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Spanish-Speaking Parents' Experiences Accessing Academic Medical Center Care: Barriers, Facilitators and Technology Use

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ABSTRACT

BACKGROUND AND OBJECTIVE: Children of Spanish-speaking caregivers face multiple barriers to care in academic medical centers. This study identified barriers and facilitators of health care and described use of health information technology in order to guide interventions and optimize services.

METHODS: In-depth, audiotaped interviews were conducted with monolingual Spanish-speaking caregivers (N = 28) of children receiving care in academic medical center clinics using a structured interview guide. Interviews were transcribed in Spanish, and key themes were identified using thematic analysis. Illustrative quotes for each theme were translated into English.

RESULTS: Language-specific barriers included arrival/registration occurring in English, lack of bilingual personnel, heavy reliance on interpreters, long wait times, and challenging phone communication. Non-language-specific barriers included medical center size and complexity, distance to services, lack of convenient and coordinated appointments, missing work/school, and financial barriers including insurance coverage or lack of citizenship. Caregivers identified interpreters, bilingual

physicians and staff, and written materials in Spanish as facilitators of care. Most caregivers had internet access and expressed interest in health information technology, including patient portals, to communicate about their children's health.

CONCLUSIONS: Caregivers of Spanish-speaking children encounter many language-specific barriers, which are compounded by non-language-specific barriers arising from complex health systems and social needs. Caregivers with limited resources described working hard to meet children's complex health care needs despite these barriers. Most caregivers had internet access and interest in patient portals. Academic medical centers may need multifaceted interventions that improve the availability of bilingual staff and interpreters and also address caregivers' social and informational needs.

KEYWORDS: academic medical center; barriers to care; health information technology; Spanish-speaking

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WHAT'S NEW

Academic medical centers provide critical specialty care yet present access challenges for Spanish-speaking caregivers. Caregivers experienced multiple barriers amplified by language differences and identified opportunities for improvement, including more bilingual staff and information, care coordination, and attention to social needs.

CHILDREN IN SPANISH-SPEAKING families face many health care access barriers.¹ Latino children, including those in Spanish-speaking families, experience more delays

in care,² are less likely to have a usual source of health care compared with other groups,³ and receive fewer specialty referrals and testing.⁴ Once children in Spanish-speaking families obtain care, satisfaction with communication is lower than for English-speaking groups,⁵ and is reported to be less family-centered, as defined by principles that include respect and collaboration.⁶

Health care access barriers and communication experiences may contribute to disparities,⁷ and are therefore essential to understand. Access to pediatric academic medical centers is especially critical due to the high concentration of subspecialists serving publicly insured children⁸; yet, the size of these systems and the complexity of children's

health problems may magnify language and cultural barriers.⁹ Many pediatricians report feeling insufficiently prepared to care for children in immigrant families,¹⁰ including those who speak Spanish. Caregivers' education levels and functional/health literacy may further compound the challenges that Spanish-speaking families face. Patient perspectives on obstacles are important to understand to guide the design of interventions aimed at addressing them.

The aim of this study was to describe Spanish-speaking families' experiences as they accessed pediatric outpatient care in an academic medical center. We sought to identify language-related barriers and facilitators to care. The overarching purpose for obtaining caregiver perspectives was to guide the design and implementation of our patient navigation program for Spanish-speaking caregivers, which has been described previously.¹¹ A secondary aim of this study was to obtain information about experiences with health information technology (HIT) by families whose children require academic medical center care, with the goal of guiding optimal service provision.

METHODS

SETTING

This cross-sectional study took place at an academic medical center serving a state with one of the fastest-growing Spanish-speaking populations in the United States.¹² Recruitment occurred at the hospital-based pediatric outpatient clinics, which include multiple medical and surgical subspecialties, and provide tertiary care for children with chronic conditions. A minority of children receives primary care at this academic medical center; most are referred from outside offices. Spanish-speaking families comprise approximately 14% of the population served. Clinic staff includes attending and resident physicians, nurse practitioners, and nurses. Staff routinely uses an electronic messaging system to request interpreters for telephone and/or in-person communication with Spanish-speaking patients per Culturally and Linguistically Appropriate Services (CLAS) standards for communication.¹³ Bilingual staff members may communicate with patients in Spanish following demonstration of proficiency through formal assessment.

INTERVIEW GUIDE DEVELOPMENT

Qualitative research guidelines¹⁴ were used to structure study design and analysis. Semistructured interviews were conducted with Spanish-speaking adult caregivers who accompanied children to outpatient appointments. Interviews were designed to elicit in-depth sharing of experiences by caregivers. An interview guide was developed by the authors ([Supplementary Material](#)), who initially observed and diagrammed patient/caregiver flow through the medical center. Through process flow diagramming, the following steps in care were identified as potentially important: previsit phone communication, arrival/registration, communication with nurses and physicians during

visits, and postvisit follow-up. Open-ended questions were developed to inquire about barriers and facilitators during each of these steps. Optional probes clarified the extent and nature of barriers and facilitators. The interview guide was developed in Spanish.

A section of the interview guide was developed based on literature review of HIT use.¹⁵ Since existing literature suggested that patient portal use by Spanish-speaking patients was infrequent,¹⁶ the interview included a brief description of patient portals. Caregivers were asked about their opinions about patient portals, followed by probes about whether they would use a patient portal. Caregivers were also asked about their access to computers, the Internet, and smartphones. The interview included demographic information about caregivers (relationship to the patient, age, education level, place of origin, length of time in the United States), the household (number of people and children in the home, monthly income), and the patient/child (sex, age, diagnoses, number of medical center appointments, whether the child had ever been hospitalized, and number/type of specialists seen). The interview guide was pilot tested with 2 individuals and refined based on their feedback.

RECRUITMENT

Interviews were conducted between September and December 2016 by trained bilingual research assistants (1 male, 2 females) of Mexican, Peruvian, and US origin. Convenience sampling was used; interviewers reviewed clinic schedules and identified Spanish-speaking caregivers, based on preferred language recorded in the electronic medical record. Interviewers attempted to approach all potentially eligible caregivers consecutively on the days that they were available, and invited them to participate in a same-day, in-person interview before or after their clinic visits. Caregivers were informed that the purpose of the study was to understand care experiences for Spanish-speaking patients and guide interventions to improve their experience. Caregivers were excluded if their children had a medical emergency. To incorporate culturally relevant concepts of *familismo* into the interview process as much as possible, all adults accompanying each child were invited to participate in interviews, as described in similar qualitative work.¹⁷ Children and siblings were present during interviews if caregivers preferred. Each caregiver signed written consent to participate and was provided with \$20 compensation.

Interviews were audio-recorded and transcribed verbatim in Spanish. Interviewers made supplemental field notes. Interviews were continued until thematic saturation was reached. Caregivers of 23 children were interviewed, resulting in 28 adult participants. Average interview length was 21 minutes (range 15–30).

DATA ANALYSIS

The analysis was conducted in Spanish using Dedoose (version 4.7, SocioCultural Research Consultants, Los Angeles, Calif). Thematic analysis was used because of its

potential for providing insight into caregivers' thoughts, experiences, and identifying themes and patterns.¹⁸ The analysis was led by an experienced qualitative researcher (C.T.). Three transcripts were read and independently coded by 2 coders (K.B.F. and C.R.). Codes were used to create an initial codebook and were created in 2 ways: 1) a priori codes reflected the researchers' original questions and interview guide; 2) coders identified emerging codes. The codebook was reviewed by the 3 researchers, discussed, and refined to create a final codebook that included groupings of codes (subthemes). Remaining transcripts were read and coded by both coders; differences were discussed and adjudicated. Illustrative quotes were selected for each theme and subtheme and were forward and back-translated by bilingual members of the research team. Translation differences were adjudicated until consensus was achieved.

The study received Institutional Board Review (IRB) approval at the University of North Carolina at Chapel Hill.

RESULTS

The majority of caregivers (79%) were mothers with a median age of 34 years (Table 1). A minority (13%) had attended college, and 22% had less than a seventh-grade education. Half (52%) were born in Mexico with most of the remainder from El Salvador, Guatemala, and Honduras. Caregivers had lived in the United States for a median of 14 years. Median annual household income was \$18,720; median household size was 5, with 3 children. For 22%, the interview occurred on the day of the child's first clinic visit; 39% had more than 30 visits, and 57% of children had ever been admitted to the hospital. Caregivers most commonly reported appointments with the following specialists: neurology, gastroenterology, pulmonology, urology, endocrinology, and multidisciplinary feeding team (part of the gastroenterology division). The most common pediatric chronic conditions included seizures and other neurologic problems, genetic disorders, kidney disease, pulmonary fibrosis and other lung conditions, allergies, feeding difficulties, gastritis, and liver disease (not shown in Table).

LANGUAGE-SPECIFIC BARRIERS TO CARE

Caregivers overwhelmingly described language-related barriers as the main challenge in seeking care (Table 2). Many caregivers acknowledged the predominance of language barriers in statements such as "Pues las barreras es lo primero el idioma" [Well, the barriers, first of all, it's the language]. Caregivers indicated that language barriers interfered with care at multiple time points, including during previsit communication, on arrival at the clinic, and in obtaining recommended follow-up.

Several themes were identified as caregivers discussed language-related barriers to care (Table 2). Caregivers perceived that many steps in arrival and registration were conducted in English and that a lack of English proficiency complicated seeking care. A second theme was a

Table 1. Characteristics of Spanish-Speaking Caregivers and Children (n = 28)

Characteristic	N (%) / Median (Interquartile Range)
<i>Caregiver characteristics</i>	
Caregiver role	
Mother	22 (79)
Father	4 (14)
Friend	2 (7)
Caregiver age (y), median (interquartile range)*	34 (8)
Caregiver education level*	
6th grade or less	5 (22)
7th–8th grade	6 (26)
9th–12th grade	9 (39)
Some college	3 (13)
Caregiver country of origin*	
Mexico	12 (52)
Guatemala	4 (17)
El Salvador	3 (13)
Honduras	2 (9)
US/Puerto Rico	2 (9)
Number of years in US, median (interquartile range)*	15 (6)
<i>Household characteristics</i>	
Number in household	5 (3–7)
Number of children in household	3 (1–5)
Annual household income, median (interquartile range) (\$)	18,720 (11,400)
<i>Child characteristics</i>	
Child sex	
Female	9 (39)
Male	14 (61)
Child age, years, median (interquartile range)	10 (8)
Number of appointments for child at medical center	
First appointment	5 (22)
2 to 5	5 (22)
6 to 30	4 (17)
Greater than 30	9 (39)
Child ever admitted to hospital	13 (57)
Specialty services involved in child's care	
Neurology	6 (26)
Gastroenterology	4 (17)
Pulmonology	3 (13)
Endocrinology	3 (13)
Urology	3 (13)
Feeding team	3 (13)
Nutritionist	3 (13)
Other†	13 (57)
<i>Health information technology access and interest</i>	
Access to computer/tablet	15 (65)
Access to Internet at home	20 (87)
Access to smartphone	20 (87)
Interest in patient portal	19 (83)

*Questions were asked only of adult identifying as primary caregiver; n = 23 for these items.

†Caregivers also reported the following specialty care for 2 or fewer children: orthopedics, rehabilitation medicine, otorhinolaryngology, genetics, dermatology, allergy, nephrology, speech therapy, physical therapy, audiology. Total >23 specialty services because caregivers reported all applicable services and most children had >1 service involved.

lack of sufficient bilingual personnel. This was emphasized by caregivers in areas such as reception and check-

Table 2. Language-Related Barriers to Care for Spanish-Speaking Families

Type of Barrier and Illustrative Quotes	
Arrival and registration steps occur in English <i>"The only thing is that I speak Spanish and they are giving me something in English and I'm not going to understand very well what they're saying to me."</i>	"Solamente es como que yo hablo español y me están dando algo en inglés yo no voy a entender tanto lo que me están diciendo."
Lack of bilingual personnel <i>"Yes, they need to have someone there who speaks Spanish in the check-out area because not everyone speaks English."</i>	"Sí, necesitan tener una persona acá que hable español en la oficina de "check out" porque no todas las personas hablamos inglés."
Heavy reliance on interpreters <i>"...because when the interpreter leaves I can't say anything anymore, the doctor doesn't understand me and I don't understand the doctor either, so I have to be really sure that the interpreter is there so we understand each other."</i>	"...porque ya cuando el intérprete se vaya no puedo yo decirles nada, ni el doctor me entiende ni yo entiendo al doctor, por eso tengo que asegurarme bien que esté el intérprete ahí para que nos entendamos."
Long wait times <i>"Another person had to wait because the interpreter's office has a lot of work, too much, so then they make us wait a long time. Today I had to wait, I think, an hour and a half to have one come."</i>	"Ahí se tardó otra persona porque la oficina de las personas de traductores tienen mucho trabajo, demasiado, entonces nos hacen esperar mucho. Hoy me esperé creo hora y media para que llegara uno."
Challenging telephone access <i>"Well, no, the truth is, I don't have any complaints, only that sometimes when I've called [in Spanish], they don't answer quickly and there's a delay...or they say 'leave your name, your birthdate, and we'll return your call' and they don't return it, so you go back to calling again and they don't answer."</i>	"Ah, no, pues la verdad no tengo ninguna queja, solamente que cuando a veces he llamado, no contestan rápido y demoran...o dice 'deje su nombre, su fecha de nacimiento y nosotros regresamos la llamada' y no la regresan, ahí vuelve a llamar otra vez uno y no le contestan."

out. Caregivers described a heavy reliance on interpreters for communication, with most acknowledging the value and importance of interpreters, but also describing how this reliance placed limits on their ability to communicate with health care personnel. Some caregivers expressed wishes for more direct communication than was possible through an interpreter. Many caregivers described long wait times due to language-related needs. Caregivers emphasized the importance of medical interpreters, while at the same time describing a long wait for service. Some described observing a heavy workload for medical interpreters serving a large number of Spanish-speaking patients. An additional theme was challenging telephone communication. Caregivers described a variety of challenges communicating by phone before and after visits, including that communication with health care providers was indirect due to the need to contact an interpreter first.

NON—LANGUAGE-SPECIFIC BARRIERS TO CARE

Children's caregivers described multiple barriers in addition to language that affected obtaining health care (Table 3). Many caregivers described how these barriers compounded those due to language differences. For some caregivers, the size and complexity of pediatric clinics located at a tertiary medical center were challenging, particularly during initial visits. Distance to the clinic from their home was a barrier for some caregivers and negatively impacted appointment attendance.

Caregivers described several other aspects of tertiary medical center care as challenging, including that frequently appointment times were not convenient and for those who needed to see multiple providers, not coordinated. Some caregivers described that physician availability limited the ability to schedule appointments on the days they preferred

and that having appointments on different days was difficult. Caregivers also described missing work and school as potential challenges to appointment attendance and had to manage missed work time to minimize the financial impact of absences. Despite acknowledging numerous challenges that they had to navigate, caregivers indicated a strong commitment to overcome them in order to obtain care for their children; as one said, "but then I started thinking that family is first, so I think that it's worth it to lose a day of work to go to the hospital."

In addition to the impact of missed work time, caregivers described other financial barriers to care, including medication costs and insurance coverage. For children covered by Medicaid, some caregivers still faced high medication copayments and delays in obtaining medication. Insurance coverage was linked to another theme described by some caregivers: lack of citizenship status for all household members. One caregiver expressed concern that financial assistance to noncitizens could be jeopardized: "Well, you have to stay positive but hope that the hospital won't ever take more drastic measures for people with few resources, or people who don't have identification from this country, and that's the only thing I personally hope."

Language barriers intersected with non-language barriers to amplify access challenges (Table 4). For example, caregivers described difficulty making appointments in person and lack of understanding of Spanish names by staff, which complicated registration processes. One caregiver described difficulty navigating a large hospital, which was compounded by being unable to find Spanish-speaking staff to help.

Caregivers described employing a variety of strategies when encountering language differences (Table 5). While many caregivers described that hospital staff called interpreters, some proactively requested interpreters themselves

Table 3. Non–Language-Specific Barriers to Care for Spanish-Speaking Families

Type of Barrier and Illustrative Quotes	
Size and complexity of hospital “At first it was difficult...simply because it’s big...”	“Al principio fue difícil...simplemente porque es grande...”
Distance “...since I live far away, I live almost 4 hours from here, and so when I get to the pharmacy where I live, sometimes they’re already closed and I can’t pick up [medications] that day until the next...”	“...como vivo lejos, yo vivo casi son cuatro 4 horas de aquí, y pues cuando llego a la farmacia donde yo vivo a veces ya cerraron y yo no las recojo ese día hasta el otro...”
Appointments not convenient “The doctors, some doctors work some days, some doctors work others, and it’s difficult to make the children’s appointments.”	“Los doctores, unos doctores trabajan unos días, unos doctores trabajan otros y es difícil hacer las citas de los niños.”
Multiple appointments not convenient or coordinated “Because then the person there [at reception] wants to give us an appointment...well, we try to make the appointments for our children on the same day so that we’re not coming and going twice a week...And she says that there’s not space or that they can’t do it...”	“Porque luego la persona que está ahí nos quiere dar la cita...o sea tratamos de tener las citas con nuestros hijos el mismo día para no estar yendo y viniendo dos veces por semana... Y ella dice que no hay lugar o que no se puede...”
Missing work “...and then if there were space to open up an appointment on the day that you want, because maybe today their father missed a day of work to come with me, whereas if it had been a Friday he wouldn’t have missed a day of work.”	“.. y también que si hubiera espacio para abrir una cita en el día que uno la quiere porque por lo menos hoy el [padre] perdió su día de trabajo por venir conmigo mientras que hubiera sido un viernes, no hubiera perdido su día de trabajo.”
Missing school “Sometimes yes, I can make it to all the appointments, but sometimes they tell me, for example, that there are several days that I have to come, and that’s difficult because my daughter has to miss several days of school, or my son, and they have already missed days.”	“A veces sí puedo hacer todas las citas, pero a veces me dicen que como por ejemplo van a ser varios días los que yo tengo que venir y es difícil porque mi hija tiene que perder varios días de escuela o mi hijo y ya son faltas que tiene.”
Financial and insurance coverage “Well, there have been really expensive medications and we’ve had problems with Medicare where they don’t want to give them to us, but finally the doctor always gives them the authorization they need.”	“Pues ha habido medicinas que son muy costosas y hemos tenido problemas con Medicare que no nos lo quiere dar, pero siempre al último la doctora da su autorización que lo necesita.”
Lack of citizenship for all household members “We’ve already been living here in North Carolina for fifteen years. My son was born in Mexico, my daughter was born here and is a citizen, and it’s difficult to obtain everything that my son needs...My son doesn’t have insurance, he wasn’t born here.”	“Ya tenemos quince años viviendo aquí en North Carolina. Mi hijo nació en México, mi hija sí nació aquí es ciudadana y pero es difícil obtener todo lo que mi hijo necesite... Mi hijo no tiene seguro, él nació fuera de aquí.”

and prepared their questions ahead of time to make best use of interpreter time, saying for example, “Yes, normally when we arrive, my wife and I ask that someone interpret for us, because it’s the health of my son and we want everything to be one hundred percent.” Caregivers also described developing confidence and skills as they gained experience with the medical center and with their children’s conditions. Several caregivers reflected that although initial visits were difficult, becoming accustomed to new systems made visits easier.

Caregivers relied upon several strategies to overcome the communication barriers they faced due to language differences (Table 5). Several caregivers described using their limited English skills to facilitate obtaining care and improving those skills. Caregivers also described using patients or family members to communicate. Finally, some caregivers recollected that pretending to understand completely was a strategy employed when encountering language differences.. One caregiver recounted, “There are times that I ‘ok, ok’ even though I didn’t understand anything.”

In addition to the strategies that they employed, caregivers described aspects of the health care system that facilitated their communication and experiences (not shown in Tables). One theme expressed by most caregivers was that interpreters were highly valued: “With the interpreter yes, everything is very good, I knew who was

the nurse, the doctor, what I needed to say, my concerns, what was happening, and all of that.” Many caregivers also highlighted the importance of bilingual physicians and staff: “the language, that hasn’t been any problem because they speak Spanish very well, the two doctors.” Some caregivers described written communication in Spanish, such as after-visit summaries, as helpful in managing their children’s care: “Well, for me it’s good, because in the paper that they give you they put a summary of the appointment, instructions, how to take the medicine and all of that.”

When asked about communication and health information technology, 65% of respondents indicated they had a computer/tablet, 87% had home access to the internet, and 87% had access to a smartphone (Table 6). Most caregivers were not familiar with patient portals for communication with health care providers, but when they were described, 83% indicated interest in using patient portals for health care communication. Some caregivers indicated that their internet access was limited or that they depended upon others for help. Caregivers described widespread smartphone access and usage; as one acknowledged, “The whole world already lives through their cellphones.” Several caregivers noted that patient portals would only be useful to them if available in Spanish. Caregivers also noted that the quality of translated materials varies, and that country of origin may affect comprehension. A few

Table 4. Intersection of Language and Non-language Barriers for Spanish-Speaking Families

Examples of Intersecting Barriers and Illustrative Quotes	
Difficulty obtaining appointment times due to communication challenges <i>"I have one day, the 18th, and another day, and they don't give me more choices [in person], but if I call by phone they tell me that they'll look for the day and time that I want."</i>	"Tengo un día el 18 y otro día y no me da más opciones [en persona], pero si yo hablo por teléfono me dicen que me buscan el día que quiero y a la hora que quiero."
Navigating large hospital size complicated by language barrier <i>"Well, the first times, yes, it was difficult if you'd never come to a big hospital and didn't know the language and didn't know where to go, and we had to ask several times, and the people who are there to give information don't have any Hispanic staff."</i>	"Pues las primeras veces sí fue difícil si uno no había venido nunca a un hospital grande y no sabía el idioma y no sabía a donde ir y tuvimos que preguntar varias veces y los que están aquí para dar información no hay personal hispano."
Difficulty completing check-out process due to language and culture differences <i>"...my point of view is, since people don't know Hispanic names sometimes they say "What? How do you say that?" It's the only thing that's a little strange, you tell them two or three times, and "What?" you have to show them the paper."</i>	"...mi punto de vista es, como la gente no conoce los nombres hispanos a veces dicen '¿Cómo?, ¿Cómo dices?' Es el único punto que se hace raro, les dices dos o tres veces, y '¿Cómo?,' tienes que enseñarles el papel."
Language barrier magnifying challenges to telephone access <i>"Well, it's difficult because I have to call to ask for an appointment and I ask for someone in Spanish and there isn't anyone. I have to leave a message for the interpreters and later they call me at the end of the day or another day."</i>	"Pues, difícil porque es, yo tengo que llamar para pedir una cita y pregunto por alguien en español y no hay, tengo que dejar mensaje para los intérpretes y después ellos me llaman al final del día u otro día."

caregivers expressed reservations about the confidentiality of health information technology.

DISCUSSION

This cross-sectional study identified barriers/facilitators of health care among Spanish-speaking caregivers of children served at an academic medical center. Compared with other centers, this population had a large proportion of admissions and chronic conditions, reflecting the complexity of children served. Spanish-speaking caregivers in this study described working hard to obtain care for their children with complex needs. They described confronting language-related barriers, which were often compounded by non-language-specific challenges such as work,

school, transportation, and financial costs. Caregivers navigated these obstacles despite relatively low levels of formal education and household earnings. The intersection of barriers described by caregivers reinforces previous findings that language differences affect caregivers' ability to manage children's complex health conditions⁹ and that tangible barriers such as lack of transportation complicate health care access for children of Spanish-speaking caregivers.¹⁹

Caregivers identified formal medical interpreters as highly important in their children's health care. Though multiple studies have emphasized the importance of medical interpreter use for high-quality care,²⁰ the family voices in our study highlight some ways in which interpreter use may constrain communication. Sufficient interpreter

Table 5. Strategies Employed by Families When Encountering Language Barriers

Strategies Used by Families and Illustrative Quotes	
Requesting interpreters <i>"If I need to make another appointment, I need to call an interpreter to do everything because if not, I don't understand anything."</i>	"Si necesito hacer alguna otra cita tengo que yo llamar un intérprete para hacer todo eso porque si no, no entiendo nada."
Prepared questions ahead of time to make best use of interpreter time <i>"Well, the doctors, I write notes on a piece of paper about everything I'm going to ask them, everything that I need to tell them so that I don't forget anything while the interpreter is there."</i>	"Pues los doctores, yo apunto en una hoja todo lo que voy a preguntarles, todo lo que tengo que decirles para que no se me olvide nada mientras está el intérprete ahí."
Becoming accustomed to new systems <i>"With the help of the interpreter... those numbers, the fever... when you come from a different country, the measurements are different, the whole blood pressure check is different, everything is managed differently there... now I understand it."</i>	"Con la ayuda del intérprete... esos números, la fiebre... como uno viene de un país diferente, que las medidas son diferentes, que todo ese chequeo de presión es diferente, todo se maneja diferente acá, ahora ya lo entiendo."
Using limited English skills <i>"Well, for me it was fine because I speak a little English, but it's important that maybe there was someone for the people who don't speak any English to complete their appointment."</i>	"Bueno para mí fue bien porque yo hablo un poco de inglés pero si es importante que quizá hubiera alguien para las personas que no hablan nada de inglés para realizar su cita."
Using patient or family member to communicate <i>"My daughter is the one who speaks for me, although I don't like it because I would like to say things for myself."</i>	"Mi hija es la que habla por mí... aunque no me siento a gusto porque a mí me gusta decir las cosas 'yo.'"
Pretending to understand completely <i>"...Sometimes, sometimes you... you act like you understand... So that they don't have to ask you again."</i>	"...A veces, a veces uno... uno hace como entiende... Para que no tengan que preguntarle de nuevo."

Table 6. Access to and Experiences With Health Information Technology

Respondents With Health Information Technology Access		Illustrative Quotes
<i>Access to computer/tablet</i>		
Limited/difficult computer access	<i>"I don't have a computer but I have a tablet and a phone and access to the Internet."</i>	<i>"Eh computadora sí no tengo pero sí tengo tableta y el teléfono y acceso a internet."</i>
<i>Access to Internet at home</i>		
Limited internet access	<i>"No, no, it's that I don't have internet at home yet, it doesn't work where I live."</i>	<i>"No, no es que no tengo internet en la casa todavía no llega hasta allá la internet donde yo vivo."</i>
Depend upon others for help	<i>"Um, well, the truth is that I don't even like to use the Internet, so I have my kids do it."</i>	<i>"Uhm, pues la verdad ni siquiera me gusta meterme al internet, pero pues pongo a mis hijas."</i>
<i>Access to smartphone</i>		
Smartphone provides good internet access	<i>"No, for me it's not difficult on my phone, I have internet and I come here [to the hospital] and I use the internet here also."</i>	<i>"No, para mí no es difícil porque en mi teléfono tengo internet y llego aquí y se me activa el internet de aquí también."</i>
Smartphone has limited internet connection	<i>"...the internet on my phone isn't very strong."</i>	<i>"...el teléfono internet no es muy fuerte a mi teléfono."</i>
<i>Interest in patient portal</i>		
Most initially unaware of patient portal	<i>"Well, the truth is that I haven't heard of that program [patient portal], I don't know..."</i>	<i>"Ah pues la verdad no he oído de ese programa, no sé..."</i>
Patient portal perceived as useful	<i>"Yes, it [patient portal] would be good because I see that sometimes there are a lot of people that don't have time to call and all that, so sending a message or email is much better now that the technology is more advanced."</i>	<i>"Si estaría bien porque veo que a veces hay mucha gente que no tiene tiempo de llamar y todo eso entonces por medio de enviar un mensaje o un email es mucho mejor porque ahora ya la tecnología está más avanzada."</i>
Positive experiences with patient portal	<i>"Yes, whenever I've made appointments I haven't had a problem, I always send a message to the doctor through the UNC chart and she answers and makes us an appointment, or she calls us personally."</i>	<i>"Sí, siempre las hecho las citas no he tenido problema. Siempre le mandamos un mensaje a la doctora por el UNC chart, y ella contesta y nos programa la cita, o personalmente la doctora ella nos hablaba."</i>
Patient portal only useful if in Spanish	<i>"Well yes, if it's in Spanish that's perfect, but if it's not in Spanish, then no, I don't know, it wouldn't help me."</i>	<i>"Pues si está en español está perfecto, pero si no está en español pues no, no sé, no me sirve."</i>
Quality of translated materials limited	<i>"For those that don't speak English, in Spanish it [patient portal] would be fantastic. What happens is that sometimes the translations from English to Spanish in the computer are really, well, they sound phony."</i>	<i>"Para los que no hablan el inglés, en español sería fantástico, lo que pasa es que las traducciones la mayoría de las veces las traducciones de inglés a español en computadora es muy como, se oye 'phony'."</i>
Concern about privacy and confidentiality	<i>"I would worry about privacy because I already see that what you put on the Internet, any person can hack sometimes..."</i>	<i>"Me preocuparía acerca de la privacidad porque ya veo que lo que pone en internet cualquier persona lo puede 'hackear' a veces..."</i>

supply is a widespread issue,²¹ leading to efforts to increase interpretation options and improve utilization.²² After this study, similar interpreter availability improvement initiatives were undertaken in the center studied and may be needed in other centers facing similar challenges. Increasing the number of certified bilingual health care personnel and building the workforce pipeline are additional strategies for increasing the language capacity of health care institutions.²³

We used the barriers identified by caregivers to design a bilingual patient navigation intervention to improve communication.¹¹ For example, caregivers described "getting by" through using limited English proficiency skills²⁴ in initial communication, such as appointment scheduling. Since misunderstanding during these communications can delay care, patient navigation addresses points where caregivers described challenges, including check-in, nursing triage, and appointment scheduling. To respond to caregivers' observations that few Spanish-speaking staff were available, navigators were assigned to circulate and solicit questions. Responding to caregivers' experiences that hospitals were large and unfamiliar, navigators began greeting patients and

accompanying them throughout their visits. Since caregivers indicated that language often amplified other barriers, navigators provide broad support to families, including assisting families through financial counseling and connecting to resources for parking and food. By addressing intersecting barriers to care, patient navigation that was designed in response to these caregiver interviews was associated with improved appointment attendance and satisfaction.¹¹

Spanish-speaking caregivers in this study often found written communications in Spanish helpful, including after-visit summaries (AVS). Since AVS became an expectation tied to meaningful use of electronic health records,²⁵ they have become ubiquitous, yet relatively little has been published about patient perspectives on their usefulness.²⁶ Caregiver perspectives on AVS, and other written instructions in Spanish suggest that close attention is needed to translated written information; translation quality varies, and due to heterogeneity in country of origin and culture, comprehension of written materials may vary. Based on caregivers' perspectives in this study, low-literacy adapted AVS in Spanish may be an accessible tool for supplementing verbal instructions.

Technology use, access to the internet, and interest in patient portals were high in this study population, mainly through cellphones. HIT increasingly represents an additional avenue for Spanish-speaking caregivers to communicate with health care personnel. Access to HIT is increasing rapidly,²⁷ yet the potential for a digital divide remains^{15,16,28} and could exacerbate existing health disparities. For example, prior studies demonstrate that Latinos are less likely to use the internet for health care than non-Latino populations.¹⁵ Nevertheless, in our sample, there was widespread internet access, and high levels of interest in patient portals, similar to previous reports of interest in electronic communication with health care providers.²⁷ It is difficult to know whether caregivers' reported interest in patient portals would result in utilization, since overall rates of patient portal use in children's hospitals have been low,^{29,30} particularly among individuals with limited English proficiency.²⁹ However, given the interest in patient portals among caregivers in this study, it appears worthwhile to ensure availability in Spanish. To make patient portal functionalities fully accessible, processes for responding to messages in Spanish are also needed. In addition to patient portals, HIT use has the potential to bridge communication gaps experienced by caregivers in this study. For example, providing electronic tablets and health literacy information increased health knowledge,³¹ and text messaging interventions are associated with reduced pediatric emergency room utilization and increased influenza vaccine uptake among infants of Spanish-speaking caregivers.³² As noted previously, bridging the digital divide will likely require multiple HIT strategies by health care organizations to meet the needs of patients with limited English proficiency.²⁸

Limitations of this study include that, as a qualitative study, it contributes to understanding of the particular experiences of a specific group of people. Given the heterogeneity of Spanish-speaking populations across the United States, barriers may differ in other regions with different immigration histories. However, given that caregivers in this study described barriers that are similar to those in quantitative national studies,³³ many caregivers' experiences are likely shared. Additionally, this study primarily addressed specialty care experiences within an academic medical center; data were not collected on where children received primary care, and caregivers' perceptions may not reflect primary care. Many other aspects of health care communication are important but were not included. These include caregivers' communications with pharmacies, home health companies, and equipment suppliers, and caregiver health literacy levels, all of which would be important for future study, because of their contribution to comprehensiveness and quality of care experienced by children and their families.

Many academic medical centers seek to reduce language-related disparities in care and improve experience for children and their caregivers. Multilevel interventions may be necessary to address language-related barriers to care. Profound improvements in health care processes and outcomes can be attained when language-related barriers

are addressed, such as a reduction in pediatric intensive care mortality following a linguistically and culturally appropriate bundle of interventions.³⁴ Prior initiatives have also expanded the use of telephonic interpretation to increase access.²² Additionally, care coordination, which is paramount to minimize the impact of missing work and optimize clinic attendance, was increased in the center studied through care managers. Most recently, institutional solutions have addressed the HIT needs of Spanish-speaking patients to mitigate the impact of a growing digital divide,²⁸ including increased materials and assistance in Spanish with patient portal and telehealth use. Since these interviews, our monthly monitoring of patient portal activation has revealed a widening disparity between Spanish- and English-speaking caregivers, suggesting persistence of the barriers described by caregivers in this study. As a result of the interest caregivers described in patient portals and HIT, we are building on the existing bilingual patient navigation program¹¹ to evaluate whether patient portal access can be facilitated by navigators (ClinicalTrials.gov Identifier: [NCT04410380](https://clinicaltrials.gov/ct2/show/study/NCT04410380)).

After this study, COVID-19 emerged and has disproportionately affected Latino families, underscoring the urgency to address disparities and ensure adequate access and communication for Spanish-speaking caregivers.³⁵ Crossing communication divides between Spanish-speaking caregivers and academic medical centers may require innovative strategies that combine personnel and technology, and that evolve to meet the changing needs of children and their caregivers.

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SUPPLEMENTARY DATA

Supplementary data related to this article can be found online at <https://doi.org/10.1016/j.acap.2020.10.008>.

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