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Decreasing health disparities for children with asthma and their families: Conceptualizing cultural weaving & identifying the cultural characteristics of a head start organization in the United States

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ABSTRACT

The overall purpose was to identify cultural competency characteristics of a community organization and its staff in caring for chronically ill children from diverse backgrounds. The study used a qualitative design to explore the elements of cultural values and beliefs within the context of a Head Start organization that cares for chronically ill, low income children. A small convenience sample of organization employees provided demographic data, completed cultural competency assessment instruments and participated in focus groups. Qualitative data were analyzed first coding and identifying themes related to cultural values and belief of the individuals who manage a local Head Start. The results indicated previous experience influences the working with diverse populations. Whereas the socialized culture had a greater effect on working with diverse groups of children and their families. Although there is a need to provide knowledge on communicating with diverse population of children and families, importantly the past beliefs and values have a powerful effect on the ability to working with diverse population. Nurses need to be more involved in the community and provide educational training on cultural diversity to various organizations. The training should include the personal values and beliefs. In addition, there is the need for the nurses to provide health care training to community organizations on management of chronically ill children in their care. The findings support the benefits of cultural competency training for all those who care for children from diverse backgrounds with health problems.

Introduction

Cultural weaving is a phenomenon that has drawn researchers to explore the significance of health disparities among diverse populations. A health-care organization may influence disparities in health and health outcomes among specific populations by providing accessible health care in remote communities or to under-served populations in suburban and rural areas (Major, McQuistan, & Qian, 2016). This improved access has a positive effect on children's health outcomes. Moreover, organizations not typically

viewed as health-care providers may contribute to reversing health disparities by providing accessible health services. Children with chronic illness, such as asthma, spend most of the day outside the healthcare setting, usually in school and/or other environments. Such environments may be an after-school program, community center, YMCA or an organization such as Early Health Start and Head Start. Early Head Start and Head Start started in 1965 to provide catch-up for low-income children and expanded in 1981 to children in poverty. Head Start is the longest running program that provides access to health and nutritional aid for children in poverty. Head Start in certain communities also provides after-school programs for siblings of the child that attends Head Start. These older children may stay until the parent returns from work to pick up all children, ones in Head Start and after-school programs. Although there has been an interest how organizations like Head Start affect the health of children with acute and chronic illnesses, little is known about how such an organization affects health disparities among children with asthma from diverse populations. For years, Children in the public-school system have had access to food and health services such as school-based health centers or the school nurses. In the 1852 Saint Elizabeth's Hospital (Known now as Dorothy Dix in North Carolina) created by Act of Congress for the insane to link health services to individuals who otherwise had limit access specifically military individuals and their families (cite). In May 1967 Howard University was established as a place for Negroes education. It was not until the 1950s that there was a specific interest to link health services for children and farm families in remote areas (cite). For years in the United States organizations such as Health Departments, Head Start Programs, and School-Based Health Centers have implemented "*culture weaving*" to eliminate the disparities. These organizations have reached rural, suburban, and urban areas where there was limited access for immunizations, medications and/or healthcare provider for improving health outcomes for low-income children and their families. Cultural weaving has been defined as the integration of culturally competent organizations which provides pathways toward assessable health care. Intergenerational programs have demonstrated to be an advantage for young children as a few researchers found in the public-school systems in 1988. In summary, how do community organizations other than health organizations influence health disparities among low-income populations of chronically ill children?

Culture provides a lens through which caregivers, including low-income urban and suburban African American and Latino caregivers, perceive their environment and assess safety for their children with asthma (Arcoleo, Zayas, Hawthorne, & Begay, 2015; Coutinho, 2013; Dowell, 2015; Sato et al., 2013). Cultural weaving has been defined as the integration of culturally competent organizations which provides pathways toward accessible health care (National Center for Culture Competence, 2007; Olsen, Scholderer, Brunso, & Verbeke, 2007; U.S. Department of Health and Human Services OPHS Office of Minority Health, 2001; Wu & Martinez, 2006). Hamilton et al. (1999) found, in 1988, that intergenerational programs in public school systems provide an advantage for young children (Hamilton et al., 1999). Intergenerational programs are the pre-school programs. These programs provide are a part of the cultural weaving phenomena that may have influence and may accessible health services and nutrition. Others researchers identify cultural weaving as creating a path for resources (Boyle, Bunting, Hodnicki, & Ferrell, 2001). Thus, school-based

health centers with a health-care provider may create a path to a medical home, which low-income children often lack.

While a definitive definition on cultural responsiveness is difficult to parse out, the literature clearly indicates that there are two main trends with cultural competence; 1) individual level and 2) organization level (Horevitz, Lawson, & Chow, 2013). Originally, Cross, Bazron, Dennis, and Isaacs (1989) defined cultural competence or responsiveness as knowledge, interpersonal skills, and behaviors that enable a system, organization, program, or individual to work effectively across cultures by understanding, appreciating, honoring, and respecting cultural differences and similarities within and between cultures (Cross et al., 1989). The construct, "*cultural weaving*", has been operationalized as a path toward the understanding of culture and subsequent incorporation of behaviors and practices to provide accessible healthcare (Campinha-Bacote, 2009; Horevitz et al., 2013). In conclusion, establishing pathways to fewer health disparities and better health for increasingly diverse populations of low-income children may be facilitated by training on cultural responsiveness.

The prevalence of Childhood Asthma, the most common chronic disease and the leading cause of morbidity from chronic disease as measured by school absences, emergency department visits, and hospitalizations has steadily increased (Pedersen et al., 2011). Over the past 10 years, there has been great effort to improve health outcomes of low-income African American and Latino children with asthma. Intervention research has been limited in the literature of cultural responsiveness training for community providers that are not health-care providers of children with asthma and the positive effect on the quality of life for these children and families (Changoor et al., 2017). The overall purpose of this mixed methods study was to explore culture competence or responsiveness characteristics and the predictors of cultural responsiveness among the staff at a local community Head Start that cares for chronically ill children from diverse backgrounds.

Although prior studies have revealed training in culture diversity for the health-care professionals, our study was to focus on non-health care professionals who are exposed to children with chronic illness. For this study, we explored strategies used by the staff and examined how their personal values and beliefs influence their decisions in caring for children with chronic health problems. The proposed aims were: Aim 1. To determine the predictors for cultural competence and/or responsiveness of individual staff members within a local Head Start program that cares for chronically ill children. Aim 2. To explore a few predictors of the cultural competence and/or responsiveness within an organization delivering health services. Aim 3. To determine if there is a difference between self-report in written instruments and actual self-reported behaviors in the delivery of health services to chronically ill children as described in focus groups.

Method

This study design was mixed methods to explore the elements of cultural values and beliefs within the context of a local Head Start organization that provides health services to children ages 0–5 with chronic health problems. An exploratory sequential mixed methods approach was to have staff from a local Head Start identify their cultural characteristics and explain how their own beliefs and value affects their ability to work with diverse groups of children (Creswell, 2015). We used the qualitative arm to confirm the cultural characteristics more in depth. Approval for this pilot study was obtained from The Ohio State University

Institutional Review Board (IRB). Participants were drawn from a large child development center in central Ohio. The child development center, also known as a Head Start program, is a nationally recognized leader in providing a variety of services to children and their families from different backgrounds. The organizational structure consists of 16 freestanding centers and multiple community partnerships. More than 2,988 children from different racial and ethnic backgrounds are served by this organization. The Head Start program provides day care services for children 0–2 and pre-school education for children 3–5. Children, who have chronic health problems and/or acute illness receive care, including medications and other needed treatments, while at the center as shown in Figure 1 demographic of the different types of illnesses and Table 1 breakdown of illnesses related to race and/or ethnic groups.
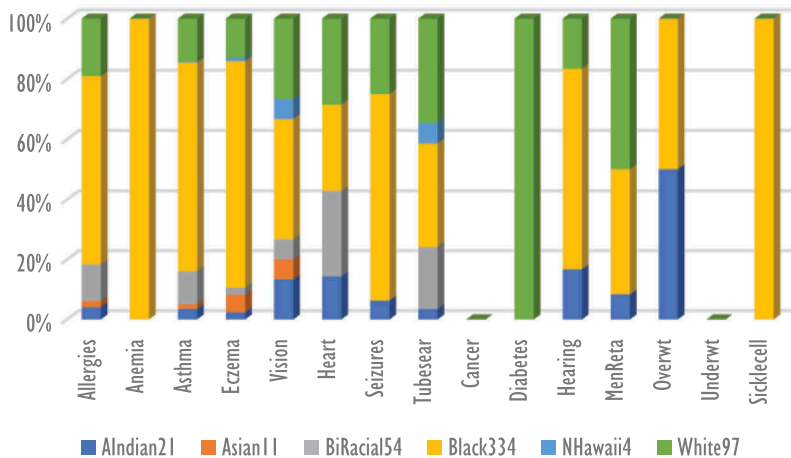

Figure 1. Franklin County Early Head Start & Head Start Demographics.

Table 1. Number children with chronic health problems by race & ethnic groups.

V1	AIndian21	Asian11	BiRacial54	Black334	NHawaii4	White97	Total
Allergies	6.0	3.0	18.0	92.0	.0	28.0	147.0
Anemia	.0	.0	.0	7.0	.0	.0	7.0
Asthma	9.0	4.0	29.0	181.0	1.0	37.0	261.0
Eczema	2.0	5.0	2.0	64.0	1.0	11.0	85.0
Vision	2.0	1.0	1.0	6.0	1.0	4.0	15.0
Heart	1.0	.0	2.0	2.0	.0	2.0	7.0
Seizures	1.0	.0	.0	11.0	.0	4.0	16.0
Tubesear	1.0	.0	6.0	10.0	2.0	10.0	29.0
Cancer	.0	.0	.0	.0	.0	.0	.0
Diabetes	.0	.0	.0	.0	.0	1.0	1.0
Hearing	1.0	.0	.0	4.0	.0	1.0	6.0
MenReta	1.0	.0	.0	5.0	.0	6.0	12.0
Overwt	1.0	.0	.0	1.0	.0	.0	2.0
Underwt	.0	.0	.0	.0	.0	.0	.0
Sicklecell	.0	.0	.0	8.0	.0	.0	8.0

Overweight = Overwt Underweight = underwt Mental Retardation = mentreta Tubes in the ears = tubesear
Note. Child Development Data.
These include the study demographics.

Sample

Study participants, staff of the Head Start, function in a variety of roles within the organization. The demographics for the Head Start staff participants for this study Figure 2. The roles of the participants in this study reflected multiple levels of management such as directors, teachers, and other staff positions as shown in Figure 2.

Procedure

Recruitment occurred in a three-step process. In Step 1, the PI and the Chief Executive Officer and Director of the center met to discuss the project. Next, the Center Director assigned a liaison to assist both in focus-group recruitment and collection of data from the different centers. Finally, in Step 3, Project packages were distributed to freestanding and partner centers. Packages included information about the study, a letter inviting participation in the study and information about when [date and time] and where the two focus groups were to take place. Interested staff notified the liaison who in turn, contacted the PI. Project participation was voluntary. The inclusion criteria were that the participants were English speaking, 21 years of age and older and had contact with the families of children with asthma and/or reactive airway disease within the past year. Participants received an honorarium for participation. Twenty-one community Head Start employees constituted the final sample size for this study (N = 21).

Once we met with the study participants, we established times and dates for the focus group meetings. With the help of the administrative assistant the liaison for the study, we distributed announcements for the first two focus groups and kept records of the participants' attendance. Participants were assigned numbers at the first meeting to establish a de-identified data set. Participant numbers were placed on each of the questionnaires and other documents obtained during the study. Participants were divided into two focus-groups and were assigned a meeting day. One group of 10 met on Monday afternoon for four weeks, the other group of 11 met on Tuesday afternoon for the four weeks. Each
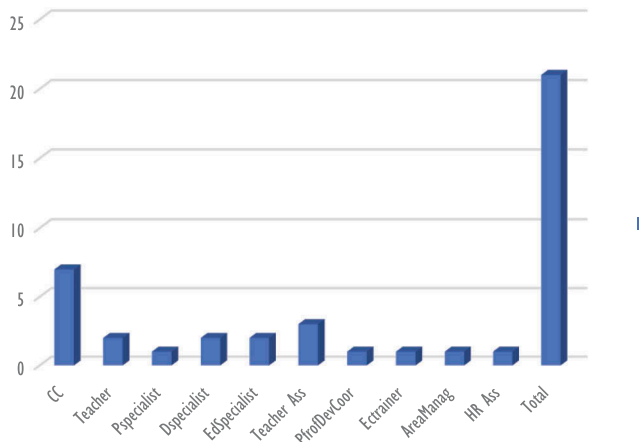

Figure 2. Position held by the participants.

focus-group met weekly for four weeks in 60–90-minute sessions, facilitated by the PI. A total of 8 recorded sessions were available for analysis.

Measures

The researcher used a PI-developed demographic form to obtain baseline assessments on factors such as age, years of employment at Head Start, and educational background (Appendix B).

Participants completed two measures as part of the baseline assessment to measure staff and organizational characteristics. The Cultural and Linguistic Competence Self-Assessment Checklist for Early Head Start and Head Start Programs (CLCSAC) is a 51 item 5-point Likert-like scale with a Cronbach alpha score of 0.90 for this sample. The subscales are values and attitudes, communication styles, physical environments, materials, and resources. It is intended to increase awareness and sensitivity of administrators, program managers, and staff to the importance of cultural diversity and cultural and linguistic competence in Head Start and Early Head Start programs. The CLCSAC is a self-report checklist that had no previous published psychometric analysis at the time of the pilot study. The Community Cultural Competence Assessment (CCCA) is an innovative tool designed for behavioral healthcare providers serving multicultural populations, a 38 item 5-point Likert-like scale. The subscales were awareness, sensitivity, and behavior. The scale is proactive, facilitating progress by offering providers the criteria to self-assess their programs, identify successes as well as area in need of improvement, and monitor their change. CCCA demonstrated adequate test-test reliability ($r = .85$, $P = .002$) in hospice providers over 4 months. Among healthcare providers in non-hospice settings, the CCA had an internal consistency reliability of 0.89 overall (.91 and .75 for the two subscales). Construct validity was supported by principal axis factor analysis, which showed two factors with item loading above .40, explaining 56% of the variance (Doorenbos, Schim, Benkert, & Borse, 2005). Mean scores of the CCCA were significantly higher for providers who reported previous diversity training compared to those who had not (Doorenbos et al., 2005). For this study, the Cronbach alpha score of 0.84 was for this sample.

Focus groups

A scribed guide was used to generate a discussion on cultural characteristics of the community organization. Sessions began with a question asking the participants to tell the story about their beliefs and values with children from diverse backgrounds and with chronic illnesses. Discussions were followed-up to encourage the staff to talk about their individual and the organization's beliefs and values about caring for children including those with chronic illnesses. All sessions were audio-taped. In addition, the PI took detailed field notes immediately following the discussion to capture information not recorded on the audio tape, such as response to discussions and setting after the sessions ended. Timeline (T1) included the baseline assessment. T2 included the focus groups data collection. Total time of the project was twelve months. Each of the participants received an honorarium upon completing 3 out of 4 focus groups. There was 100% attendance for all sessions.

Data analysis

The analyses considered the Quantitative and Qualitative strands separately. Statistical Package for Social Science-Predicted Analytics Software (SPSS-PASW) version 21 was used to complete the analysis of quantitative data from the two measures, the CLCSAC and the CCCA, and the demographic questionnaire. The quantitative strand was analyzed first using frequency analysis and factor analysis. We computed descriptive analysis that included means and standard deviations for demographic data and the measures. Once the completion of the quantitative analysis, the qualitative analysis was done to confirm the results from the quantitative data. For the qualitative analysis, the transcribed data was entered in a software package, ATLAS.ti version 7, for rigorous coding process. Four coders were identified and trained by the PI. In the first step, four trained coders coded 25% of the data to established inter-rater reliability. Once all coders established inter-rater reliability, the raters continued to code all the data. The codes were further analyzed to identify themes by the PI and coders. The themes were examined to reveal the relationship between cultural characteristics.

Integration

First, we used two questionnaires [Cultural and Linguistic Competence Self-Assessment Checklist for Early Head Start and Head Start Programs (CLCSAC) and Community Cultural Competence Assessment (CCCA)] that have been used in research to identify cultural responsiveness. The goal was to provide the opportunity for the staff to identify cultural responsiveness in a self-report questionnaire. The next step we used qualitative design (focus groups) to further confirm cultural responsiveness that was self-reported using questionnaires and provide the meaning of cultural responsiveness more in depth (Creswell, 2015). The goal was of the focus group was to confirm the results of the staff self-report on cultural responsiveness. The integration plan further was to describe similarities between self-report and focus group discussions description of cultural responsiveness. The design further provided an explanation of cultural responsiveness by staff members and how the characteristics influence their management of children with chronic health problems.

Results

The findings from the study reveal variations in cultural responsiveness. The population of children within this specific Head Start was predominantly low-income African American who had limited access to health services related to poverty and social economic status. There were several other ethnic groups of children within the Head Start that the staff also provided services. This Head Start made it feasible for children of different backgrounds to have a variety of health services who otherwise did not. The cultural weaving of this organization linked accessible health services to these low-income families. Services also provided a link to resources that otherwise was difficult for these families. The focus group participants were mostly African American (17) and included three Caucasians and one Latina (Puerto Rican) teacher. Participating staff were drawn from different management levels within the organization. All participants had a minimum of a high school education,

more than half had education beyond high school level. The demographics of the participant is summarized in Table 2. Children's chronic illness included allergies, asthma, diabetes, and other chronic childhood illness. 17.3% of children served by the Center had one or two chronic illnesses. The other illnesses included cancers, asthma, eczema, anemia, heart problems, diabetes, hearing deficit, overweight, underweight, sickle cell disease, mental delay, vision problems, and allergies that the staff managed on daily basis shown in Figure 2.

The CLCSAC subscales included the individual's values and attitudes, communication styles and physical, environmental and material resources. We used the physical, environmental, and material resources subscales as a way of capturing the organization's cultural characteristics and cultural responsiveness. The results revealed that the staff was more likely to be influenced by race, their own background of cultural and their current values and beliefs. Regardless of the child's ethnic background, the staff was more likely to use their own culture's influence in the day-to-day management of a Head Start child's care. Race, background experience with cultural in the family and their own beliefs and values were predictors of cultural competency (Table 3). In summary, individual cultural competency training may not influence decision-making with diverse groups as opposed to their own personal beliefs and values.

Values and attitudes

In the values and attitudes subscale of the CLCSAC, some differences among participants were found. Teachers and administrative staff were more likely to review policies and procedures related to cultural diversity, cultural competence and linguistic competence than were other staff members as shown in Table 3. Younger staff were more likely to seek information about children and families to better be informed about the appropriate delivery of services or care than were older staff. For the CCA measure, there were 27.8% of the staff reported resentful of others like the diverse populations Table 4.

Table 2. Participant age in years, race & ethnicity, marital status & education.

Age	29		30–39	
Race & Ethnicity	African American	Latino	White	
	16	1	4	
Marital Status	Married	Divorced		
	10	11		
Employment Status	HR	Management	Teacher	Trainer
Level of Management	1	9	5	6
Education	100% had at least 1 year of college			

Table 3. Using the CLCSAC, we computed the values & attitudes of the staff

1. Does values and attitudes among the Early Childhood and Head Start teachers and administrative staff vary with position?

   The teachers and administrative staff are more likely to review policies and procedures related to cultural diversity, cultural competence and linguistic competence as opposed to other staff members. Although they are often seeking information about the families and members to better inform the appropriate delivery of services or care, this may differ by position.

Table 4. Using the CCA, we computed correlations. These are the results

Items	%
The staff that is influence by their own culture will likely to remove obstacles	47.6
Spiritually & religious beliefs are important influenced on culture influences	61.9
To be good listener the staff will avoid stereotypes	52.4
If the staff is a good listener, they are more likely to adapt to individual and group cultural preferences.	
If the staff member may take advantage of the individuals, they help and may feel resentful toward them.	28.7

Focus group results

There was consensus of the final four themes: 1) Socialized culture-generational effect (Figure 4); 2) desire to communicate-check personal assumptions (Figure 5); 3) self-fulfilling achievement-acceptance (Figure 4); and 4) Controlling power-patriarchy (Figure 6). Transformation occurred when we conducted frequency analysis using ATLAS.ti. Coders identified multiple characteristics of cultural beliefs and values in over four iterations of coding. Overall themes included: 1) desire to communicate; for the participants, this means having the need to learn how to communicate to the diverse population of children in their care. 2) Controlling power; this is where the participant has control of the situation without respect to the diverse population children and family member in their care. 3) socialized culture; for the participant, this means that everything they knew about diversity learned from their own surroundings. 4) Self-fulfilling achievement; self-fulfilling is the self-efficacy that the participants feel upon with their success in solving a problem for these families from diverse backgrounds. A summary of the themes and their contributing codes is included in Figures 3–5. For example, specific codes included within socialized culture were individualized beliefs: from line 20–22; focus group A. "*Although I am from L.A., there are things of that I do different as an individual or as a person*" and generational
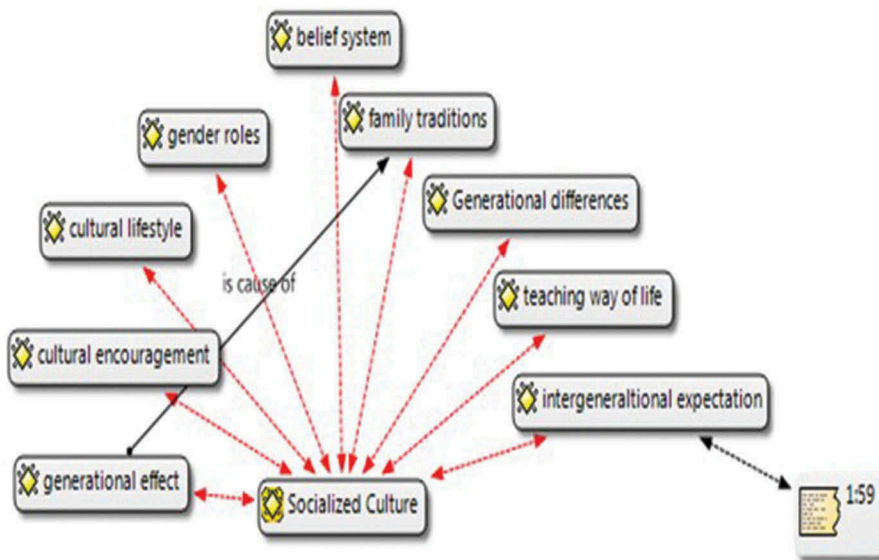
Figure 3. Socialized Culture.

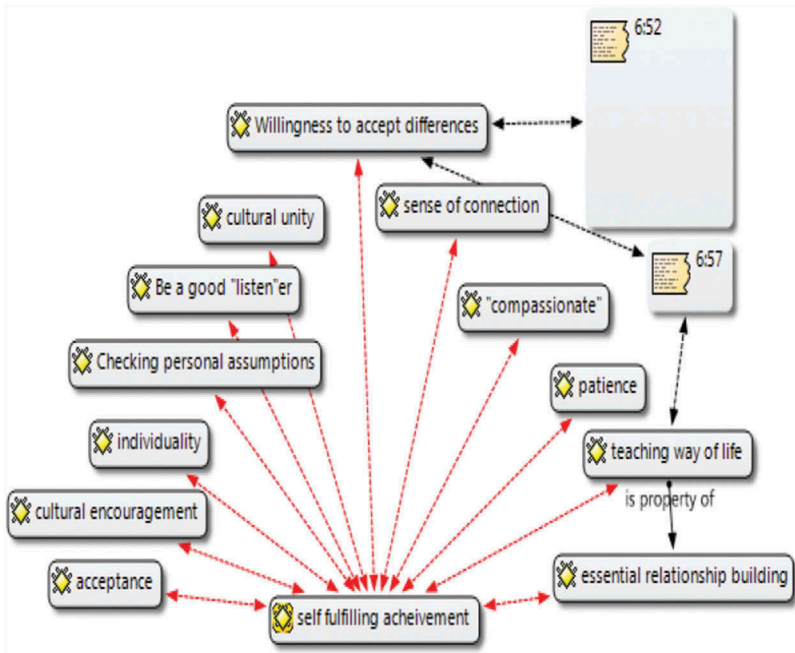**Figure 4.** Self-fulfilling achievement.

effect: line 24–26 "*because the older generations they believe in certain things versus younger generation want to change certain things*".

Further summaries of these super codes will be displayed in subsequent figures. The qualitative data further confirm the findings; that some cultural characteristics (e.g., values
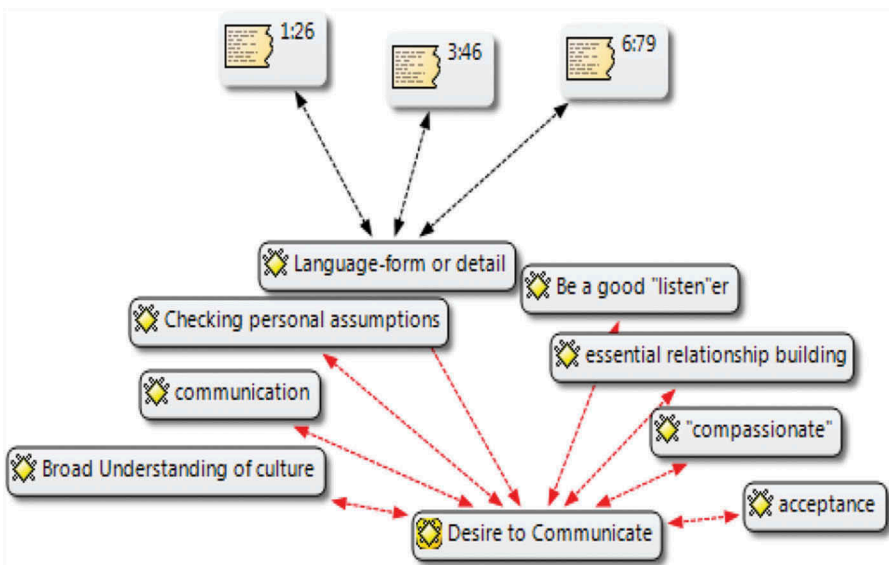
Figure 5. Desire to communicate.
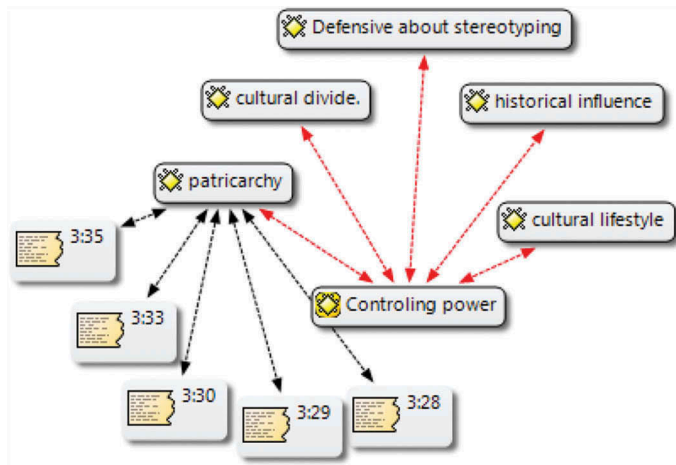
Figure 6. Controlling power.

and attitudes) of the individual participants may influence their cultural and clinical competency.

The comparison of individuals' self-assessment measures and the focus group resulted in further examination of both cultural and clinical competency of the participants. A
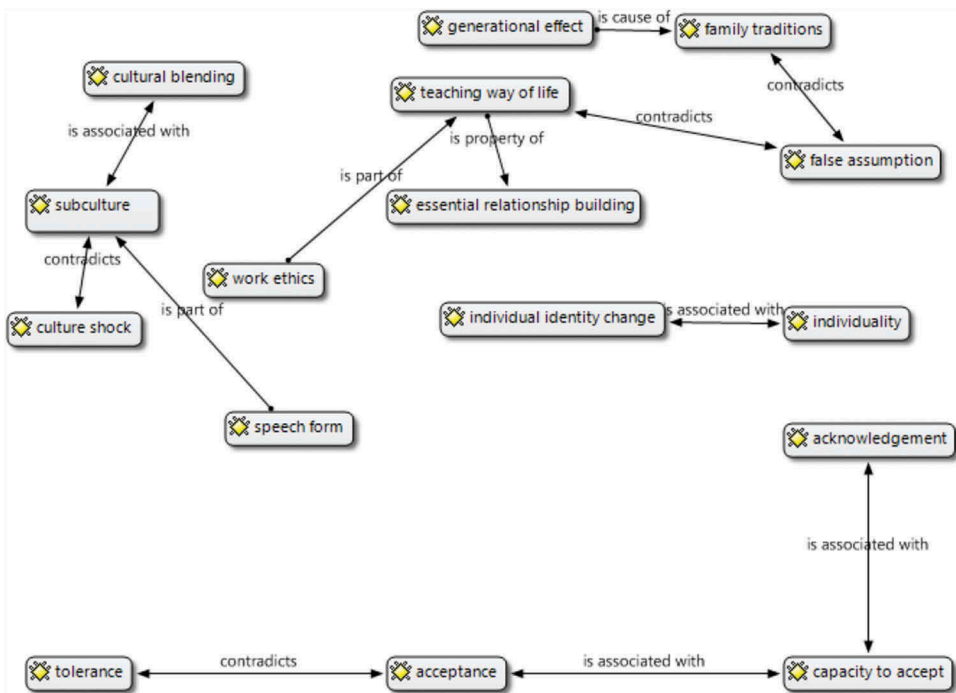
Figure 7. Proposed model results of the culture and families' Influences on the participants.
A model that illustrates how the qualitative data of the past lived experiences and these traits ultimately influence their decisions in caring for children with diverse backgrounds.

participant reported, "*Although I am from L.A., there are things of that I do different as an individual or as a person*" confirms the clinical competency of the individual. In the focus groups, individuals reported that their past cultural experiences influence their management of diverse populations. For some participants' answered the question on self-satisfaction such as "good listener" and "recognize the barriers" were confirmed as a self-fulfilling achievement. In summary, the study further shows that social experiences may be a powerful driver of culturally competent care as opposed to cultural competency training.

Integration

The primary focus of the integration for this exploratory sequential mixed method was to confirm the results of the self-report survey using focus groups. We found similarity related to core values and beliefs. The major themes from the qualitative data were the socialized cultural which relates the beliefs and values that an individual inherit.

Discussion

In a previous study, the PI conducted research with the caregivers of children with asthma to explore their experience in caring for chronically ill children (Dowell, 2015). Findings from the previous study led the investigator to explore the experience of other community members who care for these children outside the health-care system. As part of an effort to develop a community alliance with the local providers of children with asthma, the investigator identified a local child development center and invited their participation in a collaborative exploration of culture and caregiving. After meeting and reviewing the proposed study, the center administration was receptive to learning how to better manage chronically ill children, and with the PI, planned project implementation strategies that fit within organizational constraints.

This study explored strategies used by the staff of a child development center and examined how their personal values and beliefs influence their decisions in caring for children with chronic health problems. There were three specific aims: Aim 1. To determine the cultural competence of individual staff members within a local Head Start program that cares for chronically ill children ages 0–5 years of age. Two measures, the CLCSAC and the CCCA elicited responses from participants. Results from the measures suggest that participants had high levels of cultural awareness for providing both education and health care to the children. Both measures provide a better understanding of how the participants relate their own personal beliefs and values to cultural competency. Although there were high levels of cultural awareness, the results from the measure did not provide the day-to-day management with a diverse population of children with illnesses and how their own personal belief influence the management of chronic illnesses.

Aim 2. To explore a deeper understanding of the core beliefs and values of the staff and the influences on managing the diverse population. The major findings for the center coordinators, teachers, teacher aids, and staff were similar in that their *faith and beliefs were passed from one generation to the next generation*. There were several *family influences that help guide* their role in the management of day-to-day workload

with these diverse children and their families. The participants believe that *"mind-fulness"* is a characteristic of a culturally competent individual. This would mean that the staff would do self-reflection such as *"check personal assumptions"*. Such an individual is someone who accepts and respects others who are different from them. Another major finding with regards to characteristics of cultural competence within the organization included attempting to hire staff members that were similar to those of the children in the center.

In addition, an overarching theme was the need for ongoing workshops to train the staff on working with diverse families (e.g., different nationalities, languages, religious beliefs, cultures) with different core values and beliefs. One of the participants identified that there is a need for training by the organization on how to communicate effectively *"communication"* with parents from diverse populations. A enter coordinator further emphasis the need for ongoing training: *"I think they'd definitely benefit from more trainings."* This may include having training in interpersonal relationships that would enhance the ability of the staff to interact with different cultures. Yet another participant emphasized who needed to be trained: *"The organization has changed in conducting workshops on cultural competency training for all the staff to include upper level management."* In summary training on cultural competency was a general theme from these focus groups.

Aim 3. To determine if there was a consistency between the self-report and the focus groups on cultural competence, beliefs, and values among the participants. We wanted to describe self-report surveys (belief and value) and if the focus groups results further confirms the results of the self-report surveys. An interesting finding was that self-reported responses attributed values and beliefs to influence from preceding generations, while members of focus groups emphasized the need for organizational training on cultural competency. Although the staff may be culturally aware, cultural awareness does not indicate cultural competency in working with diverse population.

In summary, this project revealed the importance of values and beliefs passed from generation to generation in the delivery of health services. Yet the cultural beliefs and values awareness does not necessarily provide the cultural competency needed to work with or manage chronic health problems in diverse population. Training may be need for cultural competency in workplace. Even though training may be needed this will not replace the internal beliefs and values of the individual. When training builds on/acknowledges internal beliefs and values, it may contribute to awareness and the development of skills reflecting cultural competence.

Limitations

A limitation of this study is its small sample size, twenty-one individuals from a single local community organization, which constrains generalizability of the findings. Despite this limitation, the study provided a rich source of information on individual beliefs and values and their impact on the ability to communicate with diverse populations. Future research should concentrate on using multiple organizations to further understand cultural characteristics of the staff and organizations. The lack of ethnic diversity among the staff and the participants for this study was also a limitation. This study provides an initial examination of how individual cultural beliefs and values interface with individual and organizational communication and care delivery to children and families who have

historically experienced the disproportionate diversity of staff, disproportionately high incidence of chronic disease, and poor health outcomes.

In summary, the results from this study revealed how a community organization may benefit from a culturally competent training intervention and the possible impact on health outcomes for children. Children with chronic health problems are faced with a fragmented family structure that symptom management for children with chronic illness may be best served by including the community organization with the family during the development of an intervention. Thus, researchers may need to include community organizations in developing an age-appropriate intervention to improve health outcomes for children.

Implications for practice

Nurses have the opportunity to work with communities, especially organizations that are involved in the delivery of health services, but not considered part of the health-care system. Further research is needed to inform the development of a community engagement partnership with cultural competent health-care providers and organizations to enhance access to a medical home and decrease health disparities among children with chronic illnesses and their caregivers. A critical component of the development of partnerships with the community is to understand the characteristics of the healthcare providers and organizational staff that cares for diverse populations. This may need to focus on both delivering prescribed cultural competency concepts and on encouraging individuals to reflect on their past cultural beliefs, values, and experiences to communicate effectively with diverse populations. In conclusion, a model building shown in Figure 7 may provide an explanation of how the themes are linked together.

Acknowledgments

Funding

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Article

The "Battle" of Managing Language Barriers in Health Care

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Abstract

Providing safe and high-quality health care for children whose parents have limited English proficiency (LEP) remains challenging. Reports of parent perspectives on navigating language discordance in health care are limited. We analyzed portions of 48 interviews focused on language barriers from 2 qualitative interview studies of the pediatric health care experiences of LEP Latina mothers in 2 urban US cities. We found mothers experienced frustration with health care and reported suboptimal accommodation for language barriers. Six themes emerged relevant to health care across settings: the "battle" of managing language barriers, preference for bilingual providers, negative bias toward interpreted encounters, "getting by" with limited language skills, fear of being a burden, and stigma and discrimination experienced by LEP families. Parents' insights highlight reasons why effective language accommodation in health care remains challenging. Partnering with families to address the management of language barriers is needed to improve health care quality and safety for LEP patients and families.

Keywords

limited English proficiency, health care disparities, interpreter, Latino, qualitative research

Latinos are the largest minority population in the United States and comprise the majority of the 25 million people in the United States with limited English proficiency (LEP).[1,2] Latino children experience disparities in the access to and quality and safety of medical care.[3] Even greater health care disparities are experienced by Latino children in LEP families. Compared with Latino children with English-proficient parents, Latino children with LEP parents are less likely to have a medical home or timely medical care, more likely to have nonurgent ED visits and compromised medication safety, and their parents report worse communication with providers and greater dissatisfaction with health care.[3-11] Health care quality and outcomes improve for LEP patients and families, however, when professional interpreters are used or language-concordant providers are available.[12,13] Unfortunately, LEP patients and families often do not receive appropriate language services.[11,14,15]

Based on Title VI of the Civil Rights Act, LEP patients and families must have meaningful access to language services.[16] The National Standards for Culturally and Linguistically Appropriate Services in Health Care (CLAS standards) issued by the US Department of Health and Human Services provide guidance on Title VI compliance.[17] Appropriate accommodations for LEP patients during health care encounters include use of

language-concordant providers with sufficient target language proficiency and/or certified, professional interpreters.[17] CLAS standards have been operationalized into the Joint Commission accreditation process, but many hospitals do not meet them, even though this poses a risk to their accreditation.[18,19] Optimally meeting the language needs of LEP patients and families remains challenging; the supply of bilingual physicians is low compared to the LEP patient population, and professional interpretation can present logistical and financial barriers for clinics and health systems.[11,14,20-22]

To our knowledge, there is limited information on parent perspectives on the management of language barriers in health care. Understanding LEP parents' perspectives on management of language barriers is necessary to increase use of appropriate and family-centered language

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services and reduce persistent health care disparities due to language. This study aims to describe the perspectives of LEP Latina mothers on their experiences with language services in pediatric health care to inform the development of more patient- and family-centered language services.

Methods

Study Design and Population

This study is a secondary data analysis of collated data from 2 semistructured Spanish-language interview studies conducted in urban settings with immigrant Latina mothers. Both studies included mothers of children with access to and use of pediatric primary care in the past year to focus on the experience of using care. Language barriers emerged as a prominent theme from both studies. Similarities in participant experiences and demographics in the 2 study populations facilitated conducting an in-depth analysis of this theme of language barriers in health care among urban Latina mothers.

The first study (n = 38) was conducted from September through December 2009 in the predominantly Latino community of Southwest Detroit, Michigan, in partnership with a local federally qualified community health center, The Community Health and Social Services (CHASS) Center.[23] Participants completed 1 semistructured interview about their pediatric health care experiences. The second study (n = 10) was conducted from October 2011 through July 2012 in Baltimore, Maryland, at an outpatient, general pediatrics practice serving predominantly immigrant Latino families.[24] Participants were family-member participants in the clinic's inaugural year of the Latino Family Advisory Board (LFAB). Participants completed a total of 2 interviews to better understand their experiences as board members. A section of each interview was dedicated to exploring their pediatric health care experiences, more generally and were used in this study. Inclusion criteria did not require mothers to have LEP for either study. We used the US Census Bureau question "How well do you speak English?" to ascertain LEP status based on a response of speaking English less than very well.[25] All mothers except for one (Detroit study) had LEP. That mother still reported preferring Spanish for health care encounters, and her responses still reflected facing language barriers and so, as with the original analysis, the corresponding interview was retained.

Data Collection and Analysis

In both studies, the majority of interviews were conducted in the participants' homes by a bilingual, bicultural experienced Latina interviewer with community

knowledge. A minority of interviews in Detroit were conducted at the health center based on participant preference. Interviews lasted between 25 and 90 minutes. Participants signed informed consent after the consent form was orally read to them and received $25 for their participation. This study was approved by the institutional review boards at the University of Michigan, CHASS, and Johns Hopkins Medicine.

Interviews were digitally audio-recorded and transcribed verbatim into Spanish, for both studies, and then translated into English using a commercial transcription and translation services company. Names of people and places were assigned a pseudonym. The principal investigator for both studies (LRD) worked with bilingual and bicultural study staff at both sites to refine translations to better reflect meanings as understood by Spanish speakers in the study communities. Final interview transcripts included Spanish and English text to allow for data coding and analysis by study team members not proficient in Spanish and coding of interviews in the original language by those proficient in Spanish. Participants in both studies had opportunities to provide feedback on original study findings and interpretations. In Detroit, 2 study participants contributed to the data analysis through periodic meetings, and CHASS staff provided feedback on study findings and interpretation. In Baltimore, LFAB participants provided feedback on study findings and interpretation periodically during board meetings the year following study completion.

We extracted Spanish and corresponding English-language text segments from the original coding of both studies for inclusion in this study. Extracted text segments included those coded under themes of communication, language barriers, interpretation, English language proficiency, and discrimination; the coding structure was similar for each of the 2 original studies. We included the discrimination code as these experiences consistently related to discrimination based on language. A total of 281 unique text segments were extracted from the Detroit-based study, and 75 unique text segments were extracted from the Baltimore-based study.

After data extraction, all codes from the original studies were removed. The coding team (LRD, ES, DVA) then reviewed the extracted transcripts to identify preliminary themes. The research team developed a codebook based on these themes (eg, physician Spanish-language proficiency, interpreter access, ease of communication). An iterative consensus process determined that codes were clearly defined and could be consistently applied by all team members. During initial development and application of the codebook, 2 study team members, who would serve as primary coders, coded 6 transcripts (LRD, ES). All remaining transcripts were

Table 1. Characteristics of Sample Mothers (n = 48) and Their Children.

Maternal age (years), mean	32.5 (range = 20-44)
Country of origin—Mexico (%)	73
Length of stay in the United States (years), mean	9.5 (range = 2-21)
Maternal education	
6th grade or less (%)	40
Greater than 6th grade to some high school (%)	30
High school graduate or more (%)	30
Annual household income	
<$20 000 (%)	81
Mother lives with husband/partner (%)	79
Mother's health status fair/poor (%)	23
Mean number of children	2.6 (range = 1-6)
Age of children (years), mean	6.6 (range = 2 months to 21 years)
US-born children (%)	81
Children's health insurance status	
Medicaid (%)	81
Uninsured (%)	19
Children's health status fair/poor (%)	8

coded by 2 coders, with at least 1 of the 2 primary coders coding each transcript. Rather than employing a measure of intercoder reliability, we used previously established methods for addressing differences in coding due to multiple coders by addressing all coding discrepancies and reconciling them through discussion and consensus.[26,27]

We used Atlas.ti V5.7.1 to apply codes to the transcripts and to organize text segments and relevant quotes abstracted during analysis.

Results

Interview data from 48 participants were included in this study. Most of the mothers were of Mexican descent and had 2 or 3 children, the majority of whom were US-born. Table 1 displays additional respondent characteristics. There only notable difference in demographic characteristics by study site was country of origin. In the Detroit study, 95% of mothers were of Mexican-origin, while 50% of the Baltimore study participants were of Mexican-origin. Non-Mexican-origin participants were from varied Latin countries in Central and South America and the Caribbean. Participants described receiving pediatric care at primary care practices, urgent care practices, the emergency room, and navigating referrals to specialty care or other child health services such as dental care or developmental services.

The majority of participants discussed their primary care experiences more positively than experiences in other health care settings. In general, participants reported more negative experiences overcoming language barriers in specialty care, emergency care, and other child health services. The majority of respondents identified that they had a primary care clinic for their child, but also commonly discussed seeking urgent/emergent care for acute illnesses. Increased satisfaction with primary care compared with other health care was related to both better accommodation of language needs by primary care providers and more familiarity with the system of care in primary care on the part of parents. Specialty and emergency care were fraught with difficulties for mothers. They reported less access to language services, which then magnified the challenges they faced navigating unfamiliar health care settings. While some mothers had access to bilingual providers in primary care, most mothers did not report having bilingual specialty or emergency department providers.

Though mothers reported on experiences in varied health care settings, 6 themes emerged relevant to pediatric care across settings: the "battle" of managing language barriers, preference for bilingual providers, negative bias toward interpreted encounters, "getting by" with limited language skills, fear of being a burden, and stigma and discrimination due to language barriers. These themes were reflected in the choices mothers made in managing language barriers, reflected known limitations in the health care system for appropriately addressing language barriers, and the larger social context of language barriers.

The "Battle" of Managing Language Barriers

Many mothers characterized their health care encounters as a "*batalla*" [battle]. Some mothers used that exact term, while others described similar experiences, but did

not apply the same language. When characterizing their experiences as a "battle," participants were more often describing health care in non–primary care settings. Many mothers reported more consistent access to language accommodation either via bilingual provider or interpretation in primary care (Quote 1; see Table 2). Most mothers, however, reported a staff member, like a nurse, frequently served as an interpreter. When discussing non–primary health care, mothers also described "battling" to bring an interpreter and to make appointments (Quote 2).

However, not all mothers had favorable primary care experiences. One mother stated, "It was a battle to say anything. . . . I couldn't ask why they had to get so many vaccines or why not. I battled for so long." Other mothers described the need to switch primary care providers to maintain access to bilingual providers.

Preference for Bilingual Providers

Mothers also had a strong preference for bilingual providers compared with interpreted encounters. Mothers stated that access to bilingual providers eased communication, improved understanding, and strengthened rapport (Quotes 3 and 4). Some made sacrifices with regard to distance traveled to the clinic, or dealing with long wait times to be seen for visits, to attend clinics with bilingual providers. As one mother put it, "There's nothing like asking in your own language." A few mothers reported a specific desire for ethnically concordant providers, though this was less of a priority than a Spanish-speaking provider. One mother said, "If he is Latino, that would be a lot better."

Negative Bias Toward Interpreted Encounters

Mothers' discussion of their desire for bilingual providers was closely intertwined with their opinions about interpreted encounters. When bilingual providers were not available, mothers more commonly described using their own or a family members' limited English-language skills or a doctor communicating using limited Spanish-language skills than interpreted encounters. Most mothers who discussed interpreted encounters reported use of nurses or other staff members serving as interpreters. Mothers reported health care encounters with interpreters could be of poor quality and could lack open communication (Quotes 5-7). One mother stated, "Oh, the information can be misinterpreted. You can't understand . . . what he's recommending . . . and not being able to ask questions . . . so you can understand what's going on." Mothers often described these situations as if their trust was being betrayed and the doctor-patient relationship was being undermined (Quotes 8 and 9).

Mothers expressed these expectations of interpreted encounters whether or not they had actually worked with interpreters. This mother described her fears about interpreted encounters, but admitted she had not actually experienced a negative encounter: "I wouldn't really know what they were saying . . . [but] no, it has not happened to me." Among mothers with interpreter experience, their biases seemed to relate to prevalent experiences with poorly interpreted encounters and lack of consistent availability of staff providing interpretation. Additionally, they described feelings of time pressures during office visits in which an interpreter was used. Lack of interpreter availability or poor experiences with interpreters provided by the health system led some mothers to pay an English-speaking community member to come with them to health care visits and translate for them. However, this solution was also often suboptimal, as some mothers reported poor-quality interpretations with these community members and significant cost burden (Quote 10).

"Getting By" With Limited Language Skills

In addition to difficulties with interpreted encounters, mothers also frequently described situations of providers "getting by" on limited language skills (Quotes 11-13). However, mothers did not always identify it as problematic. For example, one mother recounted, "No, I may not understand her too well . . . she can't speak Spanish too well, but she tries to explain . . . and if you understand fine and if not, no . . . I don't see anything wrong with her, I mean she's fine." One participant cited an experience where a doctor "would get so nervous that she would speak to me in Italian. . . . And I didn't want to make her feel bad. . . . Because, she was very nice." Other mothers did perceive problems with "getting by" and either had experienced adverse consequences from getting by or recognized the potential for them. As one mother said, "So, it is better to have an interpreter instead of trying to speak a little bit in Spanish and a little bit in English." Another mother surmised that "getting by" could lead to misunderstanding about medications (Quote 14). Finally, one mother who had been "getting by" with a specialty care physician described an especially problematic situation when suboptimal communication had resulted in lack of knowledge about the surgical procedure to be performed that was only clarified on the day of surgery (Quote 15). Participants expressed willingness to accept "getting by" because of lack of access to certified interpreters and bilingual providers.

Fear of Being a Burden

Participants also frequently described settling for "getting by" due to fears of being a burden or being singled

Table 2. Participant Experiences.

Theme 1: The "battle" of Managing Language Barriers

Mothers described frustration obtaining care and communicating during encounters due to language barriers and commonly employed the term "battle" to describe their experiences.

Quote 1

Te digo, donde son los problemas a veces es en el hospital, que, que batalla uno por, de hecho pues tienes que llevar un intérprete. . . . Ya en un problema grave pues sí en el hospital porque ahí tienes, es raro que haiga alguien que hable, casi nadie habla español, o sea.

I will tell you, usually, you will find problems at the hospital, that, you battle for, the fact that you have to bring an interpreter. . . . The bigger problem is in the hospital because you have, you hardly ever find someone, I mean, that can speak Spanish.

Quote 2

Pero lo que estoy batallando por la cita de mi hija porque, la recepcionista no hablan español y hay, no me dicen. . . . Me dicen, espérame voy a ir a hablar a tal línea para . . . ver si hay alguien que hable español. Y acá no, no más dicen que no, y que no, y que hable tal día, y no, no. Ya tengo toda la semana pasada que traté de . . . hacerle la cita a la niña y ya el lunes va a ser . . . no sé cómo lo hago.

But what I am battling with is the appointment for my child because the receptionist doesn't speak Spanish, and they don't tell me. . . . They ask me to wait while they try to find someone who can speak Spanish, and over here they just tell me no, and no, and call back such day. I tried all last week to . . . make that appointment for her, and it's going to be Monday. . . . I don't know how I do it.

Theme 2: Preference for Bilingual Providers

Mothers frequently described a strong preference for bilingual providers because it facilitated communication and improved understanding.

Quote 3

Sí, nos entendemos mejor de doctor a persona que de intérprete a persona, porque a veces cuando Ud. necesita que alguien diga algo, no lo dice como lo que Ud. siente, un doctor a lo mejor sí te lo va a entender como lo que tú le estás diciendo.

We understand each other better from person to doctor, than from person to interpreter, because sometimes when you say something you need, they don't say it like I would say it, and the doctor would probably understand better how you are saying it.

Quote 4

El doctor creo que te . . . te explica, te dice mejor la… te habla mejor que cuando te están traduciendo . . .

I think the doctor . . . explains better and tells you better than when someone is translated . . .

Theme 3: Negative Bias Toward Interpreted Encounters

Mothers were negatively biased toward interpreters even if they had not experienced an interaction with poor quality interpretation.

Quote 5

Hazte cuenta que a veces también es que yo le digo una cosa a ella y ella lo dice de otra, o sea como que no, o que no le entienden

I realized that sometimes I say something to her, and then she would say something else. It is like they don't understand you.

Quote 6

Porque el doctor hablaba con ella, y le . . . duraba el rato platicando y a mí me decía cualquier dos, tres cosas, no, no le dijo no más eso . . .

Because the doctor would talk to her . . . for a long time, and she would only tell me two or three things, and she would say that was the only thing he said . . .

Quote 7

Oh, que a veces no le dicen todo, pienso yo. Para acortarlo pues a veces más.

Oh, I think that sometimes they don't tell him everything. To make it shorter sometimes.

Quote 8

[La interprete] no me traducía bien . . . [la interprete] me decía dos o tres cosas, y el doctor hablaba mucho rato con ella, y no me, eso no me gustaba.

[The interpreter] wouldn't translate right . . . [The interpreter] would tell me two or three things, but the doctor would talk to her for a long time, and I didn't like that.

Quote 9

Lo podría decir directamente sin alguien que intervenga y que a lo mejor no entiende lo que tú estás preguntando o . . . o lo traduce de diferente manera, no sé, o sea, el hecho de que esté una persona en medio sí afecta.

I would be able to speak directly with him without having someone to intervene or that can't understand what you are asking them or . . . or will interpret a different way, I don't know, I guess, the fact that someone is in the middle, it affects you.

Quote 10

Yo decía, yo la llevo [la interprete de la comunidad] para que le explique mejor y a fin de cuentas medio le decía [al doctor] lo que yo le decía, entonces dije no, pues no. O sea realmente para llevar un intérprete, digo, pues . . .

Table 2. (continued)

I keep thinking, I bring her here so [the paid community member interpreter] can explain it better but she barely said to [the doctor] what I said. I say well in reality why take an interpreter . . .

Theme 4: Getting By

Many mothers reported Spanish-speaking providers, but with further elaboration described that the providers were actually "getting by" with minimal Spanish skills.

Quote 11

Yo le dije a la doctora que le hacían falta, a señas, a no señas yo le dije que le hacían falta sus vacunas.

I told the lady doctor that she needed some [immunizations], by hand gestures.

Quote 12

Él no habla español y yo no hablo inglés, pero sí lo entiendo.

He doesn't speak Spanish and I don't speak English, but I do understand him.

Quote 13

Siempre más o menos le entendí.

I always understood more or less.

Quote 14

No puedes entender . . . a lo mejor la recomendación que se está dando . . . o a lo mejor hasta el medicamento, cómo debe de dárselo, bueno viene la instrucción en la medicina pero . . .

You can't understand . . . at best what he's recommending . . . or even the medication, how to administer it, I know the instructions are listed on the medicine but . . .

Quote 15

Entonces cuando . . . lo iban a operar, que fue el día de la operación, una persona que hablaba español, ella nos dijo si, ya ves que tiene uno que firmar de lo que le van a hacer ese día, y me dijo le van a quitar anestesia y le van a poner los tubos en los oídos, y le dije yo, a mí no me dijeron nada de tubos, y ella se quedó así como, cómo no iban a saber, ¿verdad? . . . Ya estaba todo listo para la operación, pero yo nunca he sabido realmente por qué se los pusieron, ni . . . o sea no me explicaron.

And so . . . when they were going to operate him, on the day of the operation, a Spanish speaking person, asked if we knew, you know that you have sign before the procedure, and she said they were done with the anesthesia and now they are going to insert the tubes inside his ears, and I said, no one said anything about tubes, and she just stood there, how could she not know, right? Everything was ready for the operation, but I really never knew the reasons why they had to put them, and . . . in, in other words, they never explained it.

Theme 5: Fear of Being a Burden

Patients frequently settle for suboptimal language services due to fear of being a burden or bother.

Quote 16

Pero con ella puedes . . . a que . . . te diga . . . ¿cómo te diré? O sea que no estés molestando a otra persona, ¿sí me entiendes? A que ella te lo diga directamente.

But with her [bilingual provider] you can—she can tell you. . . . How can I tell you? You are not bothering other people, do you understand? Instead she can tell you directly.

Quote 17

Pos, cuando uno ve que si es que, cuando tiene una inquietud preguntarle, uno no sabe, pues como yo no sé decirlo, preguntarle algo— algo así. Le busca una intérprete pero uno sabe que ellas están ocupadas, pues su trabajo es otro y no . . .

Well, when I have a question, I don't know, I don't know how to say it—to ask about something or something like that. [The doctor] looks for an interpreter, but we know they are busy and that that is not their job . . .

Quote 18

Cuando voy sin cita, que no me toca el doctor que, habla español. Ya no lo menciono lo que, pos sí me quedé con la duda.

Yes, whenever I go without an appointment, and I don't get the doctor that speaks Spanish. I don't mention to him the questions that I had anymore and well I remain with doubts.

Theme 6: Stigma and Discrimination Due to Language Barriers

Mothers described episodes of discrimination or perceived racism that they attributed to their language and ethnicity.

Quote 19

Yo sé que son de aquí y yo no soy de aquí, pero no quiere decir que porque ellos son de aquí van a atender a sus hijos primero, no se trata así.

I know these people are Americans and I'm not from here, but that doesn't mean that because they're from here their children should be seen first. That's wrong.

Quote 20

Tal vez con la gente latina porque [el médico] no se me acerco mucho ni nada.

Maybe [the doctor] only acts that way with Hispanics because he didn't come near me or anything like that.

out because of their language need (Quote 16). One mother stated, "I understand a little, but not that much . . . [but] I don't want to cause any trouble." Common across many mothers were reports of not asking for clarification or bring up questions due to the perception it was burdensome. Mothers expressed concern about asking questions since they already felt that they had burdened providers with their language need that made communication more difficult or required the services of an interpreter (Quotes 17 and 18).

Stigma and Discrimination Due to Language Barriers

The desire to not be a burden, the negative bias toward interpreters, and the tolerance of "getting by" commonly were interwoven within discussions of stigma and discrimination due to language barriers. Mothers described several instances of humiliation and discrimination due to their language barriers (Quotes 19 and 20). One mother stated, "Honestly, I sort of have seen that there is a lot of racism at the hospitals." She goes on to say, "Sometimes they don't want to understand you because you are Hispanic." Another mother stated, "They humiliate you. . . . I feel they discriminate because they speak English."

Discussion

Across pediatric health care settings in 2 urban areas, LEP Latina mothers experienced frustration with their health care experiences and reported suboptimal accommodation for language barriers. While mothers described some health care experiences that met their needs, this was not the norm. Mothers described managing language barriers and navigating the health care system as a "battle." Their vivid descriptions of how frustrating the health care system could be underscore the great need to improve the care that the US health care system provides to LEP populations. Improving the health care quality, safety, and patient experience for LEP Latino populations requires improvements to language services, informed by a better understanding of the patient experiences of LEP Latino patients and families. The findings from this study highlight the complex web of health system, provider, and patient-level barriers to equitable care for LEP populations.

Mothers' preferences for a bilingual provider demonstrate that appropriate language accommodation can result in improved patient experiences. Adequate language services have been associated with improved communication and patient experience, better health care outcomes, safer care, and more efficient resource utilization.[11-13,28] Unfortunately, the physician workforce does not match the diversity of patients in the US health care system.[29] In fact, in the past 30 years, there has been a decline in the number of Latino physicians.[29] Latino physicians are more likely than non-Latino physicians to have adequate Spanish-language skills for health care communication, and may also share a cultural background with LEP Latino patients, potentially further enhancing the health care experience.[29] Increasing the number of Latino physicians is critically important to better meeting LEP Latino patients' needs.

In addition to programs that target increasing the number of bilingual Latino health care providers, care for LEP patients could also be improved by access to Spanish-speaking physicians, regardless of ethnic background. Mothers in this study did not indicate a clear priority for an ethnically concordant provider, but did strongly prefer a Spanish-speaking physician. Though research is limited, studies have not found a clear association between parent/provider ethnic concordance and improved pediatric primary care quality.[30,31] Nonnative Spanish speakers who wish to use their language skills during health care encounters, however, must have adequate proficiency. Language proficiency assessments of providers who wish to use their non-English language skills for health care communication are uncommon, and determining the threshold for adequate proficiency for safe and effective communication is challenging.[32,33] Additionally, among providers who do not meet standards for adequate proficiency, there is limited information on how health systems ensure interpreter use and how those providers can gain language skills to meet proficiency standards. Addressing the health care provider language gap may require comprehensive solutions, including providing additional incentives to providers who have adequate language skills and boosting language skills of those providers with intermediate proficiency.[28] Robust training programs for those medical providers who have intermediate foreign language skills may be an important way to increase the linguistic capacity of the health care workforce.[22,34]

Despite efforts to improve cultural competency and access to interpreters, "getting by" on limited language skills by both the patients and the providers remains pervasive.[15,35,36] Our findings shed new light on why "getting by" remains so common and indicate that there is no quick, simple solution to avoid its occurrence in health care encounters. Mothers were inclined to "get by" even though it was not ideal. "Getting by" was appealing to mothers for many reasons. They believed it was more efficient and polite, it did not increase the burden on providers, and they perceived less stigma and discrimination if they were able to "get by." The potential patient

desire to "get-by" has implications for the way language services are offered to LEP patients and indicates that encouraging providers to avoid "getting by" may not be sufficient. Through research and quality improvement processes we need to explore how best to initiate use of interpreters. Patients may decline an interpreter if offered, but if one were present as a default, it is not known how patients may respond or if this would improve health care safety and quality.

Decreasing "getting-by" through use of interpreters requires addressing patient and family distrust of interpreted encounters. Mothers in our study had significant negative bias toward interpreted encounters, even if they had not ever used an interpreter during a health care encounter. This underscores the critical need to improve the patient and family member-interpreter relationship. Trust in the interpreter's ability to translate information correctly has been shown to increase interpreter use among providers, but the concordance between provider trust in the interpreter and patient trust of the interpreter is unclear.[13,36] In our study, we had limited information on the type of interpreter used and providers' assessments of the interpreter. Thus, we cannot assess what factors may have improved the patient/family experience with interpreted encounters among participants or whether participants' lack of trust in interpreted encounters is based on only poor-quality interpretation experiences.

In addition increasing the frequency of interpreter use and improving the patient experience during interpreted encounters, we must also address the discrimination and stigma felt by LEP Latino patients and their families. There is evidence that perceived discrimination in health care among Latinos is associated with lower health care satisfaction and poor patient-provider communication, but the prevalence of this stigma is unclear.[37,38] Some prior research has found that foreign-born, Spanish-speaking Latinos are less likely to report discrimination in health care than nonimmigrants or English-speakers, but another study including immigrant Latino parents found they did perceive discrimination in the care of their child.[37-39] Since feelings of discrimination and stigma were frequently discussed among participants, more information is needed about perceived discrimination and health care quality among Latinos.

This study has certain limitations. First, we interviewed a small sample of Spanish-speaking only LEP mothers in urban communities, so our findings may not reflect the experiences of other LEP Latina mothers in the United States. Second, we only interviewed Latina mothers, so our findings may not reflect experiences of other LEP populations, though LEP populations speaking other languages report similar experiences.[40,41] Third, descriptions of some interpreted encounters involved presumed "ad hoc" interpreters (family members, friends, staff not trained in interpretation). The limited experience of participants with professional interpreters may have increased their negative bias toward interpreted encounters, but also highlights the undersupply and underuse of professional interpreters. Finally, the interview-based nature of this study may result in a negativity bias. When participants discuss their experiences, they may have more of a tendency to recall negative experiences, especially with probing, than they may otherwise.[42]

Despite these limitations, this study contributes to filling an important gap in health services research by identifying and understanding patient perspectives on language barriers in health care. The need for this research is especially important given the large and growing LEP population in the United States. As the health care system endeavors to be more "patient-centered," there is a critical need to better understand the patients' perspectives on pervasive and problematic issues that contribute to health care disparities. Our findings demonstrate that decisions regarding how to manage language barriers are complex and involve choices on behalf of both the patient and provider. Current training on appropriate management of language needs primarily focuses on services and programs to be offered by health systems and choices that providers make during individual encounters. Our findings underscore the need to partner with patients and families in the process of managing language barriers from the first point of interaction with the health care system through the encounter and subsequent management. Dialogue with the family on how best to manage language barriers may be as critical as the dialogue on the health problem to be addressed during the encounter. Partnering with patients and their families may result in changes to language use policies and practices and generate needed improvements in the health care of LEP populations.

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Author Contributions

EMS analyzed and synnthesized the data, wrote the first draft of the manuscript, and revised the manuscript for publication incorporating co-author edits. DV-A coordinated data management, analyzed and synthesized the data, supported manuscript

drafting and formatting, and critically reviewed the manuscript. JSZ and EK assisted in data collection and data analysis and critically reviewed the manuscript. LRDC led data collection, analyzed and synthesized the data, assisted in manuscript drafting and critically reviewed the manuscript.

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Pay More Attention: a national mixed methods study to identify the barriers and facilitators to ensuring equal access to high-quality hospital care and services for children and young people with and without learning disabilities and their families

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ABSTRACT

Introduction: Despite evidence of health inequalities for adults with intellectual disability (ID) there has yet to be a comprehensive review of how well hospital services are meeting the needs of children and young people (CYP) with ID and their families. We do not know how relevant existing recommendations and guidelines are to CYP, whether these are being applied in the paediatric setting or what difference they are making. Evidence of parental dissatisfaction with the quality, safety and accessibility of hospital care for CYP with ID exists. However, the extent to which their experience differs from parents of CYP without ID is not known and the views and experiences of CYP with ID have not been investigated. We will compare how services are delivered to, and experienced by CYP aged 5–15 years with and without ID and their families to see what inequalities exist, for whom, why and under what circumstances.

Methods and analysis: We will use a transformative, mixed methods case study design to collect data over four consecutive phases. We will involve CYP, parents and hospital staff using a range of methods; interviews, parental electronic diary, hospital and community staff questionnaire, patient and parent satisfaction questionnaire, content analysis of hospital documents and a retrospective mapping of patient hospital activity. Qualitative data will be managed and analysed using NVivo and quantitative data will be analysed using parametric and non-parametric descriptive statistics.

Ethics and dissemination: The study will run from December 2015 to November 2018. We have Health Authority Approval (IRAS project ID: 193932) for phase 1 involving staff only and ethical and Health Authority Approval for phases 2–4 (IRAS project ID: 178525). We will disseminate widely to relevant stakeholders, using a range of accessible formats, including social media. We will publish in international peer-reviewed journals and

Strengths and limitations of this study

- The use of a coherent patient and public involvement strategy, which includes a parent of children with ID as a coinvestigator, a Parent Advisory Group comprising parents of children with and without ID and a Children and Young People (CYP) Advisory Group established through working in partnerships with schools whose pupil population includes those with ID.
- The use of traditional, creative and digital research methods will facilitate the inclusion of a wide range of participants, including CYP with ID, often described as a vulnerable population who are frequently excluded from research.
- Matching two groups of CYP, those with and without ID, will strengthen our ability to identify inequality where it exists and understand why it arises and for whom.
- The exclusion of parents who require an interpreter due to the added challenge this presents in gaining a thorough understanding of the needs of children with ID particularly those with communication difficulties.
- The restriction of only four sites for inclusion in phase 2 due to resource constraints, hence the inclusion of a robust process for selecting sites.

present to professional, academic and lay audiences through national and international conferences.

INTRODUCTION

The preferred term for intellectual disability (ID) in the UK is learning disabilities.

However, we use the term ID throughout the protocol as this is used consistently internationally.

It is widely recognised that people with ID have more health needs that often remain unmet than the general population. In 2007, Mencap, a UK charity, published 'Death by indifference'[1] detailing case histories of six people with ID who died in hospitals from avoidable conditions and calling on the government to take 'serious action'. An independent inquiry into access to healthcare for people with ID followed, revealing significant system failures and reporting that patients with ID were treated less favourably than others, resulting in prolonged suffering and inappropriate care. The report of this inquiry, 'Healthcare for All',[2] identified the invisibility of people with ID within health services, and the lack of priority given to identifying their particular health needs. Training and education about ID were found to be very limited. Combined with ignorance and fear, lack of training was identified as reinforcing 'negative attitudes and values towards people with learning disabilities and their carers' and 'contributing significantly to a failure to deliver equal treatment, or to treat people with dignity or respect'. A need to strengthen the systems for assuring equity and quality of health services for people with ID at all levels was identified.

A confidential inquiry into premature deaths of people with ID (CIPOLD)[3] including 14 children and young people (CYP) aged 4–17 followed. It emerged that in comparison with the general population, 'more people with ID died from causes that were potentially amenable to change by good quality healthcare'. All aspects of care provision, planning, coordination and documentation were found to be significantly poorer for people with ID. A plethora of recommendations and guidelines are now available to support hospitals in ensuring that 'people with ID are included as "equal citizens, with equal rights of access to equally effective treatment"'.[2] Mencap has worked with healthcare professionals and Royal Colleges to develop the 'Getting it Right Charter'[4] highlighting key activities that all healthcare professionals should undertake to ensure that there is equal access to health, including the appointment of a learning disability liaison nurse (LDLN) in every hospital. While 200 trusts, hospitals and organisations have signed up to the Mencap Charter demonstrating their commitment to change, a current feasibility audit of adult ID care pathways found that only 56% of the nine acute trusts that took part had a liaison nurse in place.[5] Providing reasonably adjusted services for people with ID is a legal requirement.[6] Yet, the largest study of its kind to date[7] found that the delivery of reasonable adjustments in the adult hospital setting was haphazard, with a lack of (1) effective systems for identifying patients with ID and (2) clear lines of responsibility for implementing reasonably adjusted care to individual patients.

The direct relevance that current recommendations about the care of 'people' with ID have to CYP, and

guidance on the best way to implement them in the child health setting, are missing. The main thrust of initiatives aimed at reducing health inequalities faced by people with ID has been on improving access to healthcare among *adults* rather than the health inequalities faced by CYP.[8] Hence, what we still do not know is the extent to which available recommendations *should* be applied to CYP with ID; to what extent they *are* being applied to CYP with ID or, if they are being applied, what *difference* they are making to patients, parents and staff.

CYP with ID and their families

CYP with ID routinely experience particularly poor health outcomes. A review of the evidence on the prevalence and determinants of health conditions and impairments among CYP with ID in the UK[9] found that the risk of children being reported by their main carer (usually their mother) to have fair/poor general health is 2.5–4.5 times greater for those with ID compared with their non-disabled peers,[8] [10] a finding only partially accounted for by differences in socioeconomic status.[11] As well as having intellectual impairment, these children may have sensory impairments and physical impairments, such as cerebral palsy,[12] that adversely affect their speech, feeding and mobility. CYP with ID are also almost twice as likely to report three or more health problems and more than four times as likely to suffer from a psychiatric disorder than children without ID.[10] [13] Increasing numbers are dependent on technological equipment for their survival.[14]

Children with disabilities experience more frequent and lengthier hospital admissions than children without disabilities[15] and have contact with numerous professionals, often attending the same hospital many times in a week.[16] They are also more likely than other children to be absent from school. In those with profound multiple learning difficulties, 62% of absences were accounted for by illness and 13% from attending medical/dental appointments.[11] The ability for CYP with ID of *all* ages to understand information about hospital care and treatment will be limited, they may not be able to communicate their needs verbally, and may need additional support with all aspects of hospital life. While many CYP will find it hard to cope emotionally when they are in an unfamiliar hospital environment, those with ID who have challenging behaviour[17] may find it particularly difficult.

Within the National Service Framework (NSF) for CYP in hospital[18] the distinct service requirements of 'disabled' children are recognised, as is their greater need for personalised, child-centred care. However, the NSF framework precedes the latest evidence on the care of people with ID in hospital and may no longer be fit for purpose for meeting the specific intellectual, emotional, social and physical needs of CYP with ID. A number of children's hospitals have introduced nursing posts with a specific focus on improving care for CYP with ID but

provision varies geographically and over time, and has not been formally evaluated. Many reports have highlighted the need to review National Health Service (NHS) services for *disabled* children and their families. The most consistent message is that services need to be tailored to meet the individual needs of these patients and it is imperative that their views are incorporated at every level of service delivery. This message applies equally, if not more so, to CYP with ID, whose struggle to get their views heard is widely recognised.

Evidence of acceptability and effectiveness of services

Few researchers have focused on how acceptable and effective hospital services are in meeting the needs of CYP with ID and their families. More importantly, the voice of CYP with ID is largely non-existent. Conversely, there has been some research conducted with CYP without ID, including those with long-term conditions, to understand the hospital experience from their perspective.[19–23] We know from this body of work the range of fears and anxieties that CYP express about being in hospital, as well as having some understanding of what supports them to feel safer, happier and more positive about their experience. What we do not know is whether CYP with ID have the same needs and experiences. A recent review of qualitative studies reporting on the experience of *disabled* children as inpatients[24] led to the conclusion that their experience was 'variable and not always optimal' and that providing information would improve their experience. Importantly, of the eight studies included in this review, only two focused specifically on the care of children with ID and within these, only two individual children were interviewed. Of significance is that these two CYP, despite talking positively about nursing staff, were reported to be 'less positive in general about their hospital stay than their parents'. Similarly, in a small Australian study[25] exploring the views of four children with cerebral palsy about their experience of the medical consultation, it was reported that 'whilst children and mothers had similar views about communication, there were obvious differences in what was perceived to be important'. Children described wanting to be included even if they did not understand what was being said, and expressed a desire to be informed of any tests or procedures before they happened, rather than having things 'done' to them. From this small body of evidence, we can draw three important conclusions, (1) evidence of what CYP with ID think about hospital and what they want from hospital services is lacking, (2) given the opportunity, some CYP with ID are able to share views about hospital and what is important and (3) CYP with ID do not necessarily view hospital in the same way as their parents. We know from our own experience and that of Sharkey *et al*[26] that recruiting CYP with ID into research while they are in hospital can be challenging. However, this should in no way preclude their involvement.

A small body of qualitative research has been conducted with parents of CYP with ID to understand their own and their child's experience of hospitalisation[27 28] Avis and Reardon[27] explored parents' perceptions of nursing care and attitudes and how their child's experience could be improved. They report parental feelings of stress, anxiety and fear, an expectation to care for their child, a lack of trust and confidence in staff and a lack of information and preparedness. Communication with staff was reported as the biggest issue that needed addressing. More recently Sharkey *et al*[26] have reported on the barriers and facilitators to communicating with disabled children when inpatients. Interviews with parents and professionals revealed that 'communication with disabled children on the ward was perceived as less than optimal' and that 'staff perceived time pressures and lack of priority given to communicating directly with the child as major barriers'. They found that parents could feel a 'weight of responsibility' concerning their child's communication that could make them reluctant to go home and leave their child alone. An in-depth qualitative study[29] carried out by Oulton *et al* supports these findings. Parents described a sense of devoted protection towards their child with ID, which meant they were simply not willing to take any risks by leaving their child in the care of someone they did not have complete confidence in. Moreover, on the rare occasions when they felt they had no option but to leave their child, the occurrence of any problems could devastate trust in the overall system, with some refusing to access those particular services again. Ultimately, parents felt they had to take complete responsibility for their child's health and well-being, even in hospital. The general tone was one of apprehension that other care providers lacked the specialist knowledge they held about their child; anger that their advice was often ignored and concern that others did not share their dedicated commitment to their child. A feeling that professionals devalued them and their child with ID was also reported. More recent ethnographic research has revealed that meeting the specific non-medical needs of CYP with ID can present a challenge to hospital staff where the focus was on providing highly specialist, complex medical care for all its patients. Staff identified that having more time, resources and training would help them provide the individualised approach to care that these patients needed.[30]

THE CURRENT STUDY
Aims and objectives

Primary aims are as follows:
1. To identify the cross-organisation, organisational and individual factors in NHS hospitals that facilitate CYP with and without ID and their families receiving equal access to high-quality care and services.
2. To identify the cross-organisation, organisational and individual factors in NHS hospitals that prevent CYP

with and without ID and their families receiving equal access to high-quality care and services.

Secondary aim is as follows:

To develop guidance for NHS Trusts about the implementation for successful and effective measures to promote equal access for CYP with ID and their families.

Research questions

From the perspectives of the families and clinical staff:

1. Do CYP with and without ID and their families have equal access to high-quality hospital care that meets their particular needs?
2. Do CYP with and without ID, assisted by their families, have equal access to hospital appointments, investigations and treatments?
3. Are CYP with and without ID and their families equally involved as active partners in their treatment, care and services?
4. Are CYP with and without ID and their families equally satisfied with their hospital experience?
5. Are safety concerns for CYP with and without ID the same?
6. What are the examples of effective, replicable good practice for facilitating equal access to high-quality care and services for CYP with ID and their families at the study sites?
7. What indicators from the data and the literature suggest the findings may be generalisable to adults with ID and other CYP with long-term conditions in the hospital setting?

METHODS AND ANALYSIS
Theoretical/conceptual framework

This study takes a systematic approach to an empirical identification of the factors that affect access to high-quality hospital care for CYP with ID and their families. Building on the work of Tuffrey-Wijne et al,[31] a theoretical framework for understanding the range of factors at the organisational and individual level that might impact on the delivery of hospital care to CYP with ID and their families has been described (figure 1). A synthesis of existing research, policy and guidelines and the team's expertise and research in the field of ID informed its development. Included are outcomes that might be associated with effective measures for promoting equal access. We intend to repopulate this framework with barriers and facilitators to promoting equal access to safe, high-quality hospital care for CYP with ID and their families identified through inductive analysis of data and by systematically testing the theoretical and empirical framework throughout this study.

Design

A transformative, mixed methods case study design[32] will be used. A 'transformative' case study is one that focuses on under-represented or marginalised populations, such as CYP with ID and their families. It involves being sensitive to the needs of this population and conducting

research with the overall aim of improving social injustice. In terms of recruitment, our focus will be on avoiding stereotypical labels, recognising participant diversity and using sampling strategies that improve inclusiveness. We will work closely with sites to ensure that a diverse range of families are invited to take part and that a screening log is maintained, documenting any reasons for not providing eligible families with information about the study and reasons why participants decline where this information is available. With regards research methods, a transformative design prioritises those that give 'a voice to the powerless and voiceless'[33] and that are sensitive to the community's cultural context. Our combination of traditional, creative and digital research methods have been carefully selected on this basis, and will be individualised to each family and used flexibly in accordance with their needs and preferences. Using transformative research, the aim is to generate results that are useful to participants and credible to stakeholders and policymakers. Our overall aim is to identify inequality where it exists and understand what factors facilitate and prevent equality of healthcare for CYP with ID such that improvements can be made in the way that services are delivered. We believe that by getting it right for CYP with ID we can get it right for all CYP with long-term conditions.

Case study design is 'an empirical inquiry that investigates contemporary phenomena in depth and within its real-life context'.[34] In this study, a single hospital site represents each case and four cases will be included. In each hospital, for every CYP with ID recruited, a CYP without ID will be recruited as a comparator case, thereby allowing the experience of the two groups of patients to be compared. This is a complex study, requiring data to be gathered consecutively in four distinct phases over 3 years (figure 2). Case study design is characterised by a convergence of diverse sources of quantitative and qualitative data (figure 3) and is therefore well suited to evaluating the multiple elements likely to shape and influence whether CYP with and without ID and their families receive equal access to high-quality hospital care and services. The production of rich descriptions of the phenomena through in-depth interviews and digital research methods will allow the many complexities of the situation and factors that can contribute to those complexities to emerge.[35]

Sampling and recruitment
Phase 1: organisational mapping and staff questionnaire

All of the children's hospitals in England will be formally invited to take part in phase 1 via email through the Association of Chief Children's Nurses. We have estimated recruiting nine of these sites into the study. For each of the children's hospitals included, a second hospital in the same region, serving CYP with ID, will be recruited, giving a final sample of 18 hospitals. This sampling method will allow a range of specialist (children's hospitals) and non-specialist (district general, teaching)
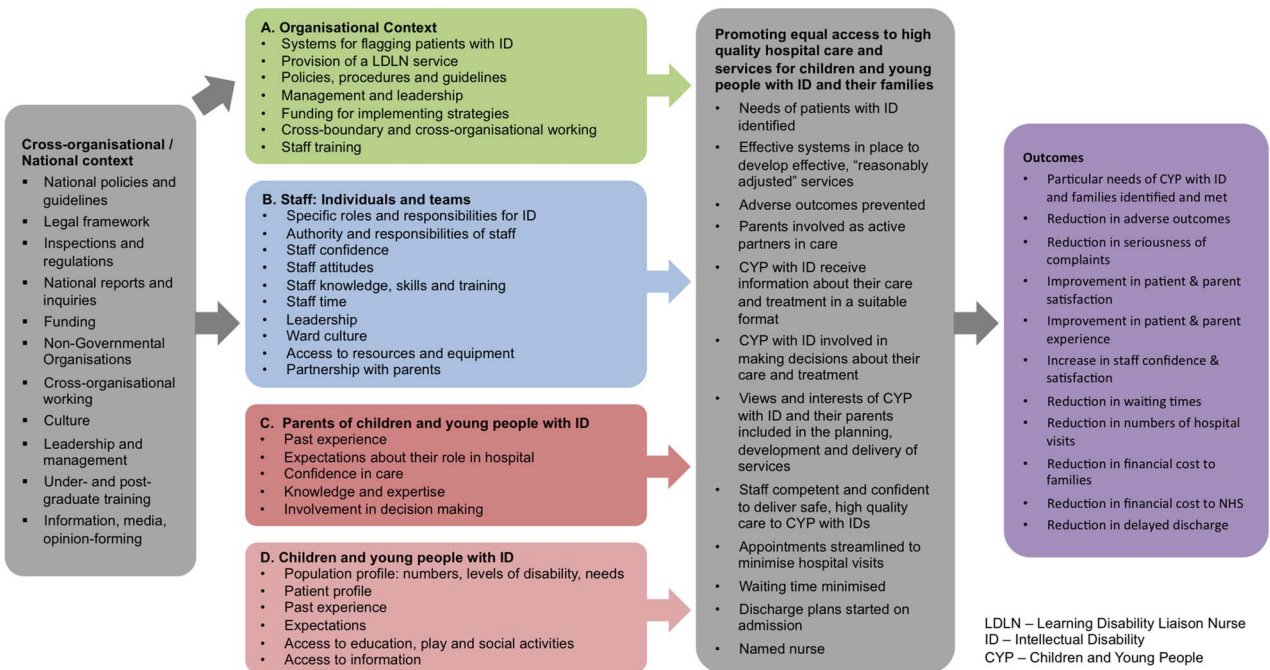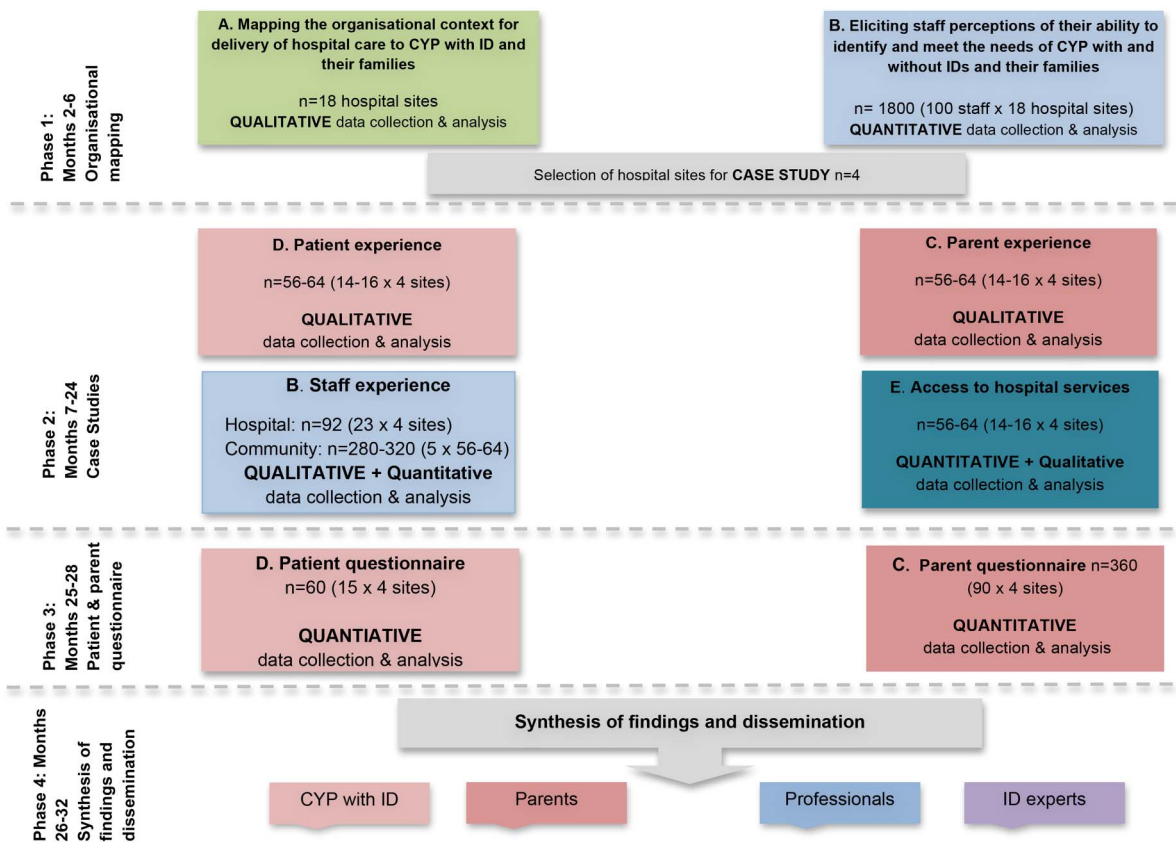
Figure 1 Theoretical framework.

Figure 2 Phases of data collection.

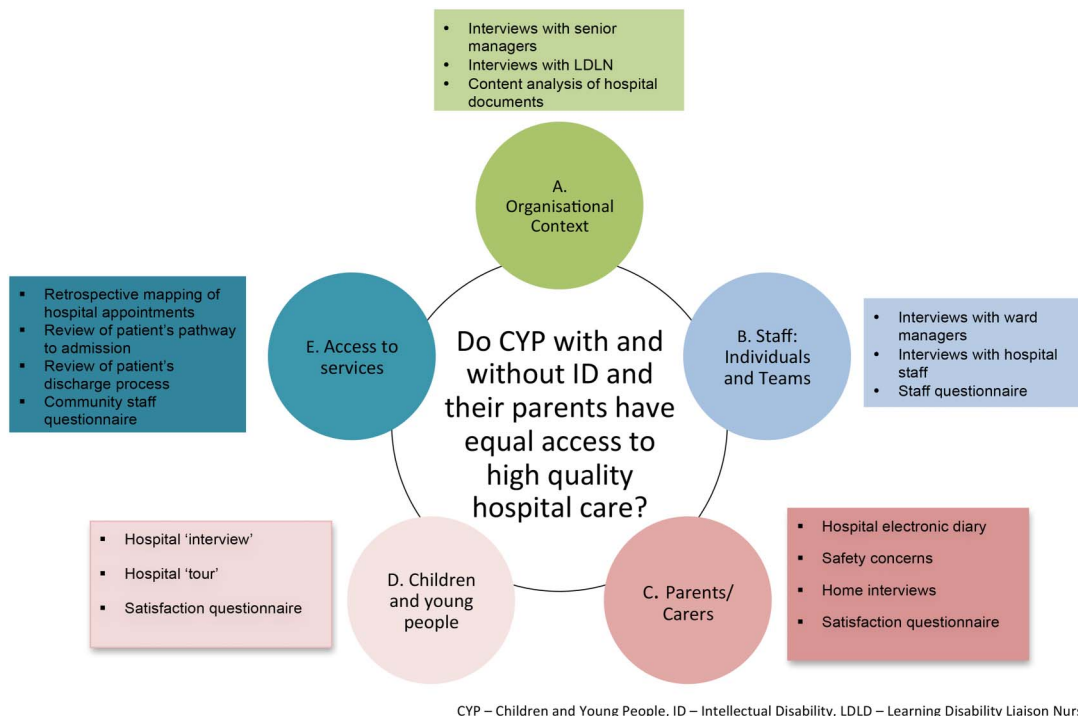CYP – Children and Young People, ID – Intellectual Disability, LDLD – Learning Disability Liaison Nurse

Figure 3 Strands of qualitative and quantitative data collection.

hospitals, in urban and rural locations to be included. To be eligible for selection, non-specialist hospitals must have at least two children's ward and be within reasonable distance of the children's hospital to aid data collection between the two sites. The sampling strategy for all phases is shown in table 1.

Phase 2: case studies

Selection of hospital sites for phase 2 will be a four-step process:

1. *Assessing eligibility*: Hospital sites will only become eligible for phase 2 if they demonstrate accessibility to sufficient numbers of CYP with and without ID and good hospital engagement. Good hospital engagement will be assessed by the core research team on two criteria: (1) timely research and development approval and engagement from the named local collaborator, and (2) timely completion of data collection activities.

2. *Ensuring variability*: To ensure site variability in amount of ID provision, eligible hospitals will be grouped by the core research team according to whether they have a lot, a little, or no initiatives/appointments of an ID professional with a remit to improve care for CYP with ID.

Table 1	Sample strategy and characteristics		
Phase	**Participants**	**Sampling strategy**	**Sample size**
1	Senior managers/LDLN	Senior managers from the trust identified by the local collaborator as having relevant knowledge of hospital services and provision. All staff with a defined role for CYP with ID.	36–54
	Hospital staff	All clinical and non-clinical staff with contact with CYP and their families will be invited.	1800
2	CYP and parents	A purposive sampling strategy using a sampling matrix to ensure diversity according to level of ID, age, ethnicity.	56–64 CYP 56–128 Parents
	Hospital staff	All ward managers on each study ward will be invited. A purposive sample of hospital staff identified by parents or CYP as making a difference to their care.	12 ward managers 112–128 hospital staff
	Community staff	All community professionals named by parents as being involved in the care of their child.	280–320
3	CYP and parents	All CYP and parents discharged from participating wards.	60 CYP 360 Parents
CYP, children and young people; ID, intellectual disability; LDLN, learning disability liaison nurse.			

3. *Designing scoring criteria*: Members of the Study Steering Committee will then be asked to design scoring criteria to enable objective selection of the sites for phase 2 based on:
   1. The strength of organisational context for delivery care to CYP with ID;
   2. Staff's perceived ability to identify and meet the needs of CYP with ID;
   3. Initiatives/appointments of an ID professional with a remit to improve care for CYP with ID.
4. *Applying scoring criteria*: The scoring criteria developed by the Study Steering Committee will be applied by the executive research team and sites will be selected on that basis.

Sites will be anonymised to prevent selection bias.

Operational definition of ID

The theoretical definition of ID is not always easily operationalised in practice. Among very young children, only severe ID is likely to be apparent[36] and some CYP never receive a formal diagnosis of ID but remain categorised as having 'developmental delay' or a 'syndrome without a name'. Hospital staff do not always know what is meant by ID or which CYP on their ward have this diagnosis. A CYP will be classified as having an ID if any ONE of the following is documented in the medical notes:

1. The CYP has an ID.
2. The CYP has a condition that is always accompanied by some degree of ID, for example, Down syndrome.
3. The CYP has global developmental delay (GDD) and they are aged over 10 years old.
4. The CYP attends a school for Children with Special Educational Needs and their parent confirms the child has an ID.

We have adopted a broad approach to defining ID because it is precisely those issues around the identification of this population that need exploring.

CYP with ID will be broadly matched with another CYP with a long-term condition. They will be matched on four criteria: (1) age, (2) number of comorbidities, (3) expected length of stay, (4) reason for admission. The aim is to recruit two samples of CYP with and without ID who are of similar age, with equal complexity of health needs and who are admitted to the same hospital during the study period.

Inclusion and exclusion criteria

Table 2 summaries the inclusion and exclusion criteria for each of the participant groups.

Methods
Phase 1
Staff interviews (research questions 1–7)

Interviews with senior managers and LDLN will be semi-structured and conducted face-to-face or via telephone. The focus of interviews will be on the delivery of services to CYP with ID at the organisational level.

Content analysis of hospital documents (primary aim)

Hospital documents will be collected electronically and a content analysis conducted. The following documents will be included: Communication Policy, Admission and Discharge Policy, Complaints Policy, Child Protection Policy, the latest Patient Experience/Satisfaction Surveys and any specific ID Policy. A search and find exercise using predefined terminology (ie, learning disability, special needs, intellectual disability) will be used to ascertain references to CYP with ID and a thematic framework will be created based on content. The first set will be examined in detail and a simple coding frame developed for subsequent documents.

Staff questionnaire (research questions 1–3)

The staff questionnaire has been devised to elicit staff perceptions of their ability to identify the needs of CYP with and without ID and their families and provide high-quality care to effectively meet these needs. The questionnaire will focus on six key areas: staff knowledge, skills, training, confidence, time and resources. The questionnaire will be piloted to ensure it is acceptable and relevant to staff.

Phase 2
Interviews with CYP (research questions 1–3)

The Mosaic approach,[37 38] combining the 'traditional methodology of observation and interviewing with the introduction of participatory tools'[37] will be used to guide interviews with CYP. The aim is to have a toolkit of creative and digital techniques available that draw on each individual's strengths, thereby enabling them to share their experience and preferences in whatever way they are able and comfortable with. The primary method of data collection will be 'Talking Mats', a communication symbols tool consisting of a pictorial framework based on three sets of picture symbols—issues relevant to the topic, factors relating to each issue and emotions to allow participants to indicate feelings about each factor. The method is suitable for CYP of all ages and communication abilities and can therefore be offered to all participants irrespective of whether they have an ID. Arts-based activities, photography and a hospital tour[39–42] are other ways that CYP will be able to share their views. Data collection sessions will take place in a quiet room on or close to the ward, depending on each CYP's personal preference and health needs. Some CYP, including those with ID, may find it difficult concentrating for long periods of time and in these circumstances a few short sessions may be preferred to one longer session. CYP and parents will guide the researcher as to what would be most appropriate. Young people's preference for their parent(s) to be present or absent during the sessions will be respected.

Parent electronic diary (research questions 1–3)

Parents will be given an android 'tablet' (password-protected and security-tagged) and invited to complete

Table 2 Inclusion and exclusion criteria

Participants	Inclusion criteria	Exclusion criteria
CYP with ID	Aged 4–18, known ID (as defined above) Expected minimum inpatient stay of 3 nights	Acute health problem only
CYP without ID	Aged 4–18 Expected minimum inpatient stay of 3 nights	Acute health problem only
Parents	Is able to speak English (phase 2 only) Is able to read English or one of five languages selected for translation (phase 3 only)	None
Hospital staff	Is involved in the care of one of the CYP recruited to the study	None
Community staff	Is attached to one of the recruiting wards	None

CYP, children and young people; ID, intellectual disability.

a hospital diary during their child's inpatient admission. This will be preinstalled with a virtual notebook for simply and instantly uploading audio and video files, photographs and written comments. Parents will be encouraged to document their thoughts and feelings in relation to key events during their hospital stay such as admission, discharge and their child's investigations and treatments. Parents will have a choice about whether and when to share uploads, thereby giving them control about what becomes data. We know that parents can be reluctant to leave their child to be interviewed, even for short periods—an electronic diary offers flexibility in how they tell their story and can be completed at any time of the day/night. By incorporating the use of novel, digital research methods, we aim to give parents flexibility and enhance the findings through the capturing of 'live data'. Parents will also be offered a paper diary as an alternative to the 'tablet'.

Home interviews with parents (research questions 1–3, 5)

Home interviews will be conducted with parents as soon as possible after discharge from hospital, preferably once the child/young person has returned to school. The interview guide will focus on parents' experience of accessing and using hospital care and services for themselves and their child. Data recorded on the parent diary will be used as a further prompt. Questions about the child's pathway to admission and their experience of discharge will be included. Parents will also be asked to identify up to five staff who made a 'difference' (positive or negative) during their child's admission, one to two of whom will be invited for interview. Details of community professionals in contact with their child will also be collected. Parent interviews are expected to last 1–2 hours.

Interviews with hospital staff (research questions 1–3, 5, 7)

Semistructured interviews with hospital staff will be conducted face-to-face or by telephone. They are expected to last 30–60 min. Flexibility will be provided as to the timing and location of interviews to minimise staff burden.

Completion of the 'daily safety reporting tool' (research question 5)

In light of qualitative evidence that parents of CYP with ID can lack confidence that their child is receiving high-quality hospital care and subsequently feel responsible for monitoring their care, parents will be asked to complete an adapted version of the daily safety reporting tool[43]—a six-item tool which asks parents to identify their safety concerns in terms of: medication, communication and information, equipment, unexpected complications of care, hygiene/cleanliness and other safety problems. Completion of the tool will enable perceptions of safety between the two groups of parents to be compared. Information collected will be used as a prompt during home interviews.

Retrospective mapping of hospital appointments (research question 2)

For each CYP, a retrospective mapping will be conducted of all inpatient stays and outpatient appointments for the previous 2 years using the electronic hospital appointment system to retrieve a range of data (table 3).

Questionnaires by community-based professionals (research questions 1–3)

Community professionals named by parents as being involved in the care of their child will be sent an anonymised questionnaire in the post, with a stamped address return envelope. The questionnaire will be a modified version of the hospital staff questionnaire from phase 1 with a particular focus on access to secondary and tertiary care for CYP with and without ID.

All interviews conducted during phase 1 and phase 2 will be recorded and transcribed verbatim with participant's permission.

Phase 3
Patient and parent satisfaction questionnaire (research question 4)

There is a lack of validated patient/parent satisfaction questionnaires, particularly for CYP and those with ID. Drawing on the best available tools (http://www.chimat.

Table 3 Data for retrospective mapping exercise

Inpatient admissions	Outpatient appointments
Age of patient	Age of patient
Diagnosis	Diagnosis
Date of admission	Date of appointment
Admitting ward	Time of appointment
Admitting team	Admitting team
Reason for admission	'Did not attend' status
Anticipated date of discharge	Reason for 'Did not attend' status
Date of discharge	
Discharge location	

org.uk/default.aspx), a questionnaire will be purposefully designed to answer the research question. Multiple versions of the questionnaire will be developed for CYP across the age range and with differing levels of cognitive functioning. Questionnaires will be piloted with a group of CYP with and without ID and their parents beforehand. A sealed box will be available on the ward for participants to leave their completed questionnaire prior to discharge and free post envelopes will also be available for return by post.

Phase 4
Dissemination workshop
A workshop will be held towards the end of the study for CYP, parents, professionals and experts in the field of ID to disseminate findings and decide the content of a DVD and/or training package that will be used in practice to inform students and staff about the barriers and facilitators to the delivery of high-quality care for CYP with ID and their families.

Data analysis
A model for mixed methods data analysis[1] will be used. Qualitative and quantitative data will be analysed within each phase using appropriate methods before merging and connecting them through a period of data synthesis. During data synthesis, the research team will use quantitative data to explain and illustrate qualitative findings, and look for congruence and incongruence between qualitative and quantitative findings. In particular, the team will look for instances where there is incongruence between policy and practice, using specific queries within the NVivo programme to address these issues and explain any incongruence. It is at the stage of data synthesis that barriers and facilitators to ensuring CYP with ID and their families receive equal access to high-quality hospital care and services will be highlighted, looking for specific examples of successful and effective measures that promote equal access. The final analytical framework will be compared with our theoretical framework and the initial common analytical framework, in order to generate a final empirical framework of factors that affect the promoting of equal access to high-quality

hospital care for CYP with and without ID and their families.

Qualitative
Multiple sets of qualitative data will be generated from this study that are best analysed inductively using the framework method. This matrix based analytic method facilitates rigorous and transparent data management 'such that all the stages involved in the "analytic hierarchy" can be systematically conducted'.[44] The method involves five distinct, but highly interconnected stages: familiarisation; identifying a thematic framework; indexing; charting; mapping and interpretation. The strength of using framework is that it allows easy access to the synthesised data so that it can be continually revisited, which is important when conducting multicentred, mixed methods research over four phases. The approach enables data to be examined within cases across a range of different themes, thereby facilitating comparisons to be made between and within case study sites. Furthermore, the process is well suited to research involving group-level and individual-level analysis. The data will be managed using NVivo, a qualitative data analysis programme.

Quantitative
Separate quantitative analyses will analyse
1. *Hospital staff questionnaire data (phase 1).* Analyses will follow previous studies of staff questionnaires of patients with ID in hospitals.[7] Descriptive comparisons for each of the six key areas of the questionnaire between responses pertaining to CYP with and without ID will be presented (eg, frequencies, percentages, means and SDs, medians and IQRs). Comparisons will also be presented for subgroups of respondents categorised by staff group (eg, doctors, nurses, professions allied to medicine, non-clinical staff), staff grade and site.
2. '*Safety concerns' data using the daily safety reporting tool (phase 2).* Number and type of safety concerns will be compared and analysed descriptively.
3. *Community-based staff questionnaire (phase 3).* Responses will be compared descriptively and analysed in the same way as for the hospital staff data, described above in 1.
4. *Parent and patient satisfaction with hospital care (phase 3).* Responses to this questionnaire will be compared descriptively and analysed in the same way as for the hospital staff data, described above in 1.

ETHICS AND DISSEMINATION
This study includes data collection involving vulnerable CYP. The research team has long-standing expertise in conducting research in sensitive areas. A range of steps will be taken in order to safeguard all informants from undue harm in accordance with the principle of beneficence. We will pay particular attention to obtaining

assent/consent from research participants with ID, using a range of accessible study information materials combining words, pictures and symbols as well as a talking photo album. A model of individualised assent, developed in line with the latest guidance from the Nuffield Council on Bioethics,[45] will be used to ascertain whether CYP are able to say what they think about the research and to make an independent decision about taking part. We will pay particular attention to the various ways in which CYP may express their wish to withdraw from the study and their response to the ending of the research relationship. An awareness of the issues associated with collecting data in the hospital setting is important to minimise risks to participants, for example, where children may be too unwell to take part in data collection activities or under infection control restrictions, being otherwise occupied with tests and treatments or being overheard by other patients and staff. A particular ethical issue associated with case study research is maintaining participant confidentiality. While it is impossible to prevent staff from knowing that a family is taking part because data collection is taking place on the ward, strict coding and anonymisation procedures will be used to ensure their data remain confidential. When publishing results, care will be taken not to report information that will enable research sites or individuals to be identified, for example, in relation to rare conditions, provision of rare treatments or geographical location.

The primary output will be guidance for commissioners and providers of NHS hospital services for CYP with ID and their families. Following synthesis of the findings and the dissemination workshop, the Executive Research Team will consult widely with members of the Steering Committee, Parent and CYP Advisory Groups about the content and format of guidance document and the wider implementation strategy. We will engage with the Association of Chief Children's Nurses and the senior management from all phase 1 sites, as well as professional bodies such as Royal College of Paediatrics and Child Health (RCPCH) and relevant third-sector organisations such as the British Institute of Learning Disabilities (BILD).

We will disseminate the results of the study through international peer-reviewed journals and national and international conferences. We will develop a social media strategy to ensure ongoing dissemination of findings and user engagement throughout the project, and to build a network/community of interested users/stakeholders. A report of the study findings will be sent to participants in a range of accessible formats.

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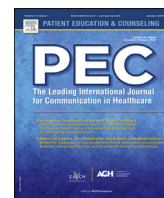
Parent activation and pediatric primary care outcomes for vulnerable children: A mixed methods study

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ABSTRACT

Objective: Among children in low-income families 1) examine associations between parent activation and pediatric primary care outcomes and 2) explore parent perspectives on Parent-Patient Activation Measure (P-PAM) questions in relation to pediatric primary care experiences.
Methods: We examined associations between P-PAM score via Spanish- or English-language survey and healthcare outcomes abstracted from electronic medical records for parent/child dyads at an urban general pediatrics clinic. Parent perspectives were elicited via qualitative interviews with a subsample of parents who "thought aloud" during P-PAM completion.
Results: Among 316 Spanish (68%) and English-language parent/child dyads, we found associations between parent activation and primary care outcomes only among Spanish-language dyads and only for weight and health status. Findings from 21 interviews provided possible explanations for quantitative findings including question limitations in assessing knowledge, skills, and confidence in pediatric primary care and P-PAM cultural and linguistic appropriateness for low-income Latino populations.
Conclusions: Pairing quantitative and qualitative methods provided insight on P-PAM measurement limitations and raised questions about its use in patient engagement interventions to reduce health disparities.
Practice implications: Practices serving vulnerable children and families should consider the limitations of the P-PAM for measuring parent healthcare engagement before utilizing the P-PAM in patient engagement interventions.

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1. Introduction

Low-income children are at high risk for health conditions that negatively impact their lifelong health including trauma, obesity, asthma, and delayed identification of developmental/behavioral disorders [1–4]. Lifecourse health promotion through illness prevention, early detection, and addressing the social determinants of health are foundational principles of pediatric primary care. [5,6]. The success of pediatric primary care at supporting low-income families in promoting and managing their children's health, may depend in part on family healthcare engagement [7]. Individual-level patient engagement has been characterized as patient activation – a patient's or caregiver's confidence, knowledge, skills, and willingness to manage their health and healthcare [8,9]. Higher activation scores, as measured by the Patient Activation Measure (PAM), have been shown to be associated with improved health and healthcare outcomes and decreased healthcare costs across varied health conditions and among low-income, vulnerable adult populations [8–13]. Interventions focused on increasing activation among adults at risk of health disparities have demonstrated efficacy in increasing activation with subsequent improvement in adult health and healthcare outcomes [8,14]. Based on these findings there is a particular interest in targeting parent activation as a mechanism to reduce healthcare disparities for children, but there is limited research to date in this area.

The Parent Patient Activation Measure (P-PAM) was adapted from the PAM for use with parents in pediatric healthcare. We reported previously that the P-PAM had acceptable reliability, but

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that the underlying factor structure generated concerns about whether the P-PAM is measuring the same construct as the PAM [15]. Other studies have since raised similar concerns [16]. Additionally, the generally higher P-PAM scores compared to PAM scores and differing patterns of association with family sociodemographics and health/healthcare outcomes have raised further questions about the P-PAM's application in child health research [16–18]. Critical next steps in understanding the implications of previously described differences between the PAM and P-PAM include more data on associations between P-PAM scores and pediatric healthcare outcomes and parent perspectives on P-PAM questions in relation to healthcare experiences. It is of particular importance to focus on populations at risk of health disparities in this exploratory research on the P-PAM. Different responses to patient engagement measurement or interventions among vulnerable populations may worsen healthcare disparities, particularly given the current focus on healthcare engagement as a key means of healthcare improvement. Among children, those most at risk of health and healthcare disparities include low-income, publicly-insured children. Nearly 40% of children have public health insurance coverage, and the majority of parents of these children speak either English or Spanish [19,20]. Accordingly, the purpose of this mixed methods study was to inform use of the P-PAM among parents of low-income, publicly-insured children by addressing the following two aims: 1) Determine the associations between P-PAM score and pediatric primary care outcomes among children of Spanish- and English-speaking parents and 2) Utilize cognitive interviewing techniques to elucidate parents' thought processes while responding to P-PAM questions to explore parent perspectives on Parent-Patient Activation Measure (P-PAM) questions in relation to their pediatric primary care experiences.

2. Methods

2.1. Study setting and design

We conducted a mixed methods study utilizing the following data sources: cross sectional data from a previously reported survey of parents including the P-PAM and electronic medical record (EMR) abstraction, and qualitative interviews with a diverse sample of low-income parents/legal guardians (referred to as "parents") [15]. The Institutional Review Board at Johns Hopkins Medicine approved this study. All participants provided informed consent after the Spanish or English language consent form was read to them and understanding affirmed.

The primary survey measure, the P-PAM, was designed to evaluate parents' knowledge, skills and confidence in managing their child's health and healthcare. The P-PAM is licensed by Insignia Health and was used with their permission [21]. Study inclusion criteria were: child ages 6 months-5 years with public health insurance who had been a patient at the urban general pediatrics clinic for at least 6 months, minimum parent respondent age of 18 years, and preferred healthcare language of English or Spanish. A convenience sample of participants was recruited and asked to consider only one of their children in the specified age range when responding to survey questions based on the child present for an appointment that day. Surveys included: information about the parent and family, information about the index child and their health status and the P-PAM. Additional information about survey content, administration, study recruitment and the P-PAM measure characteristics in this study sample are reported elsewhere [15].

2.2. Electronic medical record review

The following pediatric primary care outcomes were abstracted from the EMR for each index child for the 12 months (since birth for children <12 months) prior to survey completion via a standardized abstraction form: most recent weight and length, up-to-date (UTD) well visits, number of ED visits in the past year, UTD immunizations, receipt of flu shot, and lead screening. The American Academy of Pediatrics Bright Futures periodicity guidelines were used to determine age-specific criteria for number of well visits to be considered as up-to-date [22]. We assessed clinic utilization as sick or well care based on both billing codes and review of the note to verify a well care visit was completed. ED use was available for any location in the health system owing to a shared EMR. ED use was categorized as any vs. none in the past year. Children were designated as having UTD routine immunizations based on the age-specific schedule used in the clinic that is derived from the Centers for Disease Control and Prevention Recommended Immunizaton Schedule [23]. Children with UTD lead screening had EMR documentation of a lead level in the past year. This outcome included only children who would have had a well visit when this screening is typically obtained (12- or 24-month well visit).

2.3. Qualitative interviews

To select interview participants we stratified survey participants by education (some high school vs. less than a high school education), activation level as determined by P-PAM score (high (activation level = 3–4) vs. low (activation level = 1–2)), and survey language (English vs. Spanish). Within each of these strata, we phoned participants in order based on a random number sort and asked them to participate in an interview. A single bilingual (English/Spanish) interviewer of Honduran descent with significant prior community research experience completed interviews in the participant's home or a private research space based on participant preference. Participants received $30 remuneration. Twenty-one interviews were completed between June and October 2015. There were no significant differences between interview participant characteristics and the remainder of the study sample. During the interview, parents were asked to "think aloud" while answering P-PAM questions to understand if participants' interpretation of survey items matched what the survey question was intended to measure. Participants were also asked open-ended questions related to the topics covered in the P-PAM and their experiences using the healthcare system. The interview guide is included as a supplement. Digitally audio-recorded interviews were transcribed verbatim and Spanish language interviews were also translated into English using a commercial transcription and translation service.

2.4. Data analyses

All statistical analyses were conducted using STATA/SE Version 14 (StataCorp LP, College Station, TX). We compared sociodemographic characteristics, activation score, and pediatric primary care outcomes using chi-square statistics and student's t-tests, assuming unequal variance. Qualitative data analysis was completed using Dedoose, an online qualitative and mixed-methods analytics program [24]. The study team reviewed interview transcripts to identify preliminary themes. The coding team (LRD, NS, DVA) developed a codebook based on these themes and used an iterative consensus process to determine clear definition of codes and consistent application by all coders. Coders were not aware of survey activation score or level during coding to address bias in identification and assessment of parent health/healthcare engagement behaviors in transcripts. During initial development and use of the codebook, all three coders coded five transcripts. The remaining transcripts had one primary coder and a secondary verification coder. Rather than utilizing a measure of intercoder

reliability, we used established methods for addressing differences in coding due to multiple coders by addressing all coding discrepancies and reconciling them with discussion and consensus [25,26].

3. Results

We present analyses based on 316 completed parent surveys with review of corresponding child EMR data and 21 semi-structured parent interviews. Characteristics of the parent, family, and index child stratified by language of survey administration are presented in Table 1. As previously reported, mean P-PAM score and activation level were significantly lower among Spanish-language (SL) parents compared with English-language parents (EL) [15].

Pediatric primary care outcomes and their relation with activation by language group are presented in Table 2. Among the outcomes, none were associated with activation among EL parents. For SL parents, however, mean P-PAM score was *higher* if their child was overweight versus normal weight, while the mean P-PAM score was *lower* if their child had fair or poor health status versus more favorable health status. SL parents were more likely to report fair or poor child health status than EL parents. Children in

the SL group were more likely to have UTD well visits, immunizations, and have received the flu vaccine in the past year.

We identified four overarching themes from our interviews with parents to explore their thought processes when responding to P-PAM questions: 1) The home/family unit is central to child health; 2) Healthcare system challenges can prevent or undermine activation; 3) Selecting a response can be difficult as parents weigh the tensions between having particular knowledge and skills and recognizing limitations; and 4) There are cultural and linguistic influences on P-PAM responses. These themes were evident across activation levels of participants.

Theme 1: Centrality of home/family unit to child health

The theme that home/family unit is central to child health was most evident during discussions regarding parent responses to P-PAM questions numbers 1 and 3: "I am the person responsible for my child's health," and "I am confident that I can prevent or reduce problems associated with my child's health." When parents were asked why they agreed with these statements, they commonly cited their duty as parents (Table 3, Quotes 1–3). Their elaborations on reasons for choosing their P-PAM responses to questions particularly focused on health-promoting behaviors in the home related to diet and nutrition (Quotes 4 and 5). When parents were asked about taking an active role in their child's health,

Table 1

Characteristics of 316 parents and children. Data are presented as mean (SD) or n (%).

Characteristic		English[†] n = 102	Spanish[†] n = 214	p-value
Parent age (years)		27.8 (7.7)	29.4 (5.7)	**0.065**
Parent female gender		87 (86%)	204 (95%)	**0.004**
Parent race/ethnicity				**<0.001**
	Non-Hispanic Black	41 (40%)	0 (0%)	
	Non-Hispanic White	15 (15%)	0 (0%)	
	Hispanic/ Latino	24 (24%)	210 (99%)	
	Other/ mixed race	22 (22%)	3 (1%)	
Foreign-born parents		23 (23%)	211 (99%)	**<0.001**
Parent's Years in the US		15.1 (6.2)	8.3 (4.0)	**<0.003**
Country of origin:				**<0.001**
	Mexico	7 (32%)	78 (37%)	
	El Salvador, Honduras, Guatemala	4 (18%)	109 (52%)	
	Other Latin American countries	1 (5%)	22 (11%)	
	All other countries	10 (45%)	0 (0%)	
Annual family income				**<0.001**
	<$20,000	46 (45%)	101 (47%)	
	$20-30,000	18 (18%)	35 (16%)	
	>$30,000	24 (24%)	14 (7%)	
	Did not know/Refused	14 (14%)	64 (30%)	
Number of children in household		2.0 (1.0)	2.0 (1.2)	0.421
Child age (months)		29.4 (18.8)	27.6 (17.2)	0.420
Child with chronic condition[††]		30 (29%)	48 (22%)	0.003
Parent education				**<0.001**
	<High School	28 (27%)	157 (73%)	
	High school or GED	41 (40%)	44 (21%)	
	Some post-secondary	33 (32%)	13 (6%)	
Parent English proficiency				**<0.001**
	Very well	89 (87%)	4 (2%)	
	Well	12 (12%)	25 (12%)	
	Not well/Not at all	1 (1%)	184 (86%)	
Parent health literacy (Newest Vital Sign)				**<0.001**
	High likelihood of limited literacy (0-1)	29 (28%)	158 (74%)	
	Possible limited literacy (2-3)	34 (33%)	35 (16%)	
	Adequate literacy (4-6)	39 (38%)	20 (9%)	
Parent Activation				
Mean PPAM Score (SD)		79.1 (16.2)	70.7 (17.9)	**<0.001**
Median PPAM Score (range)		76.4 (53.2, 100)	65.5 (42.2, 100)	**<0.001**
PPAM Level				
1		0 (0%)	6 (3%)	**<0.001**
2		2 (2%)	31 (14%)	
3		37 (36%)	84 (39%)	
4		63 (62%)	93 (43%)	

[†] Denotes language of survey completion, selected based on parental report of preferred healthcare language.

[††] Obtained from EMR, includes: asthma, prematurity, developmental disorder or delay, congenital heart disease, Trisomy 21, chronic kidney disease, musculoskeletal or ocular disorders.

Table 2
Parent activation and prevalence of pediatric primary care outcomes by parent language.

	Parent Language					
	English (n = 102)			Spanish (n = 214)		
Characteristic	N (%)	Mean PPAM Score (SD)	p-value[*]	N (%)	Mean PPAM Score (SD)	p-value[*]
Well Visits up-to-date[†]						
Yes	65 (64)	80.1 (16.3)	0.431	166 (78)	71.8 (18.5)	0.069
No	37 (36)	77.4 (16.1)		48 (22)	66.9 (15.4)	
ED visit in the past year (EMR)						
Yes	45 (44)	76.7 (15.8)	0.175	88 (41)	69.8 (18.0)	0.524
No	57 (56)	81.0 (16.4)		126 (59)	71.4 (18.0)	
Immunizations up-to-date[†]						
Yes	77 (76)	78.3 (16.1)	0.242	187 (87)	71.3 (18.1)	0.216
No	24 (24)	82.7 (16.0)		27 (13)	67.9 (16.3)	
Received flu shot [†]						
Yes	65 (64)	77.6 (16.2)	0.216	168 (79)	70.4 (17.8)	0.659
No	37 (36)	81.8 (16.2)		26 (22)	71.8 (18.7)	
Screened for lead [‡]						
Yes	50 (93)	79.8 (16.7)	0.641	107 (91)	71.0 (17.7)	0.288
No	4 (7)	75.2 (17.2)		10 (9)	66.6 (11.3)	
Parent-reported child health status [†]						
Fair or poor	18 (18)	74.8 (17.6)	0.258	77 (36)	66.3 (17.7)	**0.007**
Good or excellent	84 (82)	80.0 (15.9)		137 (64)	73.2 (17.7)	
Weight Status						
Overweight or Obese[**]	27 (26)	78.5 (16.5)	0.821	80 (37)	74.2 (18.2)	**0.033**
Not Overweight or Obese	75 (74)	79.3 (16.2)		134 (63)	68.7 (17.6)	

[*] Student's *t*-test for differences in PPAM score by health outcome within the language group.
[†] Indicates that the distribution of the health outcome differs significantly (p < 0.05) among children in EL vs. SL families.
[‡] N = 54 EL group, N = 117 SL group.
[**] Children with BMI (age ≥ 2 years) or weight for length (age <2 years) greater than the 85th percentile were classified as overweight/obese.

parent-directed health behaviors in the home remained common, as well as taking their child to well-child and acute care visits and maintaining UTD immunizations.

Theme 2: Healthcare system challenges can prevent or undermine activation

The second major theme may explain the few associations between activation and pediatric primary care outcomes. Healthcare system challenges commonly were elicited by P-PAM question number 5: "I am confident that I can tell when I need to go get medical care and when I can handle my child's health problem myself." Many parents expressed confidence about their abilities to manage child illness at home and potentially avoid seeking medical care for acute illness, and they reported that this confidence increased with subsequent children (Quotes 6–9). However, acting on their engagement around childhood illness was fraught with challenges. Some parents reported phone advice from the clinic nurse as a facilitator to home management of illness, but the majority of parents who discussed phone advice did not view it favorably. Parents reported lack of trust in the nurse's advice compared with that of a physician and concerns about delaying needed medical care if the nurse's advice did not result in symptom resolution or a nurse call back was delayed (Quotes 10 and 11). Additionally, phone advice could not be accessed uniformly; Spanish-speaking parents often reported language barriers as compromising their ability to use the phone triage system (Quote 12). When parents felt their children's illness merited in-person medical care or were advised to seek in-person care through the phone advice, they commonly reported that a lack of prompt sick care availability at the clinic resulted in ED or urgent care use (Quotes 13 and 14). Another system-level factor compromising healthcare engagement was maintenance of public health insurance. While no P-PAM question asks about health insurance, parents reported difficulties with public health insurance while elaborating on their reasons for responses to other questions. For example, some reported missing preventive care appointments and vaccine delays due to insurance gaps due to a cumbersome renewal process (Quote 15). SL parents also

reported that limited availability of interpreters or bilingual staff in the social services sector made renewal challenging.

Theme 3: Difficulty selecting a response as parents weighed tensions between having particular knowledge and skills and recognizing limitations

The third P-PAM question, "I am confident I can help prevent or reduce problems associated with my child's health," was often problematic for generating a response that accurately represented parents' confidence. Parents believed that they could have an effect in some domains, such as diet, but that not all things could be prevented. When faced with this tension, parents made different decisions about their degree of agreement (Table 4, Quotes 16 and 17). Question number 8, which probes understanding of the child's health problems and what causes them, caused similar tension. Parents expressed they had some understanding, but did not know everything (Quote 18). Some parents expressed that the question appeared to ask two different things and they did not have the same answer for both domains of the question (Quote 19). Other questions, such as knowledge of available treatments and how to prevent problems, also elicited tension in response formulation due to parents' honest appraisal that they did not or could not know everything about possible treatments or prevention strategies (Quote 20).

Theme 4: Cultural and linguistic influences on P-PAM responses

Among SL parents, P-PAM question 2: "taking an active role in my child's healthcare is the most important thing that affects his/her health" resulted in identification of cultural and linguistic influences on responses. Taking an active role is an idiomatic expression for which the appropriate translation to Spanish is not clear. The language used for question 2 back translates most closely to "actively participating," but SL participants often asked for clarification on what this meant (Quote 21). In responses to other questions, however, parents commonly used the phrase "estar pendiente," to describe examples of "taking an active role." Estar pendiente can be translated as "to attend to," "manage" or "be on top of." Parents emphasized the importance of being "pendiente" in positively affecting their child's health and healthcare (Quotes 22–24).

Table 3
Parent Perspectives on the P-PAM: Themes 1 and 2[*].

<u>**Theme 1: Centrality of home/family unit to child health**</u>

Quote 1
Because you're home with them. You're with them all the time. You can't expect a one-time visit to fix everything with the doctor. You're the one that needs to care for them 24/7, so I feel like I am the big part of their health. -*Activation Level 3*

Quote 2
Porque nosotros somos los, nosotros somos los que tenemos que cuidar a los hijos, durante el día, al final del día, todo el día.
Because we are the ones who, we are the ones who have to care of our children during the day, at the end of the day, all day. -*Activation Level 2*

Quote 3
[. . .] yo trato de ser la mejor madre que puedo pues trato de pues, ¿cómo se dice? De decirles lo que está bien, lo que no está bien, que se tienen que lavar sus manitas, todo eso acerca de la higiene y todo eso.
[. . .] I try to be the best mother that I can so I try to, well, how do you say it? To tell them what's good, what's not good, that they have to wash their little hands, all of that regarding hygiene and everything.
-*Activation Level 4*

Quote 4
Porque ellos la pasan con uno las 24 horas del día, y uno, más que todo – bueno, hay cosas que uno no puede evitar, como la gripe o todo eso, pero enfermedades, porque cualquier enfermedad proviene de las comidas, la mala alimentación. Muchas enfermedades provienen de ahí, de la mala alimentación, que uno no come saludable. Entonces yo creo que ahí, yo pienso que ahí tiene mucho que ver. Si uno cuida lo que come uno se va a mantener saludable.
Because they're with us 24 hours a day, and you mostly – well, there are some things that one can't avoid, like the flu or whatnot. But as for diseases, because diseases can come from meals, bad nutrition. Many diseases come from that, a poor diet, when you don't eat healthy. So I think that [diet], I think that has a lot to do with it. If you watch what you eat you will stay healthy. -*Activation Level 2*

Quote 5
Porque los padres siempre tienen más la responsabilidad de estar pendiente de lo que comen, elegir lo que les compras o no les compras en la casa. Porque depende de lo que tú les – como padres, si yo les compro chucherías a los niños en la casa, van a comer puras cosas malas, si yo les compro cosas buenas pues van a poder elegir, entonces es mi responsabilidad.
Because the parents always have the main responsibility of being aware of what they eat, to choose what to buy them or not buy them at home. Because it depends on what you – as parents, if I buy the children junk food at home, they're going to eat all bad things. If I buy them good things, well, they're going to be able to choose. So, it's my responsibility. -*Activation Level 1*

<u>**Theme 2: Healthcare system challenges can prevent or undermine activation**</u>

Quote 6
Le checo la temperatura y le doy Tylenol, que es lo que recomiendan, Tylenol o Motrin y le doy eso y ya si veo que no se le quita entonces ya decido llevarlo al doctor, pero si no yo lo mantengo en casa.
I check his temperature and I give him Tylenol, which is what they recommend, Tylenol or Motrin, and I give him that and if I see it's not going away then I decide to go see a doctor, but if not I keep him at home. -*Activation Level 2*

Quote 7
Pues por lo mismo, una sabe cuando sus hijos se sienten bien, cuando yo puedo curarle la gripe o bajar la temperatura, entonces uno se lo hace en su casa. Cuando uno no puede, pues también es mejor acudir al doctor a que lo cheque, a que lo revise él y ya.
For the same reason, one knows when your children feel good, when I can cure a cold or lower their temperature, so you do it at home. When one can't, it's also better to go to the doctor to have it checked out, to have him check it out and that's it.- -*Activation Level 4*

Quote 8
Yeah. Most of the time I don't bring him to the doctors because it's the same thing over: a diaper rash, a fever. I have all the medicines for his symptoms. So I'm confident that I can take care of him rather than bringing him to the hospital unless he's very ill like ear infections.- -*Activation Level 4*

Quote 9
I think I got better. I got better after each child. With the first, every little thing: emergency room . . . Because sometimes I think there's something, you gotta give it time. Not every little prick, every little high temperature, you gotta run. Maybe you can control it at home, so I feel I strongly agree with that now. -*Activation Level 3*

Quote 10
[. . .] There's no one else medically that I know that could help me, be like, "Okay, well, what else can I do?" There's no one else besides calling them, and it's not like you talk personally to the doctor. You get transferred to this person, transferred to that person, and you talk to the nurse. Then the nurse calls you back, so you never really talk to the doctor unless you really go in person and see them.
-*Activation Level 3*

Quote 11
Return phone calls in a more timely manner. The last time I called, I had called about – he had a really bad diaper rash, where you could see pink and skin was majorly coming off. And I called, and it took about four days for the clinic to call back. And by then I kinda got it under control, but I didn't appreciate the four-day wait when the automated system says we'll call you in 24 hours. So that could be done a lot better.- -*Activation Level 3*

<u>*Subtheme 1: Phone system challenges for Spanish-speakers*</u>

Quote 12
Uno puede llamar a las enfermeras, pero a veces es un poco difícil hablar con las enfermeras . . . Porque por la línea de teléfono que te contestan en inglés, luego te mandan a una línea, luego te mandan a otra línea, y luego hasta que ya te contesta la enfermera y te dice que tienes que esperar, si no hay una enferma en español no te atienden entonces.
One can call the nurses. But at times it's a bit hard to speak with the nurses . . . Because they answer the telephone line in English. Then they send you to a line, then they send you to another line, and then until the nurse answers you and tells you that you have to wait. If there isn't a nurse in Spanish then they don't assist you. -*Activation Level 1*

<u>*Subtheme 2: Lack of prompt sick care availability*</u>

Quote 13
Porque muchas veces, como le digo, a veces los niños se resfrían y uno puede controlar eso en la casa, ya si como si los niños tienen demasiada fiebre entonces ya es como ahí llevarlos al hospital, pero hay veces que no es necesario porque siempre en las clínicas tienes que hacer cita y esperar 15 días, entonces tienes que llevarlo a emergencia, y en emergencia no te van a atender por una gripe . . .
Because many times, as I told you, at times the children catch a cold and one can control that at home. If the children have a high fever then you have to take them to the hospital. But there are times that it's not necessary because in the clinics you always have to make an appointment and wait 15 days. So, you have to take them to the emergency room. And at the emergency room, they're not going to treat you for a cold . . . -*Activation Level 1*

Quote 14
They take appointments, and they will see you for well child visits and immunizations, but I need a doctor for when my child is sick, most of all. And if I can't take you to the doctor that I know, and the doctor that has the records, when my child is sick, it's a little backwards. I'd rather take you to somebody that I don't know for a shot, which is just a state standardized shot than taking them to somebody I don't know for an actual health problem. It's a little backwards.- -*Activation Level 3*

<u>*Subtheme 3: Difficulties with public health insurance*</u>

Quote 15
I did [miss appointments] because of the insurance being cut off. I did reschedule multiple times when I thought the thing was situated, and it never was. -*Activation Level 3*

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[*] Spanish language quotes indicate quote is from an interview conducted in Spanish.

Table 4
Parent Perspectives on the P-PAM: Themes 3 and 4[*].

Theme 3: Difficulty selecting a response as parents weighed tensions between having particular knowledge and skills and recognizing limitations

Quote 16
I: Sí, estoy segura de que puedo ayudar a prevenir o reducir los problemas asociados con la salud de mis hijos.
Yes, I am sure I can help prevent or reduce the problems associated to my children's health.
R: Con la salud, pues sí, a veces si los puedo prevenir pero otras no.
Regarding their health, well yes, sometimes I can prevent them but others I can't.
I: ¿Sí? ¿Cómo tú lo haces?
Yes? How do you do it?
R: Hay enfermedades que no se pueden prevenir pero hay enfermedades a veces que uno sí puede cuidarlos.
There are certain illnesses that can't be prevented but there are other illnesses when one can take care of them.
I: So tú respuesta a esta pregunta es estás muy en desacuerdo, en desacuerdo, de acuerdo o muy de acuerdo?
So, your answer to that question is you disagree, strongly disagree, agree or strongly agree?
R: De acuerdo.
I agree.
-Activation Level 2

Quote 17
I: Okay. Te voy a hacer otra pregunta. Estoy segura que puedo ayudar a prevenir o reducir los problemas asociados con la salud de mis hijos.
Okay. I'm going to ask you another question. I'm sure I can help prevent or reduce the problems associated with my children's health.
R: Pues yo pienso que en algunas sí.
Well, I think in some, yes.
I: ¿Y cuáles son?
And what are they?
R: Digo yo que en lo que es la alimentación, lo que es el cuido, creo yo, físicamente, pero hay enfermedades que uno no lo puede evitar como padre.
I would say as far as food, caring for them, I think, physically, but there are diseases that one as a parent can't avoid.
I: Sí. ¿Y cuál es tu respuesta para esa pregunta, estás de acuerdo, o muy de acuerdo?
Yes. And what is your answer to that question, do you agree, or strongly agree?
R: Yo digo que no estoy muy de acuerdo porque hay cosas que uno no puede evitar.
I would say I don't quite agree with that because there are things that you can't avoid.
-Activation Level 2

Quote 18
I: Okay, entiendo cuáles son los problemas de salud de mi hijo y qué los causa. ¿Estoy muy de acuerdo, en desacuerdo, de acuerdo o muy de acuerdo?
Okay, I understand what my son's health problems are and what causes them. I strongly agree, disagree, agree or strongly disagree?
R: Ni muy de acuerdo ni muy en desacuerdo . . . a veces se enferman y no sé por qué se enfermaron y otras veces se enferman y sí sé por qué se enfermaron.
Neither strongly agree nor strongly disagree . . . sometimes they get sick and I don't know why they get sick, and then other times when they get sick I know why they did.
-Activation Level 2

Quote 19
I: [. . .] I understand my child's health problems, and what causes them.
R: Agree to an extent. I understand their problems. I don't know what causes them.
-Activation Level 3

Quote 20
I: Okay. I know what treatments are available for my child's health.
R: I know most of the treatments, not all.
I: So what would you say your answer would be for that one?
R: Oh, agree – agree. So most of the time, not strongly.
I: Why do you agree and not strongly agree?
R: Because, well, for example, some illness or sickness that my children had, they never had before. It was new to me so I didn't know what treatment to give them. But most of the time they sick I know what to give them and I deal with it . . . But sometimes I don't know. *-Activation Level 4*

Theme 4: Cultural and linguistic influences on P-PAM responses

Quote 21
I: El participar activamente en el cuidado de salud de mis hijos es lo más importante que afecta a su salud.
Participating actively in the health care of my children is the most important thing that affects their health.
R: No entiendo lo que dice.
I don't understand it.
I: Eso quiere decir que si tú actúas activamente en la salud de tus hijos eso es lo más importante en la salud de ellos.
It means that if you actively participate in the health of your children that is the most important thing for their health.
R: Claro, es importante. Nada, esa pregunta está medio confundida.
Of course, it's important. That question is rather confusing. *-Activation Level 2*

Subtheme 1: Estar pendiente

Quote 22
Yo siempre trato de hablar con los doctores de todos los síntomas que yo veo en mis hijos, de como ellos actúan. Yo no tenido problemas gracias a Dios con ellos porque ellos me hacen preguntas del bebé, de mis otros hijos. Por ejemplo, si yo tengo alguna duda, ellos siempre tratan de solucionarme y de estar pendientes de los niños.
I always try to talk with the doctors about all the symptoms I see in my children, and how they act. I haven't had any problems with them, thank God, because they ask questions about the baby, and my other kids. For example, if I have any questions, they always try to find a solution and look out for my children. *-Activation Level 4*

Quote 23
Siempre que les llevo a consultas como el WIC, a las vacunas y a todos los controles, yo siempre estoy activa y pendiente de todo, preguntándoles si está bien el peso, si la estatura.
Whenever I take then to appointments like WIC, for their vaccines, and everything that I control, I'm always active and aware of everything, asking if their weight is fine, if the height. *-Activation Level 4*

Quote 24
Porque yo tengo que estar al pendiente de ellos[los niños], que no se enfermen o por ejemplo lavarles las manos, que no se enfermen, abrigarlos bien en tiempo de frío.
Because I have to look out for them [my children], make sure they don't get sick or, for example, wash their hands so they don't get sick, that they are dressed warmly for the cold weather. *-Activation Level 2*

Subtheme 2: Respeto

Quote 25
No, siempre he tenido la confianza con ellos de, intento conocerlos y tener confianza con ellos, precisamente porque es el doctor de mis hijos.
No, I have always trusted them, I try to know them and have trust in them, precisely because he's my children's doctor. *-Activation Level 1*

Quote 26

Porque uno necesita saber y el doctor está para apoyarte, para decirte qué es lo que tienes que hacer, sí. Entonces el doctor está para apoyarte y para contestarte lo que necesites saber.

Because one needs to know and the doctor is there to support you, to tell you what it is that you have to do, yes. So, the doctor is there to support you and to answer what you need to know. -*Activation Level 1*

Quote 27

Porque a uno le digo que le da pena preguntar y uno está indeciso. ¿Le digo o no le digo? ¿será importante o no? Y sí ha habido ocasiones que uno dice, "no, mejor está bien, mejor así me voy".

Because I tell you that it makes you feel bad to ask a question or one is indecisive. Do I tell him or do I not tell him? Is it important or not? And, yes, there have been times that one says, "No, it's probably fine, I'll leave it like that." -*Activation Level 1*

Quote 28

Porque siempre que la llevo al médico, la doctora de mi niña habla español y siempre ella me respondió a todas las preguntas. A veces estoy poquito indecisa y ya le digo, "doctora, fíjese que la niña está así, no sé lo que necesito darle", y ella me explica todo. Esa es mi seguridad.

Because whenever I take them to the doctor, my daughter's doctor speaks Spanish and she always answers all my questions. Sometimes I am somewhat hesitant and I'll say, "Doctor, I noticed my little girl is like this, I don't know what to give her," and she explains everything. That's my safety.
-*Activation Level 4*

<u>Subtheme 3: Contextual factors</u>

Quote 29

A la grande yo la tengo en una clínica diferente que a la pequeña. A la pequeña la tengo en [la clínica] y a la grande en [otra clínica] y en ese aspecto yo siento la diferencia porque allá, donde llevo a la grande, se me hace un poco más difícil porque allá no hablan español y yo no hablo inglés y cuando yo necesito hacerle algunas preguntas al doctor siempre tengo que estar con el traductor. En ese aspecto es que yo he sentido la diferencia.

I have the oldest in a different clinic than the youngest one. I have the youngest in [study clinic] and the oldest in [another clinic], and in that respect I feel the difference because there, where I take my oldest, it's a little hard for me because they don't speak Spanish there and I don't speak English. And whenever I need to ask the doctor some questions I always need a translator. In that respect that's where I've felt the difference. -*Activation Level 4*

Quote 30

I: ¿Le pone a usted nerviosa o incómoda si tiene una pregunta, o compartir una preocupación sin que el médico se lo pida?

Do you get nervous or uncomfortable if you have a question or to share a worry if the doctor hasn't asked it?

R: A veces sí.

At times yes.

I: ¿Y por qué?

And why?

R: Porque uno piensa que para todo le van a pedir a uno un social.

Because one thinks that for everything they're going to ask for a Social.

I: ¿Y eso es afuera de la clínica de aquí, verdad?

And that is apart from the clinic here, right?

R: Sí. Entonces dice uno, no, mejor no pregunto porque si pregunto a veces uno por preguntar . . . te piden un ID.

Yes. So one says, no, it's better not to ask because if I ask at times one by asking . . . they'll ask for an ID.
-*Activation Level 4*

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* Spanish language quotes indicate quote is from an interview conducted in Spanish.

Among SL participants, culture-bound approaches to healthcare interactions, particularly in the domain of respect for authority or "respeto," were present. SL parents often described the trust they had in the authority of the physician, and for some SL parents the physician as an authority figure negatively impacted their willingness to ask questions (Quotes 25–28). Finally, SL respondents, unlike EL respondents, described that language barriers and fear of disclosing their immigration status influenced participation in healthcare interactions and question responses. These contextual factors appeared to wield more influence on healthcare interactions outside of the study clinic, as parents reported having significant trust in the study clinic (Quotes 29 and 30).

4. Discussion and conclusions

4.1. Discussion

This is the first study, to our knowledge, to present findings on the associations between the P-PAM and pediatric primary care outcomes *and* to provide parent perspectives on P-PAM questions in relation to their experiences with pediatric primary care. We found few associations between parent activation and pediatric primary care outcomes in this sample of low-income, generally healthy children. The qualitative portion of this mixed-methods study provided several possible explanations for the quantitative results including that the P-PAM may have limitations both in its question structure for assessing knowledge, skills, and confidence in general child health and healthcare and in its cultural and linguistic appropriateness for low-income Latino populations. Our findings suggest that further work is needed to understand how to best measure parent engagement in their child's health and healthcare and how to use the P-PAM to understand and address health and healthcare disparities among vulnerable children and families.

We found no associations between activation and pediatric primary care outcomes in the EL group and a potentially paradoxical finding of increased activation among parents of children who were overweight in the SL group. This is in contrast to the PAM, which has consistently demonstrated positive associations with varied adult health and healthcare outcomes [8–13]. Our findings are consistent with a recent study in a demographically similar sample, which found, contrary to their hypothesis, higher ED utilization among children of more highly activated parents [16]. While our findings may be due in part to sample size and selection, the qualitative findings support a decreased likelihood of association with pediatric primary care outcomes. Overall, qualitative interviews reflected the multiple factors that contribute to pediatric primary care outcomes. Structural barriers, such as a complicated public health insurance enrollment/renewal processes and limited prompt illness advice and acute care access, may exert more influence on pediatric primary care outcomes than parents' healthcare engagement. Based on parent interviews, differential success navigating system-level barriers was an important contributor to healthcare use patterns and ultimately the patients' outcomes. Knowledge, skills, and confidence about managing system-level barriers, however, are not directly addressed in the P-PAM. One question asks parents to report their confidence to figure out solutions when new situations arise with their child's health. Most interview participants interpreted this as related to health conditions, not problems navigating the healthcare system. A rewording of this question to include an explicit reference to healthcare navigation could potentially improve P-PAM specificity in identifying parents whose healthcare

engagement includes knowledge, skills, and confidence in system navigation.

Our qualitative findings also suggest that lack of specificity in P-PAM questions may explain the limited association with pediatric primary care outcomes. Parents encountered difficulty with response selection because the P-PAM addresses their child's health generally and some parents recognized that answering affirmatively would indicate a knowledge, confidence and skills that were unrealistic given the volume of potential child health conditions. This suggests that the P-PAM may be more useful as an intermediary intervention target for specific conditions or with children with chronic health conditions or medical complexity. Studies in child mental health have employed both the general P-PAM and a specific mental health P-PAM and have demonstrated findings more consistent with adult studies [27,28]. This suggests that employing the P-PAM in a more specific context may be a more appropriate application as parents may be more focused on knowledge, skills and confidence as it relates to a particular condition. Finally, during interviews parents often focused on behaviors related to child diet and physical activity when explaining their reasoning for selecting a P-PAM response. Use of the P-PAM in a general context to focus on child weight, diet and physical activity practices merits further exploration through research focused on childhood overweight and obesity [29].

We did find two pediatric primary care health outcomes that were associated with activation score among SL parents: child overweight and parent-reported child health status. The direction of these associations, lower activation associated with lower ratings of parent-reported child health status and higher activation associated with child overweight, suggest that the P-PAM may be measuring, at least in part, acculturation among SL parents and families. US-born Latino children of immigrant parents have been shown to have the highest prevalence of overweight among Latino children, in part due to the family adopting US obesogenic behaviors [30,31]. Families that adopt obesogenic behaviors as they integrate and assimilate into US communities likely also have had more exposure to the US healthcare system. Increased exposure to the US healthcare system via a child with a chronic medical condition has been associated with increased parent activation [16,17]. Less favorable health status reporting among Spanish-dominant immigrant Latinos, despite better objective measures of health than non-immigrants, has been posited to be related to traditional cultural beliefs among immigrant Latinos and linguistic challenges with self-reported health survey measures [32–35].

We did not employ a measure of acculturation in this study. Nor was there an association between length of time in the US, a common proxy measure for acculturation, and parent activation. Spanish-language parent interviews, however, demonstrated evidence of participants' culture-bound approaches to healthcare encounters. Among immigrant Latino adults there has been a variable association between length of time in the US and activation [12,36]. A recent study employing an acculturation measure among a sample of low-income immigrant Latino parents found no relation with activation [18]. Some studies employing activation as an intervention target have specifically addressed the cultural orientation towards respect for authority, harmonious interactions and unfamiliarity with the US healthcare system as increasing activation among Latinos [28,37,38]. Addressing these factors may increase activation scores, but it is still uncertain whether this will improve health or healthcare outcomes [39–41]. A lack of precision to distinguish activation and acculturation could impact interventions that include Latinos and are focused on increasing parent activation to promote child health given that

acculturation can be associated with less favorable health outcomes [42–44].

Our findings also highlight the challenges associated with translation and adaptation of measures into non-English languages. We employed translation best practices for the P-PAM including translation, back-translation and pilot testing, yet the qualitative interviews revealed limitations in the Spanish-language version that may or may not have impacted P-PAM scores among Spanish-speakers [45]. A standardized Spanish-language P-PAM is not currently available from the licensing company and it is unknown, therefore, how similar or different the Spanish language versions have been across studies. Limitations in translated versions of measures is not unique to the P-PAM. Measures may not have an available version in a non-English language for use across studies, limited information about the translation process may be reported in studies, and validation of non-English languages may not have been completed in comparable samples [46,47]. As the US population increases in diversity of languages and cultures, the potential impact of item response variation due to linguistic or cultural impact on question interpretation merits attention.

Our findings should be interpreted in the context of certain limitations. This study was performed in a single US pediatric primary care clinic designed to address the sociocultural needs of immigrant Latino families and which also has particular supports for low-income families. Within this context, common barriers to healthcare access and use for immigrant and low-income families are fewer than in other settings, particularly with respect to language barriers given most providers and staff are bilingual. This could impact activation and the distribution of pediatric primary care outcomes for the study population. Health system contextual factors can reduce barriers to activation, thus our findings may not be generalizable to settings that are not specifically oriented towards low income and immigrant populations [39]. Second, our sample includes parents attending a pediatric primary care clinic who were willing to participate in a survey, perhaps leading to selection bias. More than 80% of approached parents agreed to screening and 92% of screening-eligible parents agreed to participate and completed the survey. We did not collect demographic information on approached parents. Study sample demographics reflected the demographics of children seen at the clinic generally, but parents who present for primary care visits are likely different from those who do not. Finally, the sample size may have been inadequate to detect a difference by activation score for pediatric primary care outcomes given the favorable outcome profile and the relatively high P-PAM scores among parents compared to PAM scores in similar populations.

4.2. Conclusion

Research on patient engagement, specifically measured via the P-PAM, is nascent in child health. Emerging research trends indicate that there are particular limitations of the P-PAM, especially among low-income and racially/ethnically diverse populations. Children and their parents are more racially, ethnically, and culturally diverse than the US adult population, particularly older adults. Measurement limitations of the PAM in diverse populations may be magnified in the P-PAM raising questions about whether activation, as measured by the P-PAM, should be a focus of interventions to reduce child health and healthcare disparities.

4.3. Practice implications

Among generally healthy children, the self-efficacy and self-management skills for a particular illness that may be related to

activation in adults may be less impactful in pediatric primary care settings due to increased influences of health system-level and other contextual barriers. Practices serving vulnerable children and families should consider the limitations of the P-PAM for measuring parent engagement in their child's health and health-care before utilizing the P-PAM in patient engagement interventions addressing health disparities.

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Appendix A. Supplementary data

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Qualitative Study of Foster Caregivers' Views on Adherence to Pediatric Appointments

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ABSTRACT

The current study is a qualitative investigation of how foster caregivers, primarily Latinos, view adherence to pediatric appointments. Our purpose was to identify how the child welfare system, pediatric clinics, and pediatric health providers serving foster children might promote appointment attendance. Participants in the study had a return appointment at an outpatient pediatric clinic that served only children in the child welfare system. Twenty-eight caregivers (13 related and 15 unrelated) participated in telephone interviews after the date of their scheduled pediatric appointment; 32% missed their return appointment. Semistructured interview guides included general questions about what promotes attending the pediatric appointment, what makes it difficult to attend the pediatric appointment, and how pediatric care affects the foster child. Analysis of qualitative data using content analysis identified three themes: (a) *Multiple Methods to Attend Appointments,* which included caregivers' organizational and problem-solving skills; (b) *Positive Health Care Experiences,* which consisted of caregivers' personal relationships with providers and staff members and clinic organization; and (c) *Necessity of Pediatric Care,* which included recognition of the need for health care, especially timely immunizations. All caregivers also reported that appointment reminders would be helpful. Unrelated caregivers said more often than related caregivers that appointment attendance was facilitated by clinic organization. Nonadherent caregivers more than attenders mentioned their need to solve problems to attend appointments or reschedule appointments. In summary, caregivers said they valued regular pediatric health care to treat their children's chronic conditions and prevent illnesses, but they acknowledged that their home lives were hectic and that attending scheduled appointments was sometimes difficult. Foster caregivers in this study identified the ideal pediatric clinic environment that encourages adherence to health care appointments. This environment is an organized clinic with easy access including parking, engaged pediatric health providers, ability to reschedule appointments when necessary, and an individualized and consistent appointment reminder system. J Pediatr Health Care. (2017) 31, 104-110.

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KEY WORDS

Children in foster care have higher rates of chronic illness and greater health care needs than the general population (Ringeisen, Casanueva, Urato, & Cross, 2008; Stein et al., 2013). Therefore, the child welfare system has an important responsibility to promote access to and use of health care services

(Szilagyi et al., 2015). In Los Angeles, California, almost all children supervised by the Department of Children and Family Services receive an initial medical evaluation at a clinic that is part of the Medical HUB System (Department of Children and Family Services, 2014). Some foster caregivers elect to continue accessing pediatric medical care at a Medical HUB System clinic, or pediatric providers sometimes request a follow-up appointment for a medical problem. This presents an opportunity to tailor the provision of health care services to the needs of this specific population. In a recent study, almost 40% of children receiving medical care from a Medical HUB System clinic did not attend their follow-up appointment (Schneiderman, Smith, Arnold-Clark, Fuentes, & Kennedy, 2016). The only predictor of missing an appointment identified in that study was the length of time between the initial and return appointments; longer time between appointments was related to a greater chance of missing the return appointment.

The current study is a qualitative investigation of how foster caregivers, primarily Latinos, view adherence to pediatric appointments; our goal was to identify how the child welfare system, pediatric clinics, and pediatric health providers serving foster children might promote appointment attendance.

> Our goal was to identify how the child welfare system, pediatric clinics, and pediatric health providers serving foster children might promote appointment attendance.

We selected foster caregivers as the population of interest in this study because caregivers are vital gatekeepers through which children access health care services (Schneiderman, Smith, & Palinkas, 2012; Schneiderman & Villagrana, 2010). Although child welfare system workers and Medical HUB System clinic providers offer health care services to children, caregivers are ultimately responsible for ensuring that children attend appointments. We included a specific focus on how related (or kinship) versus unrelated caregivers viewed pediatric appointment attendance, because previous research has indicated that children living with related foster caregivers may be less likely to receive pediatric health services than children placed with unrelated caregivers (Timmer, Sedlar, & Urquiza, 2004). Changes in U.S. public policy have increased the number of children living with related foster caregivers (Geen, 2004). These related foster caregivers have to navigate potentially complex and burdensome health care regimens, which often require frequent pediatric medical appointments, with fewer resources

than unrelated foster caregivers (Sakai, Lin, & Flores, 2011; Stein et al., 2014). The present study provided an opportunity to explore how related foster caregivers might view medical adherence differently from unrelated caregivers.

An increasing number of Latino children are entering foster care in the United States (Children's Bureau, 2015). In Los Angeles, where the present study took place, 60.2% of children in foster care are Latino (Department of Children and Family Services, 2016). Although Latino children tend not to be overrepresented in child welfare compared with other minority groups (Hines, Lemon, Wyatt, & Merdinger, 2004; Summers, Wood, & Russell, 2012), there is some evidence that particular counties and states have disproportionate numbers of Latinos in child welfare (Dettlaff, 2014). The child welfare system prefers to place children with kinship caregivers or culturally similar unrelated caregivers; thus, Latino children most often have Latino caregivers (Bass, Shields, & Behrman, 2004). This growing demographic requires additional attention from researchers and providers to deliver appropriate and effective health care, particularly because Latino children have poorer health and more barriers to accessing health care than children of other ethnicities (Flores, 2010).

Qualitative methods are well suited to investigating how vulnerable populations interact with health care systems, largely because they allow individuals from underserved or disempowered groups to describe the phenomena they have experienced in naturalistic language that is meaningful to them (Green & Thorogood, 2013; Sullivan-Bolyai, Bova, & Harper, 2005). Furthermore, using qualitative interviews with health care consumers before developing adherence interventions provides a foundation for health promotion efforts that meet specific expressed needs (Campbell et al., 2007; Nilsen, Myrhaug, Johansen, Oliver, & Oxman, 2006). Because this was a qualitative study, we did not use a theoretical framework, because our goal was to generate explanation; however, we were informed by the health belief model (Rosenstock, 1974), which describes how individuals' perceptions of medical conditions and health behaviors influence the actions they take. We interviewed foster caregivers using general prompts about barriers, supports, and benefits of appointment attendance. However, instead of structuring interviews to map closely onto the health belief model or any other existing theory of medical adherence, interviewers used open-ended questions and reflections to allow foster caregivers to express their subjective views on pediatric appointment attendance. The aim of this study was to investigate the specific experience of Los Angeles foster caregivers accessing pediatric medical care at a clinic focused on the child welfare system. Results of this investigation are

expected to inform strategies that child welfare systems and pediatric health providers could implement to improve appointment adherence in the future.

MATERIALS AND METHODS
Recruitment and Sample
The initial recruitment of participants for a quantitative study of return appointment adherence occurred at the Community Assessment and Treatment Clinic (CATC), which is part of the Medical HUB System in Los Angeles, California. Caregivers were recruited by physicians and nurse practitioners if the caregivers wanted or were requested to attend a return appointment at CATC. All health care providers were bilingual. The physicians and nurse practitioners obtained consent from the caregivers at their initial appointment, and the caregivers completed a questionnaire with their demographic information, including telephone number. The consent form included a statement that caregivers might be telephoned by the researchers. The research protocol was approved by the affiliated university and health center's institutional review board. When a caregiver scheduled a return appointment, a written reminder card was given to them by the clinic personnel making the appointment. Only 14% of caregivers received a telephone reminder before their scheduled appointment because of lack of staff availability.

After the date of the scheduled or rescheduled return appointment, we recruited caregivers for this qualitative study, including both caregivers who returned for their pediatric appointments and those who did not return. Because almost all participants (89%) in the initial study were foster caregivers and access to and use of health services differ between foster caregivers and birth parents, we decided to recruit only foster caregiver participants. Possible participants were 77 foster caregivers. Of the 40 caregivers we initially reached by phone, 70% decided to participate in the interview. All caregivers received a $10 gift card, even if they decided not to participate. The caregivers who decided not to participate often stated that they did not have the time. The final sample was 28 caregivers. We concluded that we had sufficient data to reach saturation with 28 interviews.

Interview Procedure
The telephone interviews lasted approximately 20 minutes and were recorded by the interviewer. The interviews occurred between January 2014 and August 2014. The interviewers repeated what they recorded to the caregivers on the phone to assure accuracy. The interviewers conducted the interviews in Spanish or English, depending on the caregivers' preference. The two interviewees were doctoral social work or clinical psychology students trained by the primary investigator.

The interviews used a semistructured approach. The three general questions were: *What helps you attend the pediatric medical appointment for your foster child?*

What makes it difficult to attend the pediatric medical appointment for your foster child? and *What does your child get from attending pediatric medical appointments?* Interviewers were not aware of whether the caregiver attended the pediatric return appointment or not. After each interviewer completed five interviews, the research team convened to see if the questions and prompts were adequate to elicit the information needed to answer the research questions. Prompts were added to the script as needed.

Analysis
In preparation for analysis, two of the authors read through the interviews and used content analysis to identify possible themes in the interview transcriptions (Krippendorff, 2013). The researchers discussed with one another their feelings about health care use for this population to make sure that their experiences and interests did not bias the coding procedure. The data were organized using ATLAS.ti software, and two of the authors coded the data separately. After each researcher coded five transcripts, the authors met and revised and added codes based on their discussion. The reliability of the coders after the initial coding was 77.5%. The authors reviewed each discrepancy, and the differences were resolved using consensus discussion, adding complexity to the analysis. Themes were identified if at least 50% of the interviews included the code. Interviews were separated by caregiver type (unrelated vs. related) and by adherence (attended appointment vs. missed appointment) to identify differences in themes. Differences in themes were identified if there was at least a 20% difference in codes by group.

RESULTS
Participant Demographics
Participants were 13 related and 15 unrelated foster caregivers who resided in Los Angeles County, California. Demographic information for related and unrelated caregivers is presented in the Table. Most caregivers were female and an average of 44 years old. An equal number of caregivers spoke English and Spanish. All related caregivers identified as Latino, compared with unrelated caregivers who were predominantly Latino but also had some diversity in reported race and ethnicity.

Summary of Findings
Of the study population, 19 caregivers (67.9%) attended their return appointment, and 9 caregivers (32.1%) missed the return appointment. Universally, caregivers stated that an appointment reminder would be helpful for them. The caregivers suggested possible appointment reminder methods including telephone (22 caregivers; 78.6%), text message (19 caregivers; 67.9%), e-mail (6 caregivers; 21.4%), or postal mail (3 caregivers; 10.7%). Some caregivers proposed multiple

TABLE. Participant Descriptive Statistics (N = 28)		
	Kinship (n = 13), n (%)	Unrelated (n = 15), n (%)
Race and ethnicity		
Black	0 (0.00)	1 (6.67)
Hispanic	13 (100.00)	10 (66.67)
White	0 (0.00)	1 (6.67)
Other	0 (0.00)	2 (13.33)
Not listed	0 (0.00)	1 (6.67)
Language		
English	8 (61.54)	6 (40.00)
Spanish	5 (38.46)	9 (60.00)
Sex		
Male	1 (7.69)	2 (13.33)
Female	12 (92.31)	13 (86.67)
Age, years[a]	44.08 (12.05)	44.13 (12.80)

[a]Age is reported as M (SD).

In addition, caregivers brought up ways that they used problem-solving skills when they could not attend a scheduled appointment. The most common response was to reschedule any appointment that was missed. Some caregivers, however, commented that rescheduling can take time, and therefore it is better to attend the original appointment. One participant stated that if they missed a scheduled appointment, "the rescheduling, it would probably be for another month or so, so that's why it's important that we attend each one because it usually takes a while to reschedule." Other problem-solving methods included making appointment adherence easier, like scheduling the first appointment in the morning to save time in the waiting room or bringing a laptop and working during long wait times. "I can be in France right now, I can be on a boat. I can be anywhere there's an Internet connection because I have one of those little things you stick in the side of the computer. So it doesn't matter if I'm sitting in a doctor's office or not."

methods. Three primary themes emerged in this study. The first theme, *Multiple Methods to Attend Appointments,* involved using caregivers' organizational and problem-solving skills in an effort to help them attend medical appointments. The second theme, *Positive Health Care Experiences,* consisted of acknowledging caregivers' personal relationships with providers and staff members and clinic organization as important in improving adherence. The last theme, *Necessity of Pediatric Care,* involved recognizing the need for health care, especially timely immunizations.

Theme 1: *Multiple Methods to Attend Appointments*

Foster caregivers reported multiple strategies that helped them attend appointments. Caregivers expressed the importance of being organized both to remember appointments and to make it easier to attend appointments. One of the main organizational methods participants used to remember appointments was writing appointments on their calendars right away and posting any reminder cards on their refrigerators. One caregiver said, "I have two babies with special needs so I keep a calendar for the whole family on the fridge, and I usually write that appointment down as soon as I get it." According to caregivers, keeping an accurate schedule and planning appointments around other important activities helped them attend appointments. Securing transportation in advance was often cited, with multiple caregivers saying that having a car was the primary mechanism that helped them attend appointments. Planning for the appointment was another organizational tool that helped caregivers attend the appointment. In an effort to make the appointment and any wait times more manageable, foster caregivers recommended things like bringing snacks, toys, and games to occupy children during the wait.

Theme 2: *Positive Health Care Experiences*

Caregivers noted that positive health care experiences influenced how they felt about keeping return appointments. This theme included both caregivers' personal relationships with providers and staff members and clinic organization as important in improving adherence. Caregivers described opportunities to ask a lot of questions and receive personalized attention as incentives to attend medical appointments. "It helps that the staff are amazing and I want to make their job easier." One caregiver reported a willingness to drive a longer distance to a particular clinic because of the level of care received there. Having multicultural staff is also important, as one caregiver pointed out. "I like Dr. [name] and he speaks Spanish and is Hispanic like me. He speaks to my culture and everything." Clinic organization and good service were crucial in improving adherence. In particular, a few caregivers said they liked receiving reminder calls about their children's appointments from the clinic. One participant said, "They remind me that I have an appointment the next day, so I don't forget…because sometimes the appointment is a really long way off." Fast waiting times, ease of parking, and location were all mentioned as other clinic characteristics that make it easy to attend return appointments. "Because they saw me very fast, it was very helpful."

Theme 3: *Necessity of Pediatric Care*

Recognition of the need for health care was particularly strong in the interviews; 22 caregivers (78.6%) of caregivers reported that improving health was an important concern and a primary reason that attending medical appointments was essential. Despite foster children at times having severe physical health problems, caregivers were particularly concerned with immunization schedules. Caregivers said, "You want to keep them

current with shots and check-ups," and "They need to get their vaccinations." A smaller group was concerned with obtaining the proper medication or adjusting medication levels for their children, stating things like, "He will get meds if needed and peace of mind if no meds are needed." Participants frequently reported viewing these return appointments as a preventive measure for ensuring child health. Respondents noted that if an appointment was missed, a medical condition might go undetected and worsen a child's health. Caregivers said things like, "Something might not be detected right away" if an appointment was missed, and "If there was something wrong it could be addressed right away."

Comparison Among Caregivers

Despite general consensus regarding these three themes, related and unrelated caregivers and adherent and nonadherent caregivers differed in what they described as important for appointment adherence. Unrelated caregivers more often said that appointment attendance was facilitated by clinic organization compared with related caregivers. Unrelated caregivers were also more likely to state that attending appointments was necessary, not only for a child's health but also to avoid repercussions from child welfare workers. They cited reasons such as not wanting to lose their license and desiring to avoid reprimands or problems with the social worker. When speaking about not attending a follow-up appointment, unrelated participants said, "A whole bunch of social workers would be calling me," and "I don't want to lose my license." Nonadherent caregivers mentioned their need to solve problems to attend appointments more than attenders. Primarily, they talked about the necessity of rescheduling appointments if they had to miss an appointment. Although there were no questions or prompts about whether appointments were missed, three caregivers noted in their interview that they had never missed a pediatric appointment. These three caregivers were all in the nonadherent group. Caregivers who attended appointments were more likely to credit their relationships with clinic staff members and their own organizational skills as helpful compared with nonadherent caregivers.

DISCUSSION

The foster caregivers in this study voiced that they were invested in bringing their children back for follow-up medical appointments, although they needed assistance to ensure it happened. Caregivers stated that they valued regular pediatric health care to treat their children's chronic conditions, prevent illnesses, and ensure their children had all needed immunizations, but they acknowledged that their home lives were hectic and that always making their scheduled appointments was difficult. Remembering appointments was identified as problematic for them, and they universally identified that a reminder system would benefit them greatly. Instituting an automated telephone or text message reminder system may be the most cost-effective and efficient way to provide the desired reminder to caregivers (Hofstetter, Vargas, Kennedy, Kitayama, & Stockwell, 2013).

Unrelated caregivers in particular noted the importance of clinic organization, potentially because they often have more foster children to care for compared with related caregivers (e.g., Chamberlain et al., 2006). Although the goal of child welfare is to provide a nonpunitive, supportive approach (Pecora et al., 2010), some of the unrelated caregivers expressed fear of reprisals from their child welfare case workers as a motivation for attending appointments. In a previous study of patients' perspectives on nonattendance at primary care appointments, most participants reported that they did not think punitive approaches to improving attendance would work very well (Martin, Perfect, & Mantle, 2005). Related caregivers did not identify any fear motivation and may have felt more secure in their role as foster care providers because of the familial relationship to the foster child.

Caregivers who did not bring their children back to the return appointment expressed more often that they needed to use problem-solving skills than caregivers who attended their appointments. The nonadherent caregivers may have had more logistical problems in their daily lives that made the need to reschedule appointments more likely. It is also possible that these caregivers brought their children to another pediatric facility rather than CATC because of difficulties getting to CATC. However, the fact that one third of caregivers who did not adhere to their appointment at CATC stated that they never missed a pediatric medical appointment is concerning. Foster caregivers are responsible to the state for providing needed care to foster children, including medical care (Putnick, 1998).

Caregivers who attended appointments appreciated engagement with clinic personnel more than nonadherent caregivers. Making foster caregivers feel important and welcome in the health care environment has been shown to improve adherence in other environments, such as mental health (Pecora, Jensen, Romanelli, Jackson, & Ortiz, 2009). Thus, an organized clinic environment with engaged medical personnel and a seamless, easy appointment system featuring the ability to change appointments may improve adherence. In busy pediatric practices, this type of clinic environment may not be easy to achieve, but it may help increase appointment adherence in this population of caregivers. Furthermore, it is important to make a clinic environment welcoming for ethnically diverse caregivers by offering linguistically and culturally appropriate services, ensuring that caregivers understand the purpose of follow-up appointments (Taveras & Flores, 2004).

There are limitations to consider. The primarily Latino and urban population of caregivers in this study limits transferability of the findings. The clinic where this research took place serves only children in the child welfare system and is connected to that system; thus, some problems that caregivers in general might have in terms of interfacing with both child welfare and health systems might have been missed. There may be differences in findings between caregivers who participated and those we telephoned but who declined to participate.

In summary, foster caregivers in this study identified the ideal pediatric clinic environment that encourages adherence to health care appointments. This environment is an organized clinic with easy access including parking, engaged pediatric health providers, ability to reschedule appointments, and an individualized and consistent appointment reminder system. Further research is needed to evaluate if a reminder system developed based on the individual preferences of foster caregivers improves appointment adherence in this population. By identifying foster caregivers who have a particularly hectic home life and making sure that they get special attention from the clinic staff and feel engaged with their children's health care plans, it may be possible to improve their pediatric appointment adherence. Pediatric nurse practitioners provide much of the primary care for underserved child populations, including children in foster care (Coddington, Sands, Edwards, Kirkpatrick, & Chen, 2011; Hapak, 2014). Pediatric nurse practitioners can help foster caregivers by making sure that the clinic environment supports their needs and by engaging caregivers in their children's health care. Attending pediatric appointments is an important part of improving the health outcomes of children in foster care, although future research is also needed on adherence to home health care recommendations.

> Foster caregivers identified the ideal pediatric clinic environment: an organized clinic with easy access including parking, engaged pediatric health providers, ability to reschedule appointments, and an individualized and consistent appointment reminder system.

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First We Have to Engage Them: A Mixed Methods Assessment of Low-Income Parents' Preferences for and Barriers to Receiving Child Health Promotion Information

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ABSTRACT

Introduction: The aim of this study is to understand low-income parents' preferences for and barriers to receiving child health promotion information.
Methods: A mixed-methods approach was used. Data were collected in an urban pediatric primary care setting serving predominantly low-income African American families. Parents (n = 190) of 3- to 8-year-old children completed a survey; a randomly selected subset participated in focus groups.
Results: The quantitative and qualitative samples differed with regard to whether they would like to get parenting information from their doctors. The most commonly cited obstacles to attending parenting classes were time (50.6%), work schedule (40.6%), transportation (37.7%), and own health (22.4%).

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Discussion: New and creative methods are needed to promote child health and development that do not increase the burden associated with raising children in the context of limited resources. J Pediatr Health Care. (2015) *29*, 501-508.

The importance of the early childhood period on later child outcomes has been established (Bornstein & Bradley, 2003; Brooks-Gunn, Linver, & Fauth, 2005; Day, 2011; Hanson et al., 2011; Lee, Huang, Halpern, & Newsschaffer, 2007; Ramey and Ramey, 2004; Sameroff, 2010). Because parents are largely responsible for structuring the physical and psychosocial environments in which their children grow and develop, promoting positive parenting behavior during early childhood has tremendous implications for a child's quality of life, lifelong health and development, and health care resource utilization (Bornstein & Bradley, 2003; Bradley, 2002; Dumas et al., 2005; Sameroff, 2009).

Evidence shows that some parenting programs are successful in improving child outcomes for some children. However, parental attendance has been suboptimal even for parents whose children have documented or perceived behavior problems (Dumas, Nissley-Tsiopinis, & Moreland, 2007; Perrin, Sheldrick, McMenamy, Henson, & Carter, 2014; Thornton & Calam, 2011). For example, Thornton and Calam (2011) found that only 9% of the parents who indicated an intention to attend a parenting group through their local school actually attended the group. Additionally, they found that parents who attended reported higher child problem behavior scores than did those who did not attend the parenting class. Similarly, parents whose children had screened positive for behavior problems were enrolled into another study to evaluate a parent intervention program in a primary care setting (Kolko, Campo, Kelleher, & Cheng, 2010). Of the 573 eligible families, 70% actually enrolled and were randomized (Kolko et al., 2010). Despite monetary incentives, only 112 initiated treatment and only 89 completed treatment within the 6-month study period. In yet another program, Perrin and colleagues (2014) enrolled parents of 2- to 4-year-old children who screened positive for disruptive behavior problems. Of the 830 parents who agreed to be contacted, 33% were enrolled in the intervention or wait-list group. An additional 29% of the enrolled parents dropped out of the study prior to completion (Perrin et al., 2014). The study demonstrated the feasibility of offering a parenting program in a primary care setting with nurses, nurse practitioners, and social workers, and the intervention was successful in reducing behavioral problems in a diverse sample. Thus, data from several studies indicate some success with recruiting parents for interventions related to their child's behavior problems. These recruitment and retention rates may not be sustainable without grant funding to support the inclusion of incentives and the staff necessary to encourage participation.

BACKGROUND
The importance of health promotion of children is well known. However, few data are available regarding attendance at health-promotion programs or use and effectiveness of other health-promotion methods (e.g., written materials, Web sites, social media, and text messages). A better understanding of the preferences for and barriers to receiving parenting education is needed so that health promotion and prevention content can be more widely accessible, acceptable, and effective in promoting positive parenting behavior that supports children's optimal development.

It has been reported that parents are more likely to intend to attend a parenting class if they believe that their children have behavior problems than they are to intend to attend a parenting class to prevent problems (Dempster, Wildman, & Keating, 2013). Richerson (unpublished data, 2013) discovered that parents prefer to have enrichment and parent support activities in their communities rather than take parenting classes.

Poverty, minority status, and low levels of education of parents are well-documented risk factors for adverse outcomes in children across multiple domains (Bornstein & Bradley, 2003; Bradley & Corwyn, 2002; Brooks-Gunn, Rouse, & McLanahan, 2007). Parents with less education may not have the health literacy skills needed to act upon the knowledge that is given to them. Additionally, much health information that is provided to patients is not suitable or is at a reading level that is not appropriate for many U.S. adults (Freda, 2005; Ryan et al., 2014). In one study, parents with a high school education or less indicated that they did not receive education or did not understand the education that was provided on important anticipatory guidance topics to a greater extent than their more educated peers (Davis, Jones, Logsdon, Ryan, & Wilkerson-Memahon, 2013). More data are needed to ensure that appropriate strategies are developed and implemented to communicate with parents in ways that they find acceptable so they can truly be partners in their children's care.

Nurses and nurse practitioners in primary health care settings are obvious choices for supporting the family's optimal functioning because they are consistently involved in the lives of children from birth. The premise of the patient-centered medical home is that health care providers and the patient or family are integral partners and that the family is actively involved in the health care decision-making process (Yin et al., 2012). However, parent preferences for receiving educational messages frequently are not solicited. Support of parents in

providing optimal child care may be better achieved by using parent preferences to improve the uptake of anticipatory guidance. Additionally, understanding parents' preferences for and barriers to receiving health information can inform the development of interventions to meet the needs of a diverse population.

> … understanding parents' preferences for and barriers to receiving health information can inform the development of interventions to meet the needs of a diverse population.

A recent study of White parents from the rural Midwest in a pediatric primary care setting explored how parents would like to receive information about parenting and the factors that might encourage or impede their intention to participate in a parenting program (Dempster et al., 2013). In this sample, parents preferred to receive parenting advice from their pediatricians. Factors that influenced their likelihood to attend a class were the belief that the class would be effective and the parents' perceptions that their child had a behavior problem. Stigma served as a barrier to seeking help with parenting.

METHODS

Aims

By building upon the findings by Dempster and colleagues (2013), the current study sought to better understand the preferences of parents for receiving health information in a more diverse population. Participants were from an urban setting, were predominately African American, and were predominately Medicaid recipients. This study fills an important gap in the literature because parenting anticipatory guidance is one way to promote optimal child health and development and minimize disparities between children from lower socioeconomic status families and their higher income peers.

Design

A mixed-methods design was used. Both surveys and focus groups were used to solicit input from parents of young children.

Sample

A sample of 190 parents or legal guardians completed a survey in the waiting room of a primary care pediatric academic practice that serves predominantly low-income families in an urban location in the southern United States. All parents with children aged 3 to 8 years were invited to participate. Demographic information is presented in Table 1. Additionally, a random selection of parents who indicated a willingness to be contacted participated in one of two focus groups.

TABLE 1. Descriptive data	
Variable	**Mean (SD) or %**
Parent age (years)	30.19 (6.74)
Child age (months)	63.32 (20.27)
Race	
African American	78.9
White	15.8
Other/unknown	4.3
Parent Medicaid/no insurance	81.0
Child Medicaid/no insurance	91.1
Parent education	
< 12th grade	15.4
Completed 12th grade	61.2
Vocational/some college	14.3
≥ College	3.7
Single parent	76.1
Income ≤ $22,065	65.8

Data Collection

Parents completed a survey containing demographic characteristics of themselves and their children, information regarding their preferences for obtaining parenting information, their likelihood of attending parenting classes, and the Obstacles to Engagement Scale (OES) (Dempster et al., 2013; Dumas et al., 2007). Each survey participant received an incentive of $20; focus group participants received an additional $40 stipend. The study was approved by the University's Institutional Review Board and was conducted after receiving informed consent from the participants.

Instruments

A researcher-developed survey was used to collect demographic information. Parents' preferences for obtaining parenting information (Davis et al., 2013) were assessed and participants completed the OES, a 14-item survey to assess reasons that parents may have for not attending parenting classes (Dempster et al., 2013; Dumas et al., 2007). The OES is a 4-point Likert-type scale with responses as follows: 1 = definitely no; 2 = probably no; 3 = probably yes; and 4 = definitely yes (Dempster et al., 2013; Dumas et al., 2007).

Focus groups

The focus groups were conducted by an experienced facilitator using a researcher-developed interview guide. The two groups consisted of 5 and 12 individuals, respectively. The questions and probes were aimed at gathering more in-depth information regarding the content, location, duration, and frequency of a parent education program. Additional questions aimed to determine the perceived effectiveness of various delivery methods such as a face-to-face program, video or Web-based programs, and/or written materials. The focus group sessions lasted about 2 hours.

Analyses

Descriptive analyses were used for the survey data. Focus group discussions were audiotaped and later transcribed. The transcripts were compared with the tapes and with the investigators' notes taken during the discussions to check for completeness and accuracy of the data. The investigator used QDA Miner version 3 (Provalis Research, Montreal, Quebec, Canada), a mixed-methods software program, to organize and code frequencies of the themes and patterns found in the data. A list of variables was created and used to conduct specific searches of the coded text, which allowed the researchers to calculate the frequency of comments by coded text and by question. The themes were shared with each of the coders until consensus was reached regarding each of the themes. The results are presented according to the themes that emerged from the interview data.

Validity and Reliability

The parent preferences questionnaire has been used previously (Davis et al., 2013). The instrument provides item-by-item descriptive data that does not lend itself to psychometric testing. The OES had not been validated for this population at the initiation of the study. Subsequent psychometric property testing suggested that the subscales were not valid (Davis et al., 2014), so only individual item data are reported. The focus group data analysis used acceptable qualitative data analysis methods with ongoing cross-checking between multiple team members.

RESULTS
Parenting Advice and Parenting Classes

When asked whether his/her child had a behavioral or emotional problem for which the parent believes the child needs help, 25.9% responded "Yes." Twenty-one percent of the parents indicated that they would like to receive services for the problem. Table 2 presents responses to two items in which participants were asked, "*From whom do you most often get parenting advice?*" and "*From whom would you like to get parenting advice?*" The majority of the parents received more advice from family and friends than they wanted. Only 34.9% indicated that they would like to receive parenting advice from their doctor. Preferences for other sources of information include clergy (11.8%), child care workers (5.9%), mental health professionals (14.0%), no one (21.5%), and other (6.1%). When asked how likely they would be to sign up for parenting classes if they were available, 38.5% responded "somewhat agree," "agree," or "strongly agree." Sixty percent responded that they would sign up if they believed that their child had an emotional or behavioral problem, whereas 33.5% said they would be likely to sign up to prevent problems.

Obstacles to Engagement Scale

Table 3 presents the individual responses to the 14-item OES with four response options (definitely yes, probably yes, probably no, and definitely no). Combining responses that "definitely" or "probably" would be an obstacle resulted in the following percentages: time, 50.6%; feeling frightened or nervous about being in a parenting program, 9.8%; talking about parenting with strangers, 10.3%; work schedule, 40.6%; fear of being misunderstood, 9.6%; belief that there is no hope for change, 10.9%; belief that parenting programs are not relevant to problems their family is having, 16.0%; having too much information to learn, 6.2%; transportation, 37.7%; own health, 22.4%; belief that parenting programs do not work, 12.1%; lack of trust in the agencies, 17.1%; drug or alcohol problems in the family, 2.9%; and problems with the law in the family, 5.7%.

The primary purpose of conducting the focus groups with parents was to identify ways of developing parenting programs specifically tailored to the needs and issues of low-income parents. The qualitative analysis revealed six major themes that emerged from the data: (a) hyperactive children and behavioral concerns; (b) angry kids; (c) protecting my child from bullies; (d) abuse; (e) weight, nutrition, and health; and (f) parenting advice: physicians, teachers, or family? Examples from parent responses will be provided for each theme.

Theme 1: Hyperactive Children and Behavioral Concerns

Parents expressed concern for behavioral and developmental issues of their children or grandchildren. The overriding concern for this group was with children who they perceived as hyperactive. The parents indicated a need for some type of parenting services to help them cope with their child/children's hyperactivity.

One parent expressed her frustration with her child's behavioral problem and her frustration with the doctors as follows: "My third grandbaby is so hyper. I bring him in here [clinic] and they're testing him for things but they say they have to wait until he gets to be school age …

TABLE 2. Percentage of parents wanting health information from selected sources		
Source	**Get advice (%)**	**Want advice (%)**
Friends	28.0	21.0
Family	66.7	44.1
Doctor	30.7	34.9
Clergy	12.2	11.8
Child care worker	5.3	5.9
Mental health professional	4.2	14.0
No one	19.6	21.5
Other	7.6	6.1

Note. *Participants selected multiple responses.*

TABLE 3. Obstacles to engagement in parenting classes

Reason parent might choose to attend/not attend parenting classes	Definitely no (%)	Probably no (%)	Probably yes (%)	Definitely yes (%)
Would having to find time to go to meetings for several weeks in a row stop you from attending?	40 (22.5)	48 (27.0)	61 (34.3)	29 (16.3)
Would feeling frightened or nervous about being in a parenting program stop you from attending?	99 (56.6)	59 (33.7)	12 (6.9)	5 (2.9)
Would talking about parenting with people you don't know stop you from attending?	104 (59.4)	53 (30.3)	12 (6.9)	6 (3.4)
Would your work schedule stop you from attending?	59 (33.7)	45 (25.7)	49 (28.0)	22 (12.6)
Would fear of being misunderstood stop you from attending?	91 (54.8)	59 (35.5)	10 (6.0)	6 (3.6)
Would the belief that there is no hope for change stop you from attending?	110 (62.9)	46 (26.3)	13 (7.4)	6 (3.4)
Would the belief that parenting programs have little connection with the problems your family is having stop you from attending?	88 (50.3)	59 (33.7)	24 (13.7)	4 (2.3)
Would the fact that there may be too much information to learn stop you from attending?	106 (59.0)	60 (33.9)	7 (4.0)	4 (2.3)
Would transportation problems stop you from attending?	70 (40.0)	39 (22.3)	44 (25.1)	22 (12.6)
Would your health stop you from attending?	82 (48.2)	50 (29.4)	29 (17.1)	9 (5.3)
Would the belief that parenting programs do not work stop you from attending?	104 (59.8)	49 (28.2)	16 (9.2)	5 (2.9)
Would lack of trust in the system or agencies stop you from attending?	89 (50.9)	56 (32.0)	19 (10.9)	11 (6.3)
Would alcohol or drug problems in your family stop you from attending?	130 (76.0)	36 (21.1)	4 (2.3)	1 (0.6)
Would problems with the law in your family stop you from attending?	127 (73.0)	37 (21.3)	7 (4.0)	3 (1.7)

Why do they have to wait so long before they give the baby something or let them go somewhere to try to get some help?"

Theme 2: Angry Kids

Several parents indicated having a child who frequently expresses anger. These parents were somewhat frustrated with physicians or other professionals who provide little or no assistance when they point out these behavioral problems. One parent acknowledged, "I feel like when we start noticing these problems with these kids and telling these doctors about these kids, what they're telling us basically is that they're not old enough to be diagnosed with these problems. But then later on down the road they are diagnosed with these problems, and we're looking at them like, we told you so."

The parents also sought assistance from schools for some behavioral issues because that is where many of their children's problems are initially identified. For example, one parent commented, "I've had concerns before with my 4-year-old. In the last few months she's had some behavior stuff going on in preschool … and her school is a really good school. They called us in and we had a conference and came up with a plan for what to do when she acts out like that. And that's helped a lot. And just giving her more attention helps."

Theme 3: Protecting My Child from Bullies

A third theme was how to deal with bullying. One parent voiced great concern over her child being teased and bullied:

My son he's 7 and he's big for 7 years old. He weighs 100 and something pounds. And he gets teased a lot, people teasing him in school and stuff, and I don't know what to do about that…every day he comes home and tells us something new about what somebody has said. I don't know how to handle that. All I can tell him is look, you are different, everybody is different, and everybody can't be the same …. Sometimes he might cry because he's being teased too much and I don't know what else to do about it.

Theme 4: Abuse

The discussion and conversation eventually led to how parents should deal with a child who has been abused. Almost all of the parents felt they would be able to tell if their child was being abused. They indicated that the signs would be obvious. One parent said, "The child would be withdrawn, afraid, and jittery around other people." Another parent noted, "Well, sometimes they cover it up, but nine times out of ten you can tell. Well, I can." Another participant stated, "I think a lot of times with kids it will come out in…expressions of anger and attitudes."

Theme 5: Weight, Nutrition, and Health

A few parents had some concerns about their children's eating habits, which led to weight concerns and nutrition. For example, one parent noted, "My son is 8 years old, he's like really, really skinny and he's real tall. But he does not like anything…. If I try to fix him something, something is wrong with everything."

Theme 6: Parenting Advice: Physicians, Teachers, or Family?

When participants were asked about their preference regarding sources for receiving parenting advice, the majority of parents stated that they preferred to receive parenting advice primarily from physicians. For example, one parent said, "I want to hear it from the doctor. You know, I want to talk to the doctor…with the doctor I feel that they went to school for it so they know if it's right."

Still, some participants in the groups were skeptical of advice from physicians or other health care professionals. One parent said, "I have a good support system. I don't always listen to the doctors' advice behavior wise or medically, like when they try to give my children certain things."

Some of the participants admitted that they generally receive parenting advice from their mothers, aunts, and grandmothers. Some of the advice they received from these relatives they considered good, while some types of advice, especially regarding discipline, was seen by the participants more as interference with their parenting style. For instance, one participant said, "I think it's acceptable for family members to give some advice, but sometimes they can overstep. I've been in situations where my 4-year-old is doing something that I don't want her to do and I will say, 'Stop right now.' And then my mom will say, 'That's ok.' And it makes me want to strangle my mother."

Parenting Education Format and Barriers to Participation in Parent Education

The moderator asked the group about the format of parent education programs they would find most useful. One parent said she preferred face-to-face meetings, "because you are talking to other parents that has the same problems you do."

Yet others indicated that a one-on-one meeting with a professional such as during a well-child visit or visit to a school counselor also probably would be good. Many of the participants agreed that DVDs, brochures, and Web sites would be useful tools to have for obtaining parenting information, whereas other participants indicated that they may experience problems accessing a computer or not owning a computer.

Transportation is another barrier to participation because many parents have to take the bus or wait on a ride from someone to attend classes or visit the doctor's office. Similarly, cost was considered a barrier, particularly when seeking professional help, because they may not be able to afford a co-payment every time. One parent suggested the importance of having sessions for the children when offering parenting sessions to remove child care barriers.

When participants were asked if they had previously attended any parenting classes regularly, only one participant stated she had attended classes at a local hospital. Another individual said,

> I did have one with my first child and I wouldn't…. I'm very open minded, still at this point I know I'm not the perfect parent and I'm still pretty inquisitive to see what more I can learn to interest them because I want them to be successful in life. I really want them to know there's a bigger world than this.

Parents were asked about other services the clinic could provide to assist them as parents. One participant noted, "It would be great to have one central place to find out about any kind of [information]. It would be great to have a place where you can ask questions about anything."

Another participant noted, "Definitely child care is a major issue. Insurance is a major issue, I think. Help for families about how to get food if you can't afford it, like WIC, food stamps, anything you have questions about it would be, yes, good to have."

DISCUSSION

The goal of this study was to better understand the preferences for and barriers to receiving health promotion parenting information for low-income, urban parents or legal guardians of children 3 to 8 years of age. Both quantitative and qualitative data were collected. The most striking finding in the quantitative data was that relatively few parents said they would like to get parenting information from their doctors compared with other samples in the literature (Davis et al., 2013; Dempster et al., 2013). However, in the smaller sample included in the focus groups, physicians were once again mentioned as the preferred source of health information. Additionally, in general, parents were more likely to sign up for parenting classes if they believed their children had behavior problems (60%) than they were to prevent problems (33.5%). Other investigators have had similar findings (Dempster et al., 2013; Thornton & Calam, 2011). Overall, only 38.5% of the sample responded that they were likely to sign up for a parenting program.

> The most cited obstacles for attending parenting classes were time, work schedules, and transportation.

Marketing of parenting programs for health promotion will continue to be challenging. The most cited obstacles for attending parenting classes were time, work schedules, and transportation. The qualitative analysis

identified six major themes related to behavior; anger; bullying; child abuse; weight, nutrition, and health; and sources of parenting advice.

Currently, most parent education focuses on the desired parenting behavior with little consideration given to the factors that might influence parent's uptake and use of the parenting information. In other words, the education is not patient centered, which may be a barrier to changing parenting behavior. Theories of health behaviors such as the Health Beliefs Models (Champion and Skinner 2008) and the Theory of Planned Behavior (Ajzen, 1985, 1991; Glanz, Rimer, & Viswanath, 2008) suggest that knowledge alone is not sufficient to drive persons to take action regarding health-promotion activities. These models go on to suggest that attitudes and beliefs predict behavioral intentions, which, in turn, predict health behaviors. Other investigators have demonstrated the importance of parents' attitudes and beliefs in various child outcomes and in parenting practices (Barnett, Shanahan, Deng, Haskett, & Cox, 2010; Burchinal, Skinner, & Reznick, 2010; Juby, 2009; Lau, Litrownik, Newton, Black, & Everson, 2006). Despite the evidence, most parent education is developed to provide a "one-size-fits-all" approach. To be effective in communication with parents, more emphasis is needed on using existing health-promotion theoretical models and an understanding of health literacy. To ensure optimal outcomes, the messages should be patient centered, accessible, acceptable, actionable, and in a format and language that parents can easily understand. Future studies should include comparative effectiveness methods to understand which parent interventions work for which populations and in what context. Lastly, understanding the barriers that interfere with parents' ability to participate in parenting programs should lead to new and creative delivery methods that take into account the burdens associated with raising children in the context of limited personal and/or fiscal resources. For example, programs can focus on building parent support communities, reducing travel time and expenses, and modeling positive parenting behaviors through activities-based programs.

A limitation of the current study is that data were collected at only one site, which may limit the generalizability of the findings. Additionally, the OES had not been validated for use with this population, and the psychometric properties indicated that more work is needed in the development of the subscales.

> New health information delivery methods are needed that take into account the barriers associated with parenting in the context of poverty.

CONCLUSION

New health information delivery methods are needed that take into account the barriers associated with parenting in the context of poverty. Health promotion messages should be targeted toward specific groups to increase the uptake and use of the health information, and the health literacy level of the consumer should be considered in designing and delivering all health information. Parent preferences are critical when building a patient-centered medical home.

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