

Family Language Barriers and Special-Needs Children

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Approximately 63 million Americans speak a language other than English at home, and more than 26 million have limited English proficiency (LEP, defined as a self-reported ability to speak English less than very well).^{1,2} Approximately 12 million school-age children (22%) speak a language other than English at home, a number that has tripled since 1979.² In the city of Houston, at least 145 languages are spoken at home.³ The marked growth in non-English primary language (NEPL) and LEP families is attributable to the rapid increase in America of the foreign-born population, which grew from 9.6 million in 1970 to 41.3 million in 2013.^{1,2} Numerous studies document that language barriers affect multiple aspects of health care, including access, health status, use of services, patient-physician communication, satisfaction with care, participation in clinical research, quality, and patient safety.^{1,2,4-7}

The number of children with special health care needs (CSHCN) also has increased substantially. Approximately 16% of children in the United States (18 million) are CSHCN, and the number of CSHCN quadrupled between 1962 and 2005.⁸ CSHCN comprise almost two-thirds of pediatric hospitalizations, have longer mean hospital lengths of stay, and account for 90% of medical deaths among US children.⁸ These 2 demographic surges are colliding in America, as 13% of CSHCN reside in NEPL homes. Both populations are at high risk for adverse outcomes and compromised quality of care individually; however, when they intersect, disastrous consequences can result.

For example, Cristina was a 12-year-old paraplegic girl who recently presented to a children's hospital emergency department (ED) with shortness of breath, fever, urinary tract infection, and tachycardia. Cristina spoke minimal English, and her mother spoke only Spanish, without any English proficiency. An interpreter was not available until 3 hours after Cristina's initial presentation. Neither telephone nor video interpretation was considered by staff. It took 1.5 hours for the medical staff to ascertain that Cristina had recently traveled to Mexico and been diagnosed with a renal abscess. Three hours after ED presentation, a hospital interpreter arrived. Thirty minutes after the interpreter's arrival, Cristina went into cardiac arrest. She died 23 minutes after the cardiac arrest. Autopsy revealed bilateral septic pulmonary emboli, a

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All authors conceptualized the Perspective, drafted the initial manuscript, approved the final manuscript as submitted, and agree to be accountable for all aspects of the work.

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left leg thrombosis, and sepsis as causes of death. Renal abscesses are a recognized cause of deep venous thrombosis and septic pulmonary emboli.⁹ Multiple studies, case reports, and literature reviews document that to ensure optimal outcomes and prevent serious morbidity and mortality associated with abscesses and associated deep venous thrombosis and septic pulmonary emboli, early and timely diagnosis (via a careful history from the patient and family and prompt imaging studies), antibiotic administration, anticoagulation, and surgery are crucial.¹⁰⁻¹³ Although one cannot be certain why key clinical signs, such as shortness of breath, did not trigger a more urgent workup and interventions for Cristina, the 3-hour delay in obtaining an accurate, comprehensive history through a trained hospital interpreter may have been a major contributing factor to the unfortunately tragic outcome for this LEP CSHCN girl that resulted from missed opportunities for timely diagnosis and treatment.

Both CSHCN and NEPL children face substantial barriers to health care access. Compared with children in households with English as the primary language, NEPL children have substantially higher adjusted odds of suboptimal health, having no medical or dental insurance, lacking a consistent source of medical care, making no preventive medical care visit in the past year, and experiencing problems obtaining specialty care.² Half of families with CSHCN report ≥ 1 unmet medical need, and 12% report ≥ 3 , including preventive care, specialty care, and therapeutic interventions.^{14,15}

What can be done to ensure access to needed health care and optimal outcomes for CSHCN who have LEP parents? Early identification and provision of adequate language services are crucial.¹ Only 39% to 60% of hospitals routinely collect data of any kind on patients' primary

language, and it is unknown what proportion assesses LEP.¹ A national survey of general internists¹⁶ showed 65% have LEP patients, but few practices have formal mechanisms for obtaining data on patients' primary language, only 28% record patients' primary languages in the medical record and there is no mention of whether any record LEP data, 36% of practices provide no language services, and 29% use ad hoc interpreters (family members, friends, untrained staff, or strangers from the waiting room or street), which have been shown to be ineffective and dangerous.^{1,7} Unfortunately, clinicians and trainees rarely receive education or training on how to assess LEP or work with interpreter services. For example, 80% of New Jersey hospitals offer no training for staff on working with interpreters.¹⁷ Failure to assess English proficiency deters access to language services for families needing these services. Quality and parental satisfaction are compromised when LEP patients/families need but do not have timely access to trained interpreters or bilingual providers.¹ LEP patients needing but not receiving a medical interpreter have an impaired understanding of their diagnosis and treatment, more diagnostic studies, higher costs, greater unmet needs for prescriptions, and lower satisfaction.^{1,7} In the ED or hospital, LEP patients are more likely to be discharged without scheduled follow-up appointments and to experience delays in treatment and hospital discharges.^{1,7}

CSCHN in LEP families not only require access to language services, but also health care that is culturally competent. Culturally competent care is defined as "recognition of and appropriate response to key cultural features that affect clinical care."¹⁸ In addition to providing health care and education in a language fully understood by families, health care

workers also need to be trained in normative cultural beliefs that are important to the family and can affect various factors, such as adherence to medication, disparities in health care outcomes, and the willingness to ask questions and share important information. Research documents that culturally competent care is associated with greater medication adherence and a higher quality of care.¹⁹ In children with medical complexity, it is imperative that providers have the necessary knowledge and skills to understand and identify the unique barriers and beliefs of the most common populations they work with. For CSHCN, it is particularly important that palliative care and end-of-life decisions are discussed in a culturally competent manner.¹

Two rigorous studies demonstrate that health and health care disparities for CSHCN in LEP families can be reduced or eliminated while remaining cost-effective. A randomized controlled trial (RCT) assessed the effects on asthmatic minority children and their families of bilingual parent mentors, experienced parents of asthmatic children in the study who received specialized training, met monthly with families at community sites, phoned parents monthly, and made home visits. Parent mentors reduced wheezing episodes, asthma exacerbations, ED visits, and missed parental work days, while improving parental self-efficacy in recognizing breathing problems controllable at home, and with net cost savings (~\$600 per patient).²⁰ An RCT of an enhanced medical-home model for high-risk, primarily Latino children with chronic illness showed that the intervention reduced serious illnesses, ED visits, hospitalizations, hospital length-of-stay, pediatric ICU admissions, and total hospital and clinic costs, with net cost savings of ~\$10 000 per patient year. This model consisted of a clinic that

provided treatment by primary care clinicians and specialists in the same clinic, care coordination by nurse practitioners, and 24-hour on-call phone access to clinic providers.¹⁵ Rigorous RCTs thus demonstrate that tailored, culturally and linguistically appropriate, family-centered interventions targeting CSHCN with LEP caregivers can be highly effective in improving outcomes, reducing morbidity, and saving money.

ABBREVIATIONS

CSHCN: children with special health care needs
 ED: emergency department
 LEP: limited English proficiency
 NEPL: non-English primary language
 RCT: randomized controlled trial

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