

Parental Limited English Proficiency and Health Outcomes for Children With Special Health Care Needs: A Systematic Review

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ABSTRACT

BACKGROUND: One in 10 US adults of childbearing age has limited English proficiency (LEP). Parental LEP is associated with worse health outcomes among healthy children. The relationship of parental LEP to health outcomes for children with special health care needs (CSHCN) has not been systematically reviewed.

OBJECTIVE: To conduct a systematic review of peer-reviewed literature examining relationships between parental LEP and health outcomes for CSHCN.

DATA SOURCES: PubMed, Scopus, Cochrane Library, Social Science Abstracts, bibliographies of included studies. Key search term categories: language, child, special health care needs, and health outcomes.

ELIGIBILITY CRITERIA: US studies published between 1964 and 2012 were included if: 1) subjects were CSHCN; 2) studies included some measure of parental LEP; 3) at least 1 outcome measure of child health status, access, utilization, costs, or quality; and 4) primary or secondary data analysis.

METHODS: Three trained reviewers independently screened studies and extracted data. Two separate reviewers appraised studies for methodological rigor and quality.

RESULTS: From 2765 titles and abstracts, 31 studies met eligibility criteria. Five studies assessed child health status, 12 as-

essed access, 8 assessed utilization, 2 assessed costs, and 14 assessed quality. Nearly all (29 of 31) studies used only parent- or child-reported outcome measures, rather than objective measures. LEP parents were substantially more likely than English-proficient parents to report that their CSHCN were uninsured and had no usual source of care or medical home. LEP parents were also less likely to report family-centered care and satisfaction with care. Disparities persisted for children with LEP parents after adjustment for ethnicity and socioeconomic status.

CONCLUSIONS AND IMPLICATIONS: Parental LEP is independently associated with worse health care access and quality for CSHCN. Health care providers should recognize LEP as an independent risk factor for poor health outcomes among CSHCN. Emerging models of chronic disease care should integrate and evaluate interventions that target access and quality disparities for LEP families.

KEYWORDS: access; children with special health care needs; disabled children; health services accessibility; health services research; health care disparities; language; limited English proficiency; minority health; quality of health care

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WHAT'S NEW

CSHCN with limited English proficient parents have significantly worse insurance and medical home access, family-centered care, and satisfaction with care than CSHCN with English-proficient parents. These disparities are independent of ethnicity and socioeconomic status.

WHAT THIS SYSTEMATIC Review Adds

- Parental LEP— independent of ethnicity and socioeconomic status—is associated with worse insurance and medical home access for CSHCN.
- LEP families suffer worse quality of family-centered care.

- Little evidence is available to assess relationships between LEP and objective health outcomes.

HOW TO USE This Systematic Review

- Understand how parental LEP is a risk factor for worse health care access and quality for CSHCN.
- Consider how these findings inform emerging models of chronic disease care within integrated health systems.
- Identify areas of solution-oriented research to reduce disparities.

IN 1964, TITLE VI of the Civil Rights Act mandated that federally funded programs, such as Medicaid, must avoid

discriminating on the basis of nationality by making all services accessible to individuals with limited English proficiency (LEP).¹ In the nearly 50 years since this landmark legislation, however, health care disparities related to LEP persist.^{2–5} These LEP-related disparities may have far-reaching effects on child health because 10% of US adults of childbearing age report having LEP, defined by the US Census Bureau as speaking English less than very well.⁶

Although disparities in child health outcomes associated with race and ethnicity are well known, recent evidence suggests parental LEP may act as an independent determinant of health outcomes among racial and ethnic minority children. Healthy children whose parents have LEP are more likely to be uninsured, lack a medical home and specialty referrals, and experience serious medical errors compared to children whose parents are English proficient (EP).^{7–12} LEP parents are also more likely to report poor communication with health care providers than EP parents.^{13–15}

Health outcomes for children with special health care needs (CSHCN) may be especially sensitive to parental LEP. The Maternal and Child Health Bureau (MCHB) specifies that CSHCN are “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.”¹⁶ Health outcomes for CSHCN depend on use of specialized health services and their parents’ ability to understand and manage complicated medical and nutritional regimens, community and school-based resources, and other health information.^{17–19} Because the volume, complexity, and potential health consequences of written and spoken health information are much greater for CSHCN than for children in the general population, parental LEP may be strongly associated with serious disparities in health outcomes for CSHCN. Conventional wisdom argues that other parental characteristics (eg, race, ethnicity, socioeconomic status, perceived discrimination) are covariates of LEP, and as such, may be the root causes of child health disparities. Yet, LEP itself is known to be an important proxy for acculturation and a modifiable factor for improving health care access.^{20–22} Thus far there has been no systematic assessment to determine whether parental LEP is independently associated with health outcomes for CSHCN and is therefore an important social determinant of health for CSHCN. The aim of this systematic review of peer-reviewed literature was to assess our current understanding of parental LEP as it relates to health outcomes for CSHCN.

METHODS

ELIGIBILITY CRITERIA

Our review included only observational or experimental studies (cohort, case-control, cross-sectional, and randomized clinical trials) published in the US. Policy and opinion statements, case studies, and studies with only qualitative data were excluded. Studies were

included if: 1) subjects were children aged 0 to 18 years with any special health care needs based on the MCHB definition; 2) studies included some measure of parental LEP (such as level of English proficiency, primary household language, or preferred language of interview); 3) results included at least 1 outcome measure of child health status, access, utilization, costs, or quality; and 4) findings were based on primary or secondary data analysis.

INFORMATION SOURCES

We searched 4 electronic databases of peer-reviewed literature, including PubMed, Scopus, Cochrane Library, and Social Services Abstracts, for articles that included these key search term categories: 1) language (eg, “language,” “communication barriers,” “English proficiency,” “non-English,” “multilingualism,” “minorities,” “cultural,” “ethnic”); 2) child (eg, “child,” “youth,” “adolescent,” “teen,” “family”); 3) special health care needs (eg, “disabilities,” “children with special health care needs,” “youth with special health care needs”); and 4) health outcomes (eg, “outcome,” “disparity,” “access,” “demand,” “insurance,” “uninsurance”) (Table 1). Searches were restricted to US English-language studies published from 1964 to September 4, 2012. Citations listed in bibliographies of articles that met eligibility criteria, including prior systematic reviews and meta-analyses, were also reviewed. An experienced librarian was consulted to develop search strategies.

ARTICLE SELECTION

Studies were selected in a 2-step process. First, titles and abstracts derived from database searches were independently screened and flagged by 2 reviewers if potentially meeting eligibility criteria (AP and NF). Second, flagged studies were examined in full for inclusion by a third reviewer (MEW). Reviewers met regularly to discuss study classification and coding. Disagreements were resolved through discussion with the third reviewer (MEW), who reviewed full-text articles. Interrater reliability for title and abstract screening was moderate (kappa coefficient = 0.5228; range for moderate kappa = 0.41–0.60).²³ Data were then independently extracted from included studies by 2 reviewers (AP and MEW) using a structured tool^{24–27} (Appendix) and reviewed together for completeness (AP and MEW).

ANALYSIS

Data extracted from each study included: the type and number of subjects studied, study design type, covariates used to control for socioeconomic status, whether or not studies controlled for Hispanic ethnicity by language subgroup (English-speaking, Spanish-speaking), measure of parental LEP, objective primary outcome measures, parent- or child-reported primary outcome measures, and the magnitude and direction of associations between parental LEP and the primary outcome measures, including adjusted odds ratios with 95% confidence intervals.

Two senior reviewers (LS and DB) then independently assessed the methodological rigor of each study in these

Table 1. Search Strategies

Data Source	Search Strategy
PubMed	((("Cross-Cultural Comparison"[mesh] OR "social class"[mesh] OR "language"[mesh:noexp] OR "ethnic groups"[mesh:noexp] OR "continental population groups"[mesh:noexp] OR "cultural characteristics"[mesh] OR "language arts"[mesh:noexp] OR multilingualism[mesh] OR "Family Characteristics/ethnology"[mesh] OR "communication barriers"[mesh:noexp] OR "minority groups"[mesh:noexp] OR "English proficiency"[tiab] OR "English as a second language"[tiab] OR English[ti] OR race[tiab] OR "language use"[tiab] OR ethnic*[tiab] OR "non-English"[tiab]) AND ("Child Health Services"[Mesh] OR "Adolescent Health Services"[mesh] OR "Disabled Children"[Mesh] OR ((child[tiab] OR youth[tiab]) AND (special[tiab] AND "health care needs"[tiab])) OR "children with special health care needs"[tiab] OR cshcn[tiab] OR famil*[ti] OR child*[ti]) AND (access*[ti] OR barrier*[ti] OR outcom*[ti] OR dispar*[ti] OR quality[ti] OR demand*[ti] OR need[ti] OR needs[ti] OR "Health Services Accessibility"[mesh] OR "Health Services Needs and Demand"[mesh] OR "Healthcare Disparities"[mesh])) OR (((("national survey"[tiab] AND (cshcn[tiab] OR "Special Health Care Needs"[tiab])) OR (cshcn[tiab] OR yshcn[tiab] OR "children with special health care needs"[tiab])) OR ("Diseases Category"[Mesh] AND ethnology[sh] AND ("language"[mesh:noexp] OR "language arts"[mesh] OR "multilingualism"[mesh] OR "communication barriers"[mesh]) AND ((infant[MeSH] OR child[MeSH] OR adolescent[MeSH])) AND (English[lang])), Filters: English ((child* OR youth OR adolesc* OR teen*) AND (special AND "healthcare needs" OR "health care needs")) OR cshcn OR yshcn OR ((teen* ORadolesc* OR child*) AND disabil*) ("second language" OR English OR racial OR race OR "language use" OR ethnic* OR cultur* OR socio* OR "non-English" OR uninsur* OR insuran*)
SCOPUS	((child* OR youth OR adolesc* OR teen*) AND (special AND "healthcare needs" OR "health care needs")) OR cshcn OR yshcn OR ((teen* ORadolesc* OR child*) AND disabil*) ("second language" OR English OR racial OR race OR "language use" OR ethnic* OR cultur* OR socio* OR "non-English" OR uninsur* OR insuran*)
Cochrane Library including Cochrane Central Register of Controlled Trials and Cochrane Systematic Reviews	((child OR youth) AND (special AND "health care needs")) OR cshcn OR yshcn OR (child* AND disabil*)
Social Services Abstracts	all(((child OR youth) AND (special AND "health care needs")) OR cshcn OR yshcn OR (child* AND disabil*)) AND ti(("second language" OR English OR racial OR race OR "language use" OR ethnic* OR cultur* OR socio* OR "non-English")) all(((child OR youth) AND (special AND "health care needs")) OR cshcn OR yshcn OR (child* AND disabil*)) AND ti((uninsured OR insured OR insurance)) 1 OR 2

domains: sampling, measurement of exposure and outcome variables, bias (excluding confounding), methods to control confounding, statistical methods (excluding control of confounding), and conflicts of interest (Appendix Table A1).²⁴⁻²⁷ Quality of the evidence was assessed using the GRADE criteria as a guideline^{26,27} to categorize each study's evidence as high, moderate, low and very low quality (Appendix Table A1).²⁷ Reviewers (MEW, LS, DB) met to ensure that senior reviewers (LS, DB) were assessing the quality of the evidence in a consistent fashion. Interrater reliability for quality scoring was moderate (weighted kappa coefficient = 0.448). Quality scores for both reviewers are reported.

RESULTS

Of 2765 potentially relevant articles that were identified from database searches or by searching bibliographies of included studies, 2672 were excluded on the basis of title and abstract review, leaving 93 articles. After full-text review, 31 articles met full eligibility criteria (Fig. 1). Reasons for exclusion were wrong study type; non-US study; subjects were not children with special health care needs; no measure of parental LEP; no child health outcome; or full-text article could not be obtained. Five full-text articles, which were flagged for full-text review on the basis of screening of titles and abstracts, could not be obtained despite librarian assistance. Authors of these studies were not contacted because of staffing and time limitations.

Appendix Table A2 summarizes characteristics for each of 31 included studies. Five studies assessed child health status, 12 assessed access, 8 assessed utilization, 2 assessed costs, and 14 assessed quality. Twenty-nine of 31 studies used parent- or child-reported outcome measures, while 2 used objective measures. Twenty-nine studies adjusted for at least 1 measure of socioeconomic status and/or

**Figure 1.** Flow chart of included studies.

race or ethnicity. Thirteen studies controlled for Hispanic ethnicity by language subgroup (English-speaking, Spanish-speaking). Given the heterogeneity of the outcome variables used in the included studies, a meta-analysis was not conducted.

CHILD HEALTH STATUS AND PARENTAL LEP

Five studies assessed relationships between parental LEP and child health status (Table 2). Two studies, 1 of children with systemic lupus erythematosus²⁸ and 1 of children with asthma,²⁹ found no relationship between parental LEP and objective health measures including risk of developing lupus nephritis (based on pathologic or laboratory criteria) and asthma diagnosis (based on spirometry), respectively. Two larger studies of children with asthma and 1 study of children with diabetes, however, revealed that LEP parents reported worse health status and quality of life for their children than EP parents.^{30–32}

CHILD HEALTH CARE ACCESS AND PARENTAL LEP

Twelve studies assessed relationships between parental LEP and health care access (Table 3). Of these, 9 studies demonstrated an independent relationship between parental LEP and access using parent-reported measures. LEP parents were significantly more likely to report that their CSHCN were uninsured^{33–35} and had no usual source of care^{34–37} or medical home^{35,38} compared to EP parents. Another study found that only the poorest LEP parents (those living <133% below the federal poverty level) were more likely to report no medical home for their CSHCN compared to higher income LEP and EP parents.³⁹ Furthermore, LEP parents were more likely to report that their CSHCN had long appointment wait times³⁷ and no after-hours care³⁷ compared to EP parents. There were no studies assessing relationships between parental LEP and health care access using independently documented access measures such as administrative claims data.

Access problems also extended to LEP parents who were more likely to report being uninsured themselves³⁵ and having unmet mental health needs⁴⁰ compared to EP parents. LEP parents were also less likely to access electronic health information about their child's condition and reported lower electronic health literacy than EP parents.⁴¹

CHILD HEALTH CARE UTILIZATION AND PARENTAL LEP

Eight studies assessed relationships between parental LEP and health care utilization (Table 3). Of these, 6 studies demonstrated an independent relationship between parental LEP and utilization using parent- or child-reported measures. LEP parents were less likely to report receiving prescription medications for their children's chronic conditions compared to EP parents.^{42–46} LEP parents were more likely than EP parents to report that their CSHCN required specialized therapies, despite an overall lower prevalence of special needs among children of LEP parents.⁴⁴ LEP youth with chronic mental health conditions were less likely to receive public mental health services compared to EP youth.⁴⁷ There were no studies assessing relationships between parental LEP and health care utilization using independently documented utilization measures such as administrative claims data.

CHILD HEALTH CARE COSTS AND PARENTAL LEP

Only 2 studies assessed relationships between parental LEP and health care costs (Table 3). Both studies demonstrated an independent relationship between parental LEP and parent-reported cost measures. LEP parents were more likely than EP parents to report employment consequences (such as missing or stopping work)^{34,35} and greater than \$500 out-of-pocket annual costs related to their child's health condition.³⁴ There were no studies that examined actual health care costs from administrative data.

CHILD HEALTH CARE QUALITY AND PARENTAL LEP

Fourteen studies assessed relationships between parental LEP and health care quality (Table 4). Of these, 13 studies demonstrated an independent relationship between parental LEP and quality using parent- or child-reported measures. LEP parents were more likely than EP parents to report poorer knowledge and self-efficacy in managing their child's chronic condition.³¹ LEP parents were less likely than EP parents to report being taught how to manage their child's chronic condition by health care providers.⁴³ LEP parents were also less likely than EP parents to report that their child received a diagnosis of asthma or learning disability.^{48,49}

LEP parents were also less likely than EP parents to report receiving family-centered care.^{34,35,50} With regard to specific components of family-centered care, LEP

Table 2. Summary of Associations Between Parental LEP and Primary Outcomes Measures for Child Health Status

Study	Year	Sample Size	Magnitude and Direction of Associations Between Parental LEP and Primary Outcome Measures*	Quality of Evidence Scores†
Javier ³⁰	2007	2600	↓ limitation in function [AOR 0.34 (95% CI 0.17 to 0.68)] but ↑ fair or poor health status [AOR 3.48 (95% CI 1.98 to 6.10)] in children with asthma.	1,1
Chan ³¹	2005	405	↓ mean adjusted child QoL score (77 vs 81 for Hispanic English speakers) in children with asthma.‡	1,2
Arif ³²	2006	5530	↓ health-related child QoL score [−1.88 adjusted difference in mean total QoL score (95% CI −2.98 to −0.78)] in children with diabetes.	1,1
Frankovich ²⁸	2012	98	No relationship to risk of severe lupus nephritis [hazard ratio 0.7 (95% CI 0.4 to 1.3)].	3,3
Greenfield ²⁹	2005	152	No relationship to asthma diagnosis [AOR 0.72 (95% CI 0.35 to 1.47)].	2,2

LEP = limited English proficiency; AOR = adjusted odds ratio; CI = confidence interval; and QoL = quality of life.

*Outcomes are compared to English-speaking non-Hispanic white subjects unless specified otherwise.

†Quality of evidence scores are reported for senior reviewers 1 and 2. Score ranges from highest (1) to lowest (4) quality of evidence.²⁷

‡Outcomes are compared to English-speaking Hispanic subjects only.

Table 3. Summary of Associations Between Parental LEP and Primary Outcomes Measures for Child Health Access, Utilization, and Costs

Study	Year	Sample Size	Magnitude and Direction of Associations Between Parental LEP and Primary Outcome Measures*	Quality of Evidence Scores†
Child Health Access				
Blumberg ³³	2005	9173	↑ lack insurance [AOR 2.89 (95% CI 1.63–5.13)].‡	1,2
Yu ³⁴	2004	38,866	↑ lack a personal doctor/nurse [AOR 1.98 (95% CI 1.36–2.88)]. ↑ lack usual source of care (USC) [AOR 1.89 (95% CI 1.26–2.85)]. ↑ inadequate insurance [AOR 11.29 (95% CI 7.21–17.46)].	1,1
Yu ³⁵	2009	40,723	↑ lack medical home [AOR 2.06 (95% CI 1.57–2.67)]. ↑ lack USC [AOR 2.12 (95% CI 1.42–3.17)]. ↑ lack insurance [AOR 3.60 (95% CI 2.46–5.27)]. ↑ lack insurance for family members [AOR 1.56 (95% CI 1.24–1.95)].	1,1
Brotanek ³⁶	2005	1,228	↓ usual health care provider [AOR 0.31 (95% CI 0.1–0.8)].‡	1,2
Greek ³⁷	2006	2100	↑ no USC [AOR 2.71 (95% CI 1.17–6.27)]; For those with USC: ↑ care in hospital clinics [AOR 3.98 (95% CI 1.82–8.71)]. For those with USC: ↑ long appointment wait times [AOR 5.99 (95% CI 2.19–16.36)]. For those with USC: ↓ after-hours care [AOR 2.05 (95% CI 1.22–3.44)].	1,1
Singh ³⁸	2009	38,886	↑ lack medical home [AOR 1.97 (95% CI 1.51–2.58)].	1,1
Fulda ³⁹	2009	38,866	↓ medical home for those <133% of the federal poverty level [AOR 0.33 (95% CI 0.22–0.49)].	1,1
Inkelas ⁴⁰	2007	38,866	↑ unmet mental health needs for family members of CSHCN with chronic emotional, behavioral, or developmental problems [AOR 4.48 (95% CI 1.72–11.63)].	1,1
Knapp ⁴¹	2011	2371	↓ use Internet [AOR 0.42 (95% CI 0.28–0.62)]. ↓ e-Health literacy (AOR from 0.42–0.65). ↓ confidence using Internet health information to make medical decisions (AOR 0.616).	1,1
Claudio ⁶⁷	2009	1847	↑ unadjusted likelihood to have public insurance (57.4% of children with Spanish-speaking parents vs 43.3% of children with English-speaking parents). ↑ unadjusted likelihood of having no USC (19.8% of children with Spanish-speaking parents vs 15.2% of children with English-speaking parents)	1,2
Javier ³⁰	2007	2600	No relationship to access measures for children with asthma (AOR not given).	1,1
Kogan ⁶⁸	2010	40,840	No relationship to adequacy of insurance for CSHCN [AOR 1.22 (95% CI 0.93–1.61)]	2,2
Child Health Utilization				
Aratani ⁴⁷	2012	59,804	↓ continued mental health service use (AOR from 0.30–0.63) among non-English speakers.	1,1
Halterman ⁴²	2000	524	↑ inadequate therapy for moderate to severe asthma (no use of asthma maintenance medications in past month) [AOR 64.6 (95% CI 9.19–454.00)].	2,2
Inkelas ⁴³	2008	1517	↓ controller medication use [AOR 0.2 (95% CI 0.1–0.8)] among children with asthma.	1,1
Blumberg ⁴⁴	2010	103,138	↑ specialized therapies [AOR 1.38 (95% CI 1.09–1.75)] despite ↓ prevalence of special needs [AOR 0.41 (95% CI 0.31–0.56)]. ↓ prescription medications [AOR 0.58 (95% CI 0.47–0.73)] for CSHCN.‡	1,1
Read ⁴⁵	2007	48,690	↓ prescription medication use for chronic conditions [AOR 0.19 (95% CI 0.16–0.23)].‡	1,1
Foster ⁴⁶	2009	7539	↓ use of psychiatric medications [AOR 0.25 (95% CI 0.1–0.80)] for children with chronic conditions.‡	1,1
Claudio ⁶⁷	2009	1847	No relationship to hospitalizations for asthma [AOR 1.81 (95% CI 0.87–3.80)], asthma controller medication use (AOR not given), or having asthma management devices (AOR not given).	1,2
Javier ³⁰	2007	2600	No relationship to utilization measures for children with asthma (AOR not given).	1,1
Child Health Costs				
Yu ³⁴	2004	38,866	↑ employment consequences [AOR 1.94 (95% CI 1.42–2.64)] among families with CSHCN. ↑ >\$500 out-of-pocket annual costs [AOR 1.49 (95% CI 1.05–2.10)] for medical care for CSHCN.	1,1
Yu ³⁵	2009	40,723	↑ likelihood to stop employment as a result of child's chronic health condition [AOR 1.87 (95% CI 1.47–2.39)].	1,1

LEP = limited English proficiency; AOR = adjusted odds ratio; CI = confidence interval; USC = usual source of care; and CSHCN = children with special health care needs.

*Compared to English-speaking non-Hispanic white subjects unless specified otherwise.

†Quality of evidence score based on GRADE scale with highest (1) to lowest (4) quality.²⁷

‡Compared to English-speaking non-Hispanic whites and English-speaking Hispanic subjects.

parents were less likely than EP parents to report that health care providers were sensitive to their values and customs,⁵⁰ spent time with them,⁵⁰ or treated them as partners in their child's care.⁵¹ LEP parents were also less likely to report talking with health care providers about their child's transition to adult medical care.⁵² LEP parents were more likely than EP parents to be dissatisfied with care.^{51,53,54} In contrast, a study of a medical home pilot program for medically complex CSHCN that includes bilingual care coordination found higher satisfaction among LEP parents than EP parents.⁵⁵ There were no studies assessing relationships between parental LEP and health care quality using independently documented quality indicators from administrative or clinical data.

DISCUSSION

This comprehensive review of peer-reviewed literature demonstrates a strong relationship between parental LEP and worse health care access and quality for CSHCN—independent of ethnicity and socioeconomic status. These findings suggest that parental LEP is an important social determinant of health for CSHCN.

Several studies attributed the mechanism of this relationship between LEP and child health outcomes to the quality and family-centered nature of parent–provider communication.^{34,35,50,51} LEP caregivers were more likely than EP parents to report that health care providers did not teach them how to manage their children's chronic condition^{31,43} or discuss important health care transitions.⁵² This understanding is consistent with causal pathways suggested by the Chronic Care Model, adapted for pediatric care⁵⁶ (Fig. 2). In this model, parental LEP may limit how well a family is informed and activated to understand and advocate for their child's needs, where “activation” refers to one's ability to manage his own health and health care.⁵⁷ For instance, parents who are inadequately informed and activated about their child's health condition may lack critical knowledge and motives to pursue preventative and specialty care that improve health outcomes. Problems in health care quality related to LEP—such as poor communication leading to inadequate bedside teaching or failure to nurture a partnership with parents—may lead to reduced self-efficacy for disease management and dissatisfaction with care.

Table 4. Summary of Associations Between Parental LEP and Primary Outcomes Measures for Child Health Quality

Study	Year	Sample Size	Magnitude and Direction of Associations Between Parental LEP and Primary Outcome Measures*	Quality of Evidence Scores†
Chan ³¹	2005	405	↓ adjusted asthma knowledge score (6.5 for Hispanic Spanish speakers vs 7.5 for English-speaking whites). ↓ adjusted rates of peak flow monitoring (57.1% of Hispanic Spanish speakers vs 71.3% of English-speaking whites). ↓ adjusted rates of goal setting (37.6% of Hispanic Spanish speakers vs 59.4% of English-speaking whites). ↓ adjusted likelihood of having written action plan (26.1% of Hispanic Spanish speakers vs 43.4% of English-speaking whites).	1,2
Inkelas ⁴³	2008	1517	↓ teaching on asthma management practices [AOR 0.4 (95% CI 0.2–0.6)].‡	1,1
Mosnaim ⁴⁸	2007	14,177	↑ asthma diagnosis for children of English-speaking compared to Spanish-speaking parents [AOR 1.82 (95% CI 1.63–2.00)].	2,2
Shifrer ⁴⁹	2011	10,260	↑ learning disability (LD) diagnosis for children who ever participated in “English as a second language” programs (AOR 1.71). ↓ LD diagnosis for children with non-English speaking parents (AOR 0.54).	1,1
Yu ³⁴	2004	38,866	↑ lack FCC [AOR 1.74 (95% CI 1.27–2.38)] among CSHCN.	1,1
Yu ³⁵	2009	40,723	↑ lack FCC [AOR 2.30 (95% CI 1.79–2.95)] among CSHCN.	1,1
Coker ⁵⁰	2010	40,723	↓ FCC [AOR 0.48 (95% CI 0.36–0.64)] among CSHCN. ↓ time spent with provider [AOR 0.58 (95% CI 0.43–0.79)] ↓ sensitivity to family values/customs [AOR 0.54 (95% CI 0.39–0.75)].	1,1
Lotstein ⁵²	2009	18,198	↓ meet criteria for the transition to adult medical care core outcome [AOR 2.45 (95% CI 1.43–4.19)] among CSHCN.	1,1
Kenney ⁵¹	2011	40,723	↑ likelihood to not perceive a partnership between parents and health care providers and be dissatisfied with care [AOR 1.90 (95% CI 1.49–2.42)] among CSHCN.	2,2
Ngui ⁵³	2006	36,236	↑ dissatisfaction with care [AOR 2.72 (95% CI 1.42–5.22)] among CSHCN.‡	1,1
Kerfeld ⁵⁴	2011	40,723	↑ dissatisfaction with care [AOR from 1.84–2.21] among CSHCN.	2,2
Hamilton ⁵⁵	2012	22	↑ satisfaction with care in medical home pilot program for medically complex children with bilingual care coordinator (No AOR reported).	3,3
Abbe ⁶⁹	2006	17	Interpreters important but not sufficient to overcome language barriers (no AOR reported).	3,3
Claudio ⁶⁷	2009	1847	No relationship to having asthma action plan (AOR not given) ↓ unadjusted likelihood of receiving asthma teaching from health care providers (eg, medication use for acute exacerbation, when to go to emergency department visit) ↓ unadjusted access to evening or weekend advice.	1,2

LEP = limited English proficiency; AOR = adjusted odds ratio; CI = confidence interval; LD = learning disability; FCC = family-centered care; and CSHCN = children with special health care needs.

*Compared to English-speaking non-Hispanic white subjects unless specified otherwise.

‡Compared to English-speaking non-Hispanic whites and English-speaking Hispanic subjects.

†Quality of evidence score based on GRADE scale with highest (1) to lowest (4) quality.²⁷

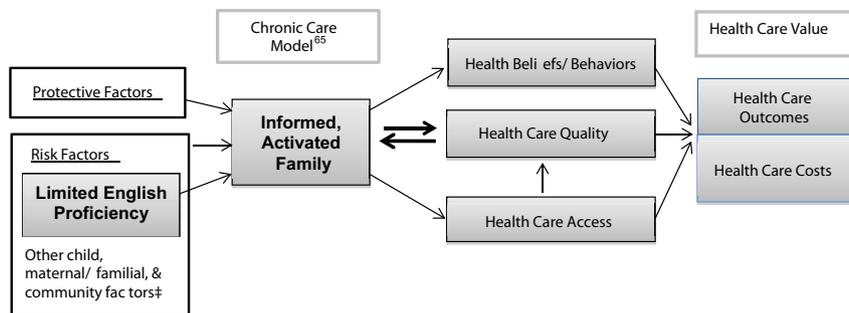


Figure 2. Theoretical model for association between parental limited English proficiency (LEP) and health care access and quality. LEP is a risk factor that affects how well a family is informed and activated to advocate for their child's health needs. An informed and activated family is a key factor facilitating productive interactions with health care providers, leading to improved health outcomes and lower preventable health costs.⁶⁵ ‡Risk factors may include maternal or familial characteristics such as late/no prenatal care, maternal depression or drug use, low educational attainment, low literacy, and poverty and community factors such as geographic isolation, economic stress, and violence.

Many language-related factors may directly affect the activation of parents with CSHCN. Prior research suggests that modifiable language-related factors in health care settings include lack of skilled medical interpreters (or use of ad hoc interpreters), inadequate cultural competency of health care providers, and limited parental health literacy.^{1,2,58,59} Families also face navigational barriers inherent to fragmented health care systems, such as cumbersome processes for scheduling appointments, obtaining referrals, and transitioning CSHCN across settings (eg, from inpatient to outpatient medical care or from pediatric to adult medical services).⁶⁰ Families may lack the activation skills necessary to effectively mitigate such barriers.

As with any systematic review of cross-sectional studies of self-reported health outcomes, there are important methodological limitations to these conclusions. Although all but 2 studies adjusted for family socioeconomic status, it is possible that other unmeasured confounders that impact health behaviors, including acculturation and health literacy, may mediate the relationship between parental LEP and child health. Reverse causality is also possible. For instance, families with access barriers, such as illegal documentation status, may be more likely to have LEP than families with adequate access. Comparison across studies is limited by heterogeneity in measures of health outcomes, varying degrees of medical severity in the study samples, ethnic and language subgroups studied, and measures of LEP used (eg, level of English proficiency, preferred spoken or interview language). A gold standard construct for defining LEP—and identifying individuals most at risk for poor health outcomes related to LEP—has yet to be defined and standardized, and this is an important area for ongoing research.^{61–63} The majority of studies with large sample sizes collected data via random-digit-dial surveys, which are subject to selection bias that may under-sample parents with LEP and therefore underestimate the association of parental LEP to health outcomes. Perhaps most critically, all but 2 studies utilized parent- or child-reported measures of health outcomes, which are subject to recall bias. Only 1 study⁵⁵ attempted to assess the effectiveness of an intervention to improve health outcomes for CSHCN with LEP parents.

With a rapidly growing population of both LEP families and CSHCN in the United States, these findings have important clinical, policy, and research implications. For health care providers of CSHCN, these findings suggest that LEP should be an important risk factor to identify when new families enter their care. For policymakers, these findings indicate that accommodations targeting LEP-related barriers should be included in all new models of chronic disease care. For researchers and innovators, LEP should be a routine metric in all studies and a critical component of any model of parent/patient activation.

The current milieu of health care reform provides ample opportunities to reduce LEP-related health disparities. The meaningful use legislation preceding and endorsed by the Affordable Care Act (ACA) should facilitate collection of electronic data on English proficiency, race, ethnicity, sex, and disability status. Moreover, the ACA supports initiatives to increase racial and ethnic diversity in health professions and provide cultural competency training, and requires expanded use of language services and outreach by health plans to underserved communities.⁶⁴ Strategies to mitigate LEP-related barriers already include recruitment of a diverse, culturally competent health workforce,^{1,2,58,60} enhanced access to skilled medical interpreters^{2,60,65} and low literacy materials,^{17,58,60} and use of the medical home model.⁵⁸ There is also a growing role for electronic and mobile technologies to reduce LEP-related barriers by improving access to medical interpretation services, health information, and care coordination through innovations such as virtual patient navigators. However, the effectiveness of such technologies to improve health outcomes for LEP families will need to be assessed to move toward best practice models.

Overall, this systematic review demonstrated that there is a lack of critical evaluation of interventions to mitigate LEP-related barriers for CSHCN. Whether there is a lack of interventions or a lack of evaluation of interventions is unclear. Development and assessment of innovative, cost-effective models of care are mandated by the ACA⁶⁴ and should include accommodations to improve health care access and quality for LEP families within integrated health systems. Key outcome measures in these assessments should include both short- and long-term health

and developmental outcomes and health care costs because CSHCN account for the majority of US pediatric morbidity and costs.^{19,66}

Addressing LEP-related child health disparities will require action on many fronts. Innovative interventions to mitigate these disparities, however, should be mindful of current evidence. As revealed by our review, the most effective interventions to improve health outcomes for CSHCN may be those that are designed to mitigate specific disparities in health care access and quality for LEP families.

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SUPPLEMENTARY DATA

Supplementary data related to this article can be found online at <http://dx.doi.org/10.1016/j.acap.2013.10.003>.

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