Cultural and Linguistic Determinants in the Diagnosis and Management of Developmental Delay in a 4-Year-Old*

CASE

Jose is a 4-year-old Puerto Rican boy diagnosed with high-functioning autism. His mother, who speaks Spanish and knows little English, has brought him in to see you, his new bilingual pediatrician. She felt that Jose’s former pediatrician did not provide her son with adequate treatment and services because “the doctor doesn’t speak my language and didn’t seem to understand my culture.” Jose’s mother also is concerned because she believes he is in a regular, English-only mainstream classroom at school and worries that he is not receiving appropriate services in the school.

Jose’s mother brought copies of her son’s medical records to the office visit. They reveal that Jose was born at term after an uncomplicated pregnancy. He had normal developmental milestones at all of his health-supervision visits through 9 months of age. During an acute care visit for gastroenteritis when Jose was 10 months old, his mother noted that she thought Jose was suffering from “empacho,” which she treated with a “special powder.” At 12- and 18-month-old well-child visits, Jose’s only words were “Mama” and “Papa.” Between 13 and 20 months of age, he had 7 episodes of bilateral otitis media, which were treated with antibiotics; the last 3 episodes occurred with antibiotic prophylaxis. During this period, tympanometry demonstrated flat tympanic membranes bilaterally. Jose was uncooperative during 2 attempts at audiometry. He underwent bilateral myringotomy and tympanostomy tube placement at 20 months old.

The former pediatrician was not concerned about Jose’s language delay because, as documented in his notes, “it is expected that children who are trying to learn 2 languages at the same time will have more speech problems and language delay.” Because of other areas of developmental delay noted on the 2-year-old well-child visit, Jose’s former pediatrician referred him to the Developmental Assessment Clinic (DAC), where a severe delay in cognition (12- to 15-month-old range) and expressive and receptive language were observed, associated with appropriate social interactions.

At this time, Jose’s mother was not concerned about his language development but was worried that he still was not toilet-trained. He was referred to an early intervention program, where he received weekly speech therapy (in English), occupational therapy, and applied behavioral analysis. At the follow-up DAC visit at 3 years of age, Jose demonstrated marked delays in all areas on the McCarthy Scales of Children’s Abilities, and mild deficits were seen on the Vineland Adaptive Behavior Scales. He was able to indicate “yes” and “no” with gestures only, and he understood fewer than 10 words. His mother reported that at times he would not use words for hours at home, and she felt that he was actually losing some of the improvements in speech that he had previously made. His diagnosis was now global developmental delay with possible autistic spectrum disorder. Subsequent evaluations were negative, including a neurologic assessment and genetic consultation, a magnetic resonance image of the brain, a Fragile X DNA molecular probe, and high-resolution chromosome analysis.

Jose is now attending an early childhood special education classroom, but the program is held only in English. Jose’s mother told the pediatrician that she is worried because his speech therapy is in English, and she was told that there are no school programs for special-needs children in Spanish. She is also worried because he rarely makes eye contact with her or anyone else, and he often screams or bangs his head when frustrated.

As Jose’s new pediatrician, 4 major issues confront you. (1) How can you provide the most culturally sensitive and linguistically appropriate pediatric care to this family, both in your office and in his specialist visits? (2) How can you arrange for appropriate bilingual treatment and services at Jose’s school? (3) Are children raised in bilingual environments at higher risk for language delays? (4) You would like to provide this mother with more information in Spanish on autism and to suggest an autism support group for Spanish-speaking parents, but you do not know where to look for such information or whether it even exists.

INDEX TERMS. bilingual children, cultural competency, language delay.

Dr Martin T. Stein

Our attention to the role of culture in all aspects of medical care has undergone significant change in the past 40 years. Before 1960, clinicians learned about the effects of culture on health and illness from novels, biographies, and their own clinical experiences. Scholarly studies from the fields of anthropology and sociology gradually came to the attention of physicians. Over the past 20 years, recognition that knowledge about different cultures must be extended to “cultural competency” shaped the education of physicians and other health workers.

The value of clinical experience in the form of
Language issues profoundly impact quality, outcomes, and patient satisfaction in pediatric care. Such ethnocultural differences can have key clinical consequences, because parents’ concerns for their children predict developmental/behavioral status. Unrealistic expectations result in delayed care, failure to address important issues with providers, lack of a stimulating home environment, and resultant developmental delays because of parental “underexpectation” and frustration that can lead to maltreatment or neglect.4

It is important to sensitively inquire about folk illnesses that affect care and to be aware of clinically significant normative cultural values.3 Jose’s mother mentioned he had empacho, a Latino folk illness in which food is believed to obstruct the stomach because of dietary indiscretion. This is critical information, because the first provider contact usually is a folk healer, not a physician, and certain empacho folk remedies can be harmful or fatal.3 Indeed, Jose’s mother mentioned treating him with a special powder, and certain lead-containing powders used to treat empacho can result in lead levels up to 124 g/dL, encephalopathy, and death.3 Lead poisoning is also part of Jose’s differential diagnosis because it can cause behavioral abnormalities, attention disorders, lower intelligence, and school problems. Fatalismo is a Latino normative cultural value characterized by the belief that the individual can do little to alter fate.2 It can lead to less preventive screening, and avoiding effective therapies for chronic diseases.3

Stark mental health care disparities exist among Latino children, which are relevant to the care of children like Jose. Latino children have a higher prevalence and severity of depression, phobias, anxiety/panic, school refusal, and disturbed relationships with other children.6 Differences among Latino subgroups are also relevant to Jose’s care. For example, by parental report, Puerto Rican children have a higher prevalence than Mexican American children of chronic developmental conditions, functional limitations, and developmental problems.5

Language issues profoundly impact quality, outcomes, and patient satisfaction in pediatric care.3 When caring for LEP families, monolingual clinicians should use trained medical interpreters and published guidelines for interpreter use or risk poor adherence, misdiagnosis, medical errors, and disastrous outcomes.57 A methodologically flawed study suggested that “language minority” children attending bilingual or monolingual English preschools rapidly lose native language proficiency, resulting in disruption of parent-child communication and a high-risk developmental course.5 More recent studies demonstrate that Latino children attending bilingual preschool, compared with those remaining at home, show equivalent gains in Spanish-language

Clinicians are caring for an increasingly diverse population in the United States. Racial/ethnic minorities make up one third of the American population, minorities outnumber whites in 8 of the 10 largest US cities, and 45 million Americans speak a language other than English at home, including 19 million who are limited in English proficiency (LEP).1,2 Cultural issues can profoundly impact quality, outcomes, costs, and patient satisfaction in health care.3 Jose’s case graphically illustrates the importance of culturally competent care.

Dramatic ethnocultural differences exist in parental expectations of normal child development,4 which can have key consequences in seeking care and screening for behavioral/developmental abnormalities. Jose’s mother was not concerned about his language delay but worried about lack of progress with toilet training. Puerto Rican mothers expect their children to name colors at a significantly later age than white mothers, but white mothers expect their children to achieve toilet training at a significantly later age than Puerto Rican and African American mothers, with mean differences in maternal expectations of these milestones of 6 months or more.4 Puerto Rican mothers also expect their children to smile and to put on their shoes at a significantly later age than mothers from other racial/ethnic groups.4

Jose is a 5-year-old Puerto Rican boy living in the United States.

Clinicians from different communities were invited to share their perspective from the point of view of a pediatrician. Dr Glenn Flores is an Associate Professor of Pediatrics and Public Health at Boston University Schools of Medicine and Public Health and the founder and codirector of the Pediatric Latino Clinic at Boston Medical Center. He has focused his research and teaching on understanding the cultural variables that impact pediatric care. Dr Elinor A. Graham is an Associate Clinical Professor of Pediatrics at the University of Washington in Seattle, where she is director of the Primary Care Clinics at the Harborview Medical Center. Dr Graham has guided the development of resident teaching and community service programs to ensure cultural competency in the care of children. Leticia Magana is a caseworker and cultural mediator who works in those programs. Dr Lindia Willies-Jacobo is an Assistant Clinical Professor of Pediatrics at the University of California, San Diego, where she practices and teaches primary care pediatrics at both an academic center and a community clinic.

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development but greater gains in English proficiency. Parents should be encouraged to raise their children in bilingual homes.

Language delay in bilingual children presents difficult challenges. Bilingual speech therapists are indispensable in such cases. They can address unique issues such as one I encountered in my practice in which a mother was distressed that her child could not correctly pronounce the unique Spanish “rr” sound. Because of shortages of bilingual speech therapists in many US school systems, often a clinician’s only resort will be outpatient speech therapy teaming medical interpreters with speech therapists.

Clinicians can download information on autism in Spanish for parents from a number of Web sites. The National Institute of Neurological Disorders and Stroke has a helpful Spanish summary (www.ninds.nih.gov/health and medical/pubs/autismo.htm), and the Autism Society of America has a new Spanish section (www.autism-society.org/site/PageServer?pagename=Autismo). The Autism Society of America also can assist parents in finding local Spanish-speaking autism support groups.

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Spanish-speaking patients and parents have a better understanding of health conditions and compliance with follow-up if they have a bilingual provider or use a medically trained interpreter. A bilingual pediatrician who speaks Spanish is a great advantage, but, in this case, the first task is the same as that of a monolingual provider—to understand the mother’s experience of her child’s disorder and the family’s needs and social supports. Jose’s mother associated his gastrointestinal illness with empacho (blocked intestine), a folk illness concept common in Spanish-speaking communities, and she treated him with a “special powder.” Exploring this incident may guide the clinician’s understanding about the mother’s view of the importance of traditional illness concepts and herbal treatments. Several Web sites are available with information about cultural and medical traditions.

Puerto Rican parents living in the United States and raising a child with a disability have needs similar to those of parents in other cultures. They want information about their child’s disability and services. They want to know how to best teach their child and manage difficult behaviors. Support from family and social systems (medical and educational) and financial support are highly ranked needs. Low English proficiency is associated with a greater need for family and social support. Connecting the family with a social worker or state-supported services for individuals with developmental disabilities can help them access services and financial support.

Jose’s mother believes he is in a regular classroom when, in fact, he is in special education. This suggests poor communication with the school, and it must be addressed. Spanish-speaking parents often report communication problems with the schools and difficulty understanding the individualized education plan (IEP) process. By law, the schools are required to notify parents in their native language of IEP meetings, provide an interpreter at the meetings, and generate an IEP report in Spanish. A pediatrician can be a powerful advocate in the school for Jose and his family through phone contacts with his teacher and principal. A meeting with his teacher and the special education services administrator is often useful.

Because language ability is a strong predictor of functional outcome in autism and other moderate-to-severe developmental disorders, the pediatrician should support the mother’s expectation for her son to have effective bilingual services. Skilled bilingual teachers and speech therapists who speak Spanish are not available in most areas of the United States. The pediatrician can help the family make an informed decision about the language to use with Jose at home and in the school. If the family desires to continue speaking Spanish at home and if bilingual instruction is not available in the school, the family must determine how they can provide well-structured, native-language input at home and supplement school instruction with tutors and language-rich activities.

Learning 2 languages does not “confuse” a child or slow language development. Bilingual children follow the same language-acquisition sequence as monolingual children but usually combine the 2 languages. For example, by 20 months they should know more than 20 words in the 2 languages combined.

The National Information Center for Children and Youth With Disabilities has an extensive list of Spanish-language publications that can be printed from their Web site (www.nichcy.org/spanish.htm). The educational level of these documents varies and may be challenging to some Spanish-speaking parents; a health professional who is bilingual or an interpreter may be helpful. They also have Spanish information about IEPs and can help link families to resources and support groups in their local region by calling an information specialist at 1-800-695-0285.
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This case presents a true challenge for any pedia-
trician caring for children with multiple develop-
mental problems. It is especially challenging to those clinicians with limited experience caring for patients who are from different ethnic and cultural back-
grounds. This particular case focuses on a Latino patient and his mother, and to adequately care for this family, it is important to first understand some of the cultural forces that may drive interactions with clinicians and educators. There are 3 primary issues that should be addressed: normative cultural values of Latinos, language issues that modify doctor-pa-
tient communication, and the health belief system embraced by this family.

Normative cultural values are beliefs, behaviors, and ideas shared by a group of people and informing their interpersonal relations.1 Many Latino people place significant value on “simpatia” (kindness), “personalismo” (formal friendliness), “respeto” (res-
pect), “familismo” (collective loyalty to the ex-
tended family), and “fatalismo” (fatalism). It is clear from the mother’s statement (“the doctor didn’t seem to understand my culture”) that her needs were not adequately met by her previous pediatrician. Whether based merely on perception or what really occurred, the outcome is ultimately the same—pa-
tient dissatisfaction. In striving for cultural com-
petency, Jose’s new pediatrician must work to under-
stand more about the family’s cultural values and learn to incorporate them into doctor-patient inter-
actions.

Jose’s mother further informed the pediatrician that “the doctor didn’t speak my language.” Al-
though achieving cultural competency goes beyond simply learning a patient’s language, it is important to use the language with which the patient is most comfortable when interacting with patients from different backgrounds. Jose’s mother clearly preferred to interact in Spanish, and her perception is that, without Spanish, effective communication with her previous pediatrician was not achieved. A variety of studies emphasizes the importance of communicat-
ing with Latino families in their native language to enhance the doctor-patient relationship and out-
come. To overcome this cultural barrier, fluency in Spanish and, when not possible, using interpreters is helpful. Jose’s mother also expressed concern about his “regular, English-only mainstream classroom” and the appropriateness of his school program. This is another area in need of further exploration; it is an opportunity for the pediatrician to share the moth-
er’s concerns with the school.

A familiarity with some of the belief systems of Latino families would be quite useful in this case. In a review of studies on barriers to health care access for Latino children, parental belief systems were identified as a significant barrier to care.2 Jose’s mother describes his diagnosis of gastroenteritis at 10 months of age as “empacho,” and she reports treating him with a “special powder.” Empacho (blocked intestine) is a very common folk illness in the Latino population, usually presenting as vomiting, diarrhea, and abdominal pain. It is believed to occur as a result of food sticking to the intestines. In a study by Risser and Mazur,3 64% of caregivers interviewed believed in the existence of empacho as a folk illness. Because the treatment of empacho often involves the use of lead oxide–containing sub-
stances such as “greta” and “azarcon,” both of which can be detrimental to the development of children, it is important for pediatricians to become familiar with folk illnesses and therapies. Substances contain-
ing lead oxide are available over the counter to many Latino families in our community. Many of the symptoms associated with folk illnesses such as em-
pacho are similar to established medical conditions.

How, then, does one address the issue of a pa-
tient’s differing health belief system? Pachter pro-
posed a model for cultural competency known as the “Awareness-Assessment-Negotiation” model.4 This model can be used for all patients but is especially helpful when dealing with patients who may have beliefs that do not fit within a standard biomedical model. Initially, the pediatrician must become aware of the traditional health beliefs and practices in the culture of the people with whom she works. As Jose’s new pediatrician, familiarity with other folk illnesses (in addition to empacho) and remedies will enhance the relationship with his mother. The sec-
ond part of the model asks that we assess whether the family with whom we are interacting relates to that particular belief system, because it cannot be assumed, for example, that every Latino believes in the existence of empacho. The third part of the model calls for negotiation. Although we would discourage the use of greta or azarcon for treating empacho, we may suggest to Jose’s mother that she use a safer intervention such as massaging the abdomen with oils.

References


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Jose's new pediatrician has embarked on a challenging path that, with the inclusion of a personal education in cultural competency, will be fulfilling. Although this case deals specifically with the Latino culture, many of the same principles of care can be used when caring for families from other backgrounds.

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Web Site Discussion
The case summary for the Challenging Case was posted on the Developmental and Behavioral Pediatrics Web site‡ (www.dbpeds.org.list) and the Journal’s Web site (www.lww.com/DBP). Comments were solicited.

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Information about Spanish-language acquisition and bilingualism is particularly relevant to a country like the United States, where Spanish-speakers constitute approximately 10% of the total population and represent the fastest-growing segment among school-aged children. Developmental studies of Spanish phonology and vocabulary have found it to be similar to English. Essentially the language acquisition among Spanish-speaking children develops at a similar pace and concentrates on similar categories of common nouns.

A distinction needs to be made between the different kinds of childhood bilingual development: (1) simultaneous language acquisition and (2) sequential language acquisition. The first occurs when both English and Spanish are spoken to the child in early infancy. I grew up in such a household. Both languages developed simultaneously in naturalistic settings, and competency in both languages is similar to that of monolinguals. The second group is referred to as sequential or consecutive language learners, and it encompasses different groups of children. Early childhood bilingualism describes preschool children who hear Spanish in the home and are later exposed to English in the community. Older school-aged children and adolescents also make up this group who acquire English in school.

Language loss and language shifts are important aspects of a child’s bilingual development. If there is little or no support for the maintenance of the Spanish language, as is frequently the case in the United States, a child’s proficiency in English will increase with the concomitant loss of language skills in their native languages. Consequently, some young children seem to have arrested their development in Spanish while focused on acquiring a second language. During this period, some normal “bilingual” children appeared to be delayed in both languages.

This lack of proficiency in both languages does not occur in infant bilinguality. It seems that children who learn 2 languages simultaneously in naturalistic interactive contexts seem to acquire both Spanish and English with only minimal interference. Now, virtually all bilingual children do mix elements from their 2 languages in the same utterance (code switching). However, code switching is widely used and accepted and may vary from one bilingual community to another (ie, Tex-Mex in Mexican American community and Spangles in the Puerto Rican Community).

The differentiation of children with temporary LEP and children with language disorders is often difficult. Bilingual children with LEP are often normal language learners. Children with LEP should eventually attain proficiency after receiving adequate bilingual education. In children who learn English after the age of 6 years, age-appropriate academic language proficiency may take up to 7 years to develop.

An assessment to differentiate an LEP child from a language-disordered child presents numerous complications. The American Speech-Language Hearing Association stipulates that in order for LEP children to be considered communication handicapped, they must have limited communicative competence in both languages. Non–English-speaking children should be tested in their native language to determine if that too is delayed. This recommendation is supported by the federal mandates PL 95–142 and Title VII of PL 95–561. Interpreters and translators are recommended when the staff speech-language pathologists are not proficient speakers of Spanish.

Identification of speech and language delays among primary Spanish speakers may be challenging, especially if the physician and staff do not speak Spanish. Assessment of bilingual Hispanic children may be even more challenging. There are available screening instruments to be used in these situations. An English/Spanish articulation screening test, the Texas Acevedo Screening of Speech and Language, developed by the Texas Department of Health, is for children 3 to 6 years of age. The Inventario del Desarrollo de Habilidades Communicativas focuses on vocabulary development of Spanish-speaking children. I have found it like having a Spanish version of the MacArthur Communicative Development Inventory.

Even without a standardized screening instrument, pediatricians can make use of traditional clin-
ical skills by (1) listening to parent’s concerns, (2) asking questions through an interpreter, and (3) maintaining a high index of suspicion when parents do express concerns. Cross-lingual comparison between Spanish and English may be useful. I use the Early Language Milestone Scale as a screening instrument for infant or toddler language development when a parent voices concerns that a suspicion of delay is seen during developmental surveillance at the time of a well-child visit.

Editor’s note: An excellent recent review of language development in bilingual children can be found in Dr Graham’s and Ms Magana’s comments under ref 6.

Dr Martin T. Stein

“Culture” encompasses shared beliefs, customs, traditions, values, and a sense of self. It is an enduring internalized psychological structure that determines a person’s ideas about health and illness.1 I cannot imagine practicing medicine without a recognition of the importance of understanding the role that culture plays in the expression of disease states, understanding of disease mechanisms, and adherence to therapeutic recommendations.

The ancient reminder to “know oneself” is especially significant when working with a patient and family from a different culture. Researchers in cultural competency agree that effective cross-cultural learning takes place when clinicians are aware of their own culture and its influence on their own values, beliefs, and behaviors.2 It is through a knowledge of one’s own origins and cultural beliefs that a clinician can begin the process of recognition, understanding, and incorporation of a patient’s culture into the therapeutic process.

Although the sequence of maturation of neurologically based, developmental milestones is similar among different cultures, the meaning of a particular developmental acquisition may be quite different between cultures. Dr Flores pointed out many examples of these differences. He observed that “Jose’s mother was not concerned about his language delay but worried about lack of progress with toilet training”—a reversed priority compared to that of many Anglo-European parents. When cultural differences are extended to disease states, the concept of the “explanatory model” may be useful. It refers to a culturally based model for understanding health status at time of health and disease.3 It implies that a parent or child’s interpretation or explanation of symptoms may be different from the assumptions of the clinician. A family’s explanatory model of health and illness will emerge usually after asking specific questions such as “What would you call this problem?...Why do you think your child has developed it?...What do you think caused it?...What do you think is happening inside the body?...What will happen if the problem is not treated?”4

The recommendations enumerated in the commentaries were focused on the health care of a preschool-aged child with multiple developmental delays who was living in a community that did not share many of the values and language of his own culture. Most of these recommendations are also applicable to more common problems seen in primary care pediatric practice.

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