

#### **FACT SHEET**

# Strategies for Strengthening Communication with Spanish-speaking Families of Children with Medical Complexity

### Tips for health care professionals from a parent mentor

#### by Ali Rivera

Clear communication between families and health care providers is essential to the delivery of high-quality care for children with medical complexity (CMC). Miscommunication can lead to inequity in care, treatment, and resources, especially for CMC from families of color. A 2018 <u>study</u> in *JAMA Pediatrics* concluded that hospitalized children of parents with limited English proficiency are at higher risk for adverse events than children of English-proficient parents.

Additional <u>research</u> centered on the cultural and language barriers for Spanish-speaking families of CMC suggests that bilingual care coordinators can help improve communication. At the Lucile Packard Children's Hospital Stanford, Marsha Perez provides bilingual support as a parent mentor for Spanish-speaking families in CORE, the hospital's care coordination program for CMC and their families. She was motivated to join the CORE team after her child received a kidney transplant at age 15 at the hospital. Now she teaches families how to manage their child's care and helps them realize how much their voice matters in their child's treatment.

Here are her key strategies for health care professionals on how best to communicate with Spanish-speaking families:

#### 1. Never assume that because families can speak a little English, they don't need an interpreter.

Many people can speak some English and have somewhat of a conversation with you, but if it's information that they really need to understand, then ask them if they need an interpreter. Always ask, even if it says English-speaking on their chart.

#### 2. Ask whether they're able to read or write in Spanish.

It's always good to ask if they are able to read English or Spanish because maybe they can speak Spanish but are not able to read it. I see a lot of families who tell me, I can't read this, so I don't know what it is. What good does it do to give them information if they aren't able to utilize it? So, we really need to be conscientious, and I don't think it's just Spanish, I think it's any language. We see this huge diversity of patients with a range of literacy, so you have to try to connect and see what tool works best for them to be able to work with you.

## 3. Don't assume everyone thinks the same way or has grown up using the same health care system. Be very specific in your instructions and have families repeat what is supposed to happen.

Growing up we learn how our family manages things simply from being exposed to it at home. For example, children in the U.S. may overhear their parent scheduling a medical appointment on the phone saying, "Ok, when am I supposed to call back if you don't call me?" We learn that this is how medical appointments should be managed. In other cultures, they also pick up on things in their homes, but if they don't hear their parent calling back for an appointment or asking questions, then that becomes a barrier to good care. If Spanish-speaking families are not told they should, or have the right to, call to follow up, they are not going to bother anyone because they don't want to be a burden.

As parent mentors, we help Spanish-speaking families manage their child's care across multiple medical services, so they can avoid miscommunication issues and learn how to navigate the U.S. health care system. For example, it's really important to help families understand how to order and refill medications within a certain time frame because unlike in the U.S., in some Spanish-speaking countries they can get a lot of medications without having a prescription. Many Spanish-speaking families don't understand that difference, and they go into the pharmacy without a prescription and end up missing a dose. Some have to travel from far away to get to the pharmacy, then they don't know what to do. Then, families start to panic, and they don't know who to turn to for help in getting these issues resolved. They just know that their child is supposed to take it every day, and they only have enough for tomorrow morning.

It's also important to help families understand how often to administer their children's medication and how to read the prescription bottles. After receiving a simple instruction like "two times a day," a family might say, "Ok, I'm going to get it done right now so I won't have to deal with it later, because I know I'll forget." And maybe the prescription is really meant to be taken "every twelve hours." I think that could happen in any language and in any health care setting, but I think it's important to understand that issues may be exacerbated for families with limited English proficiency.

# 4. Bridge the cultural barrier by building a trusting relationship with Spanish-speaking families and encouraging them to speak up and ask questions, so that they learn to understand that they are a crucial part of their child's care team.

I find that some Spanish-speaking families seem to be less assertive and more passive. Often, they will just agree with everything, even if they don't understand what is being said. They have such high respect for the health care team that they don't want to bother doctors and take away their time from taking care of other people. For some Spanish-speaking families, it takes time to build a relationship and to have them understand that they are part of the medical team. They are really the ones caring for their children, so they need to express their concerns and speak up, and if they don't understand something, to ask again.

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- Marsha Perez, parent mentor

I've also heard from Spanish-speaking parents that they have experienced miscommunication with interpreters and care providers. They say that these situations make them feel disrespected and ignored, as if no one is standing up for them. So those types of things do happen, and I think it's unfortunate. I remind them they have the right to speak up and explain how they feel.

#### 5. Finally, be patient and try to understand things from their perspective.

Most of the families I work with are not born here and not all of them are from Mexico. We have families from Nicaragua, Guatemala, and El Salvador. Some Americans may think that anyone who speaks Spanish is Mexican — but they're not necessarily Mexican. I've had an experience where I corrected someone, "No, they're from El Salvador," and they said, "Oh, same difference." And I'm like no, that's not the same difference, it's a different country. We need to be very open-minded and understand that just because they speak this language doesn't mean they're just from the one country.

We just have to be very conscious of each other and try to open our minds and realize that things are not easy for anyone. We all have things we have to deal with, and it just adds a little bit more stress when English is not the primary language. I think it's helpful to imagine ourselves being in their country and having no choice but to be there. If we had to deal with these issues and were not able to communicate, how frustrated we would be.

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