adjusted for several sociodemographic characteristics, significant differences in the odds of having a medical home still existed for a foreign-born child and for a child with a foreign-born parent, compared with children with US-born parents (Table 2). Although the adjusted prevalence of having a medical home was
somewhat higher than the crude prevalence among foreign-born CSHCNs and CSHCNs with a foreign-born parent, the adjusted prevalence of having a medical home was still significantly lower than for CSHCNs with US-born parents. Among specific medical home components, foreign-born CSHCNs had a significantly lower adjusted prevalence of care coordination, and CSHCNs with a foreign-born parent had a significantly lower prevalence of family-centered care than CSHCNs with US-born parents.

In our supplementary analysis, CSHCN status did not moderate the effect between immigrant family type and having a medical home, as the interaction term was not statistically significant.

**Children Without Special Health Care Needs**

Among children without special health care needs, foreign-born children and children with a foreign-born parent had lower prevalence of a parent-reported medical home compared with children with US-born parents (Table 3). Compared with children with US-born parents, the unadjusted odds of having a medical home was significantly lower for foreign-born children and children with a foreign-born parent. Significantly lower odds of each of the medical home components were also found for children living in immigrant families compared with

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**TABLE 1** Characteristics of Sample From the 2011 NSCH, by Immigrant Family Type

<table>
<thead>
<tr>
<th>Age, y, mean (SD)</th>
<th>Foreign-Born Child, Unweighted, n = 1620</th>
<th>≥1 Foreign-Born Parent, Unweighted, n = 13475</th>
<th>US-Born Parents, Unweighted, n = 72667</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender, % girls</td>
<td>45.8</td>
<td>48.0</td>
<td>49.1</td>
</tr>
<tr>
<td>Race/ethnicity, %a</td>
<td>Non-Hispanic white 8.9</td>
<td>15.5</td>
<td>67.0</td>
</tr>
<tr>
<td>Non-Hispanic black 8.6</td>
<td>7.6</td>
<td>14.8</td>
<td></td>
</tr>
<tr>
<td>Hispanic 59.3 (SD)</td>
<td>59.1</td>
<td>11.1</td>
<td></td>
</tr>
<tr>
<td>Other 25.3</td>
<td>17.8</td>
<td>7.2</td>
<td></td>
</tr>
<tr>
<td>Language, % non-English</td>
<td>76.9</td>
<td>51.9</td>
<td>1.1</td>
</tr>
<tr>
<td>Insurance, %a</td>
<td>Private 36.7</td>
<td>45.2</td>
<td>64.3</td>
</tr>
<tr>
<td>Public 36.0</td>
<td>47.8</td>
<td>31.7</td>
<td></td>
</tr>
<tr>
<td>Uninsured 27.3</td>
<td>7.1</td>
<td>4.0</td>
<td></td>
</tr>
<tr>
<td>Parent’s education, %a</td>
<td>&lt;High school 35.2</td>
<td>25.9</td>
<td>5.6</td>
</tr>
<tr>
<td>High school 20.1</td>
<td>21.6</td>
<td>19.2</td>
<td></td>
</tr>
<tr>
<td>&gt;High school 46.8</td>
<td>52.5</td>
<td>75.3</td>
<td></td>
</tr>
<tr>
<td>Household poverty status, %a</td>
<td>≤133% FPL 57.7</td>
<td>44.1</td>
<td>25.7</td>
</tr>
<tr>
<td>134%–200% FPL 11.6</td>
<td>12.9</td>
<td>12.1</td>
<td></td>
</tr>
<tr>
<td>&gt;200% FPL 30.7</td>
<td>42.9</td>
<td>62.2</td>
<td></td>
</tr>
<tr>
<td>Child with special health need, %a</td>
<td>7.9</td>
<td>11.9</td>
<td>22.5</td>
</tr>
</tbody>
</table>

All proportions are displayed as weighted % FPL, federal poverty level.

* Differences across immigrant family types significant at \( P < .001 \).

**TABLE 2** Unadjusted and Adjusted Odds and Prevalence of Parent-Reported Medical Home and Medical Home Components Among CSHCNs, by Immigrant Family Type

<table>
<thead>
<tr>
<th>Medical Home Overall</th>
<th>Medical Home Components</th>
<th>Care Coordination, If Needed</th>
<th>No Referral Problem, If Needed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unadjusted OR (95% CI)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Foreign-born child</td>
<td>0.22 (0.11–0.47)***</td>
<td>0.18 (0.05–0.63)**</td>
<td>0.37 (0.18–0.86)*</td>
</tr>
<tr>
<td>≥1 Foreign-born parent</td>
<td>0.48 (0.38–0.58)***</td>
<td>0.77 (0.47–1.25)</td>
<td>0.42 (0.28–0.63)**</td>
</tr>
<tr>
<td>Parent’s education, %a</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;High school 35.2</td>
<td>0.18 (0.05–0.63)**</td>
<td>0.37 (0.18–0.86)*</td>
<td>0.43 (0.18–1.01)</td>
</tr>
<tr>
<td>High school 20.1</td>
<td>0.77 (0.47–1.25)</td>
<td>0.42 (0.28–0.63)**</td>
<td>0.47 (0.38–0.58)**</td>
</tr>
<tr>
<td>&gt;High school 46.8</td>
<td>0.42 (0.28–0.63)**</td>
<td>0.75 (0.59–0.96)*</td>
<td>0.89 (0.68–1.02)</td>
</tr>
<tr>
<td>Unadjusted prevalence, %</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Foreign-born child</td>
<td>19***</td>
<td>72</td>
<td>85</td>
</tr>
<tr>
<td>≥1 Foreign-born parent</td>
<td>32***</td>
<td>92</td>
<td>87**</td>
</tr>
<tr>
<td>Parent’s education, %a</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Child with special health need, %a</td>
<td>7.9</td>
<td>11.9</td>
<td>22.5</td>
</tr>
</tbody>
</table>

Adjusted ORs are displayed for regression models that also included child’s age, gender, race/ethnicity, insurance, parent’s education, household income-to-poverty ratio, and household primary language. * \( P < .05 \); ** \( P < .01 \); *** \( P < .001 \) compared with children with US-born parents. CI, confidence interval; OR, odds ratio.
children with US-born parents (Table 3).

After adjustment with sociodemographic characteristics, foreign-born children and children with foreign-born parents remained significantly less likely to have a medical home, compared with children with US-born parents. Among the medical home components, there were significant differences in the adjusted odds and the adjusted prevalence of family-centered care (Table 3). The medical home component with the lowest adjusted prevalence among all immigrant family types was family-centered care. Although the odds of having a personal doctor also varied significantly by immigrant family type, the adjusted prevalence was higher than for several other medical home components.

**DISCUSSION**

In this study of immigrant family type and presence of a medical home, with a focus on CSHCNs, foreign-born children were at greatest risk for not having a medical home, and children with a foreign-born parent also experienced reduced odds of having a medical home compared with children with US-born parents. Medical home disparities for immigrant versus nonimmigrant children have been previously described, but our study reveals heterogeneity in medical home presence among children from different immigrant family types (ie, for foreign-born children and children with a foreign-born parent).

Our analysis also underscores the low prevalence of a parent-reported medical home for foreign-born CSHCNs and CSHCNs with a foreign-born parent. Unlike earlier findings regarding health care access among CSHCNs in immigrant families measured in California in 2003, differences in presence of a medical home appear to remain exacerbated by immigrant family type, even after controlling for parents’ education, household poverty status, and primary language. Although the prevalence of experiencing family-centered care was low among children without special needs who were born outside the United States or whose parents were foreign-born and among CSHCNs with a foreign-born parent, we found that care coordination was the component least often endorsed by foreign-born CSHCNs. Our findings underscore the need for a careful examination of which components of the medical home may be driving differences across immigrant family types.

For children without special health care needs in an immigrant family and for CSHCNs with a foreign-born parent, our results suggest that primary care providers are not communicating effectively with families in the medical home setting. Improving family-centered care appears to be one essential element to target. Previous studies have described decreased family-centered care among children from non–English language households and for English-speaking racial/ethnic minority families. Racial/ethnic and language disparities in family-centered care are also present among CSHCNs. More generally,
the family-centered care component is one of the more complex domains of the medical home composite variable. The inequality in the family-centered care domain means that parents are reporting that their children’s providers are not spending enough time with the family, listening carefully, being sensitive to the family’s values, giving needed information, or partnering with the family for their child’s care. English proficiency rather than primary language at home, the language variable available in our dataset, may be a stronger factor determining parents’ understanding of family-centered care.29 Understanding how language proficiency affects immigrant families’ understanding of their child’s needs, how to communicate their needs with health providers, and how the health care system generally works will be an important part of overcoming barriers to care for CSHCNs.15 Further investigation is warranted to parse out which primary care approaches, such as team-based models engaging navigators, health educators, or home-visiting providers, could enhance family-centered care, particularly for children in immigrant families.

Based on our supplementary analyses, we did not find a statistical difference in medical home presence between immigrant children without special health care needs and immigrant CSHCNs. Importantly, among CSHCNs, foreign-born children had the lowest adjusted prevalence of having a medical home. Foreign-born CSHCNs were most at risk for unmet needs in care coordination. Our results complement previous findings reporting gaps in receipt of effective care coordination among black and Hispanic/Latino children, and among children in immigrant families.24,30 Care coordination often becomes a challenge for CSHCNs because of the severity or complexity of their chronic conditions, requiring multiple specialists and services.31 The measure of care coordination addresses access to mental health providers and specialists and also to nonmedical services, such as early intervention programs, schools, and special education. Studies have also shown that family-centered communication is tied closely with effective care coordination,24,32 and differences in cultural understanding of the health care system by foreign-born parents may influence care coordination.

Our findings must be interpreted in the context of potential limitations. We were unable to capture immigration status of parents or children, as the NSCH does not gather this information. Presumably immigration status, defined as the legal status of foreign-born residents in the United States, could limit accessibility to some medical services for foreign-born children. Without controlling for immigration status in our analysis, our measures of medical home disparity may overestimate the effect size of the immigrant family type, as immigration status determines eligibility to public insurance that facilitates access to a medical home. In addition, concern may exist about how parents interpreted the questions that identify CSHCNs, especially for non-English-speaking parents. In a recent review, Bethell and colleagues23 found that parents with Spanish as their preferred language correctly understood the concepts in the CSHCN screening instrument fielded in the NSCH. We were additionally limited by the NSCH definitions of immigrant family types and medical home. Our categories of immigrant family types are consistent with US Census Bureau definitions for household generational status.33 The medical home variable definition is replicated in other large datasets of children’s health in the United States, although the association of the parent-reported medical home variable in the NSCH to practice designated medical homes is not well described.34 As with most observational studies, it is not possible to draw causal inferences. Future studies could help better ascertain the mechanisms by which children of various immigrant family types have differences in medical home presence.

CONCLUSIONS

CSHCNs in immigrant families face health disparities and risks for serious morbidity that make improving primary care through the medical home imperative. Our study suggests that approaches to improving the medical home may vary based on specific immigrant family types. Educating parents about their child’s needs and assisting them with access to needed resources are important first steps that providers can currently take in addressing the disparities in receiving family-centered care and care coordination for children in immigrant households, with and without special health care needs. At the same time, exploring how family-centered care and care coordination can be enhanced in extended medical home models involving family support services in public health and education will be important for this population. Further monitoring of how changes in health care systems and policies may also differentially impact CSHCNs in immigrant families will be critical to achieving parity.

ABBREVIATIONS

AAP: American Academy of Pediatrics
CSHCN: children with special health care needs
NSCH: National Survey of Children’s Health
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POTENTIAL CONFLICT OF INTEREST: The authors have indicated they have no potential conflicts of interest to disclose.

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