Published in final edited form as:

Matern Child Health J. 2013 January ; 17(1): 95–109. doi:10.1007/s10995-012-0951-9.

The Voices of Limited English Proficiency Latina Mothers on Pediatric Primary Care: Lessons for the Medical Home

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Abstract

The objective of this study is to inform medical home implementation in practices serving limited English proficiency Latino families by exploring limited English proficiency Latina mothers' experiences with, and expectations for, pediatric primary care. In partnership with a federally-qualified community health center in an urban Latino neighborhood, we conducted semi-structured interviews with 38 low-income Latina mothers. Eligible participants identified a pediatric primary care provider for their child and had at least one child 3 years old or younger, to increase the probability of frequent recent interactions with health care providers. Interview transcripts were coded and analyzed through an iterative and collaborative process to identify

participants' satisfaction with and expectations for pediatric primary care. About half of the mothers interviewed were satisfied with their primary care experiences. Mothers suggested many ways to improve the quality of pediatric primary care for their children to better meet the needs of their families. These included: encouraging providers to invest more in their relationship with families, providing reliable same-day sick care, expanding hours, improving access to language services, and improving care coordination services. Limited English proficiency Latina mothers expect high-quality pediatric primary care consistent with the medical home model. Current efforts to improve primary care quality through application of the medical home model are thus relevant to this population, but should focus on the parent-provider relationship and timely access to care. Promoting this model among practices that serve limited English proficiency Latino families could improve engagement and satisfaction with primary care.

Keywords

Disparities; Primary care; Latino; Qualitative research; Medical home

Introduction

Pediatric primary care is the cornerstone of health care for children, but high-quality pediatric primary care is not the norm for many Latino children in the United States. Latino children with limited English proficiency (LEP) parents, or who live in households where the primary language is not English, disproportionately experience poor primary care access and quality compared to Latino children in English-speaking families [1–16]. Increasing access to primary care through provision of health insurance is commonly discussed as a key mechanism to address health care disparities among Latino children as they have the highest uninsurance rates [3, 17–22]. However, focusing only on access barriers ignores important disparities in the quality of care for Latino children who have health care access [4, 6, 9, 11, 13, 23, 24]. A comprehensive approach to reducing health care disparities requires addressing disparities in the quality of care among children with access [25, 26].

The medical home is defined by the American Academy of Pediatrics (AAP) as access to a usual source of care, a usual provider at the usual source of care, and care that is comprehensive, coordinated, family-centered, compassionate, and culturally-effective [27]. It is promoted as a model of primary care delivery that could reduce disparities in quality among vulnerable children [27–29]. However, most current studies of the medical home for children assume that all aspects of the model are relevant for all populations and frequently rely on survey measures that do not allow families to express a broad range of experiences and opinions about primary care as they may relate to the medical home. Additionally, applying all medical home principles may be difficult for primary care practices [30]. To date, families have had little input into the planning and implementation of medical homes [31, 32]. This could result in changes to primary care that do not address families' existing problems with care and reduce the potential of the medical home model to address disparities [31, 32]. As Latinos are the largest minority group among children, and the majority of children in LEP families in the United States are Latino, there is a need to add the voices of LEP Latino families to the discussion about how primary care practices should

implement the medical home [33]. Accordingly, the purpose of this qualitative study is to explore LEP Latina mothers' experiences with, and expectations for, pediatric primary care to inform medical home implementation in practices serving LEP Latino families.

Methods

Study Development and Design

We developed this qualitative study using community-based participatory research (CBPR) principles in collaboration with the Community Health and Social Services Center (CHASS) located in predominantly Latino southwest Detroit [34]. CHASS is a federally-qualified health center that aims to provide high-quality primary care in the medical home model. From this project, CHASS wanted to learn how to better meet the pediatric primary care needs of local Latino families. Through initial partnership discussions, we decided that understanding local families' experiences with and expectations for pediatric primary care would provide information about gaps in services or service areas in need of improvement at CHASS and in the community at-large. Additionally, to focus recommendations on improving care quality, we decided to include only families who reported having access to and regular use of primary care. We agreed to these inclusion criteria: (1) mothers who self-identified as Latina; (2) spoke primarily Spanish; (3) identified a pediatric primary care provider (PCP) for their child; (4) had used this PCP in the past 6 months; and (5) had at least one child 3 years old to increase the likelihood of frequent recent health care interactions. During the interviews, participants were invited to talk about their pediatric primary care experiences for all of their children. Some questions were specifically targeted towards the youngest child as we were most interested in current experiences with care, and the periodicity of recommended care for young children is frequent. The AAP Medical Home definition served as the basis for interview guide development [27]. However, topical areas remained broad to facilitate identification of expectations for care not included in the current definition. (See "Appendix" for Interview Guide.)

Sampling and Data Collection

From September to December 2009, we conducted 41 semi-structured interviews in Spanish with Latina mothers living in southwest Detroit. The study sample was primarily recruited from past participants in a prenatal healthy lifestyle program held in the community between 2003 and 2008 ($n = 30$). Additional study participants were recruited through referrals from participants in the current study ($n = 5$), or through recruitment in the CHASS waiting room ($n = 6$). Of the 41 interviews completed, we included 38 in the analysis. Two of the three excluded interviews did not meet inclusion criteria after further review by the primary author (LRD), and one was an initial practice interview.

The interviewer was a bilingual research assistant of Mexican descent who had lived in southwest Detroit for much of her life. The primary author (LRD) observed the majority of the interviews, but did not actively participate. Interviews lasted 45–90 min. Participants were interviewed in their homes or at CHASS, depending on their preference.

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 and CHASS.

Data Analysis

Interviews were digitally audio-recorded and transcribed verbatim into Spanish. Names of people and places were assigned a pseudonym. A company specializing in translation services translated transcripts into English. The primary author (LRD), with input from bilingual and bicultural study staff, refined translations to better reflect meanings as understood by Spanish-speakers in the community. Final interview transcripts included both Spanish and English text to allow for data coding and analysis by study team members not proficient in Spanish, and review of interviews in the original language by those proficient in Spanish.

During data collection, the research team identified preliminary themes, and through an iterative consensus process refined them until data collection was complete [35]. The research team developed a codebook based on these themes (e.g., primary care services offered, descriptions of the family provider relationship), and, again, through 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, three study team members, who would serve as primary coders, coded two transcripts (LRD, SMD, JSZ). Two team members coded each the remaining transcripts, with at least one of the three 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 [35–37].

We used QSR NVivo Version 8.0 to apply codes to the transcripts and organize text segments and relevant quotes abstracted during analysis. One coder with input and approval from the second coder summarized each transcript. Summaries included key themes and text evidence for those themes. Additionally, summaries organized participant experiences and expectations into three levels: provider, clinic, and health system. These summaries served as the basis for cross-case comparison and categorization of the number of participants with a particular experience or opinion among prominent themes. We then employed this system in the text to describe the findings: with respect to numbers of participants “few” indicates <10, “some” indicates 10–19, “many” indicates 20–29, and “most” reflects 30 or more participants [36].

Two study participants also contributed to the data analysis through periodic meetings. These meetings served to clarify questions about community processes (e.g., the bus and taxi system, networks of community members that provide transportation and interpretation services) and to discuss whether conclusions drawn by study team members reflected their views, feelings, and experiences. Consistent with a CBPR approach, CHASS staff provided feedback and assistance throughout the study planning, data collection, analysis, and dissemination phases of the study.

Results

Most of the 38 study mothers were of Mexican descent and had two or three children, the majority of whom were US-born. Table 1 displays respondent characteristics. About half of the mothers in this study assessed their primary care experiences positively and were satisfied with the care their child/children received. The remainder had negative assessments of their current PCP due to either dissatisfaction with the provider, clinic services, or both.

Provider Level Experiences/Expectations

Parent/Provider Relationship—The quality of the parent/provider relationship emerged as central to mothers' satisfaction with care. Mothers with a high-quality relationship with the provider felt that care from these providers was “worth the wait.” (Table 2, Quotes 1&2). Even if the mother expressed dissatisfaction with the relationship with their current PCP, most mothers had had a positive relationship with one of their child's health care providers and felt that this could be achieved despite language and cultural differences. The value mothers placed on a high-quality relationship with the provider seemed to outweigh the desire for a Spanish-speaking provider (Quote 3). We also asked all mothers about their desire for a Latino provider, and few women reported a specific desire for an ethnically-concordant provider.

Mothers described an ideal provider as someone who had a warm, friendly manner, could relate to and engage the child, did not make the mother feel rushed during the visit, performed a thorough physical exam, provided the correct diagnosis and medication for illnesses, and elicited and answered parent questions. Though the provider's perceived clinical skills were important, the provider's manner of interaction was most related to mothers' perceived satisfaction. Mothers paid attention to, and valued, details such as whether or not providers knew their children's names. They described providers who knew the child's name “without looking at the chart” more positively than those who did not (Quote 4). Mothers also expected providers to relate well with them. They positively regarded providers who engaged them by asking how they were doing, or joking with them, and who respected them in their role as a mother (Quotes 5&6). Finally, mothers expected providers to engage the child to make the child feel comfortable with the exam, and to ask questions directed towards the child (Quote 7).

Taking Time—Mothers frequently described feeling rushed during visits. They expressed higher regard for providers who were able to decrease the sense of time pressures. Mothers appreciated that clinics were busy, but they felt they had invested time and effort to come to clinic and that this should be reciprocated. Examples provided by mothers of “taking time” generally included encounters in which the provider performed a thorough physical exam (Quotes 8&9). Mothers worried that when providers performed only a focused exam they might overlook a finding that would change the diagnosis or treatment. They also felt a thorough exam represented genuine concern for their child's health and well-being. An additional critical element of “taking time” included eliciting and answering questions. Mothers appreciated a sincere interest in their questions, and were able to detect providers who asked for questions “out of routine” (Quotes 10&11).

Effective Diagnosis and Treatment—Mothers' expected diagnoses and treatment that resulted in prompt resolution of the child's symptoms, without the need for additional medical care (Quote 12). While mothers strongly desired medications to be prescribed as treatment for illnesses, they were critical of doctors who prescribed medicine that did not result in symptom improvement (Quote 13). However, some mothers acknowledged that medications were not always necessary, and others mentioned negative experiences when medications were prescribed that they perceived to be harmful (Quote 14). Mothers seemed more willing to accept a provider's recommendations for illness management that did not include medication if a provider was perceived to "take time" (Quote 15).

Provider Continuity—Most of the clinics used by families had one to three providers. At clinics with multiple providers, most families did not have continuity with one provider. While many mothers described continuity with a single provider as ideal, seeing multiple providers was not considered a problem if they saw them frequently enough for their child to know the providers and for providers to know the child's history (Quotes 16&17). Of mothers using a single provider clinic, the majority reported that a previous provider had left the clinic, and they were now using a relatively new provider. Mothers generally did not like the new provider as well as the previous one (Quote 18).

Clinic Level Experiences/Expectations

Clinic Characteristics—Study families used ten to twelve different local clinics. Some mothers only knew the name of either the provider or clinic so an exact count was not possible. Many mothers used one of four clinics for their child/children.

Appointment Process and Wait Times—Three of the four main clinics and several others saw patients primarily on a walk-in basis for both well- and sick-care. Mothers often preferred a walk-in system due to the unpredictability of children's illnesses (Table 3, Quotes 19&20). If a mother's desire for same-day sick care could not be met through a walk-in system at their own clinic, many chose to use other community clinics or the emergency room for sick care. Most participants had some experience with an appointment system, through their own or their child's health care. Mothers using an appointment-based system reported that often appointment times were not "respected," that their child could rarely be seen the same day for illnesses, and that they had to wait weeks to months for well-visits. Of the mothers who currently used an appointment-based clinic, only several reported preferring appointments to a walk-in system. These mothers used clinics where wait times for appointments were short and same-day sick care was reliable.

Regardless of the appointment system, many mothers were frustrated with long waits to be seen at clinics. Waits for walk-in care were generally longer (Quotes 21&22). Wait times were generally 1–2 h; some mothers reported waits as long as 5 h. Mothers who experienced especially long waits felt tension between wanting a walk-in system that allowed them the flexibility of going whenever they wished and the potential for less waiting with an appointment-based system (Quotes 23&24).

Clinic Hours—Few mothers reported their PCP had evening or weekend hours. Some mothers expressed frustration about the unavailability of evening or weekend hours and stated this led them to seek care in the emergency room (Quote 25).

Office and Nursing Staff—Many mothers expected and highly valued office and nursing staff friendliness and wanted nursing staff that could calm and comfort the child during blood draws or immunizations (Quotes 26&27).

Phone Care—Few participants reported after-hours phone care for questions or assistance with management of illnesses. When available, participants found it variably helpful (Quotes 28&29). The few mothers who reported that the PCP followed-up by phone with test results, or after significant illnesses, appreciated these calls.

Language Services—At least four community clinics had one or more Spanish-speaking providers; some of whom were Latino. At clinics without a Spanish-speaking provider, the clinic nurses generally provided interpretation. However, the nurses were not usually continuously present in the exam room, which disrupted the flow of the appointment and impeded communication (Quote 30). At clinics without any Spanish-speaking staff, families used their own limited English skills, or the providers' limited Spanish skills, to get by (Quote 31). Some mothers reported language services were especially limited for specialty and emergency care, resulting in both misinformation and frustration (Quote 32).

Care Coordination—Obtaining health care services besides primary care posed greater challenges for families. Some primary care clinics arranged for specialty appointments, but others required the family to call. When families had to call, they often struggled, as most specialty care offices did not have Spanish-speaking front desk staff (Quote 33). Transfer of information between specialists and PCPs was unreliable, with families often filling in information gaps (Quote 34). Mothers whose children were referred for developmental evaluation or services usually could not obtain them as they could often not reach someone at the office, or were told they would receive a call back and never did (Quote 35).

Health System Level Experiences/Expectations

All respondents had at least one child with public health insurance, either currently or in the past. Mothers reported difficulties obtaining and maintaining public health insurance coverage for their children. Key barriers to coverage included lack of forms in Spanish and limited availability of interpreters or Spanish-speaking staff at social services offices. Families who experienced difficulty with obtaining or maintaining public health insurance described deferring care when their child lacked coverage. Additionally, parents faced challenges navigating Medicaid managed care, including finding providers that accepted their child's managed care plan and facing restrictions on when they could change their child's plan or provider. Mothers who had difficulty interpreting managed care rules for provider selection reported decreased continuity of care due to a forced PCP switch, or remained at a clinic they did not like due to actual, or perceived, inability to change their PCP.

Discussion

About half of the LEP Latina mothers in this qualitative study expressed satisfaction with their children's pediatric primary care. Satisfied mothers described pediatric primary care that met their expectations for a high quality parent/ provider relationship, access to timely well- and sick-appointments, family- and child-centered staff, and language services that permitted effective communication with office staff and all care providers. Regardless of their satisfaction, mothers identified many ways to increase the quality of care, including encouraging providers to invest in the relationship with families, providing reliable same-day sick care, reducing wait times, improving access to language services at all points in the clinical encounter, expanding hours, increasing phone care availability, and implementing, or expanding, care coordination services. Mothers' main recommendations focused on key elements of the medical home including family-centered, compassionate, and comprehensive care. Thus, medical home implementation focusing on these elements has the greatest potential to improve the quality of, and parental satisfaction with, care among Latino children in LEP families.

Mothers in this study saw the parent/provider relationship as the foundational element of pediatric primary care. While language barriers were discussed in the context of the parent/ provider relationship, language was not the focus of women's concerns. Having a bilingual provider was of value to mothers, but they placed more emphasis on parent/provider relationship quality and effective communication, regardless of language, with the provider. This finding builds on prior research demonstrating the importance of the provider relationship and interaction style among Latinos [38–41]. The centrality of the parent/ provider relationship for Latinos is important for conceptualizing and implementing improvements in care for this population. While significant and necessary attention has been paid to access to language services and providing culturally-competent care for LEP Latino families, utilizing known, effective patient/provider interaction skills should continue to be promoted regardless of cultural or linguistic differences [42]. Mothers in this study emphasized the value of basic patient/provider interaction skills such as addressing the patient by name, interacting warmly with both the child and caregivers, and genuinely asking for and responding to parent questions. Based on the results of this study, improvements in these basic skills cannot be overemphasized in addressing disparities in primary care quality and satisfaction among Latino children in LEP families.

A central component of the medical home model is tailoring care through a family-centered care approach [27]. In our study we found that clinics did tailor some of their services, but not always with positive benefits. Many clinics in the community adapted to families' desire for same-day sick care through designing clinics that saw patients nearly exclusively on a walk-in basis. However, families often waited many hours to be seen, were seen by whichever provider was available, and felt rushed during visits. The importance of same-day sick care among Latina mothers is not unique to this study and may be related to immigrant Latinos' being accustomed to a walk-in system of care, common in Mexico and many Central American countries, or culturally-based fears about fever and other signs/symptoms of illness [38, 39, 43–45]. Prioritization of same-day sick care among Latina mothers, may contribute to reported disparities in the timeliness of care for Latino children [13, 46, 47].

Designing an optimal clinic appointment system in a clinic serving Latino families may require integrating the priority for same-day sick care with other aspects of care, while maximizing efficiency. Open access systems have been successful in some settings at reducing wait times, providing sufficient same-day visits, and increasing patient satisfaction with care [48–54]. Whether a well-functioning appointment system, such as open access, could overcome Latina mothers' biases towards a walk-in system should be evaluated.

While the majority of children in this study had health insurance, aspects of the public health insurance system still emerged as barriers to high-quality primary care. Certainly, health care access is the foundation of the medical home model, and thus insurance-related barriers must continue to be addressed. In our study, and in previous research, Latino parents expressed misperceptions and confusion about public health insurance rules that negatively impacted insurance enrollment and maintenance [55]. Overcoming barriers imparted by the public health insurance system may be best accomplished through local programs in Spanish that assist families with enrollment, renewal, and management of their child's health insurance, given the regional variation in public health insurance processes [56].

This study has certain limitations. First, we used a small, non-representative sample of mothers who use pediatric primary care in a particular community. However, many of our findings echo results from previous studies suggesting that the pediatric primary care experiences of the LEP mothers in this study may reflect the experiences of other LEP Latina mothers in the United States [13, 38–41, 46, 47, 55]. Second, many of our study participants had participated in a prior research study in the community. However, the prior study was distinct in purpose and in scope, and we did not identify systematic differences between participants by prior research participation. Third, we did not verify the reports of mothers about clinic structures or services offered, although participants involved in the analysis and community partner staff did clarify and validate concepts. Finally, we did not make quantitative measurements of maternal satisfaction with care; thus, any assessments of satisfaction are our inferences from the texts of the interviews.

Despite these limitations, this study offers a unique perspective on strategies to address disparities in pediatric primary care by allowing Latina mothers to speak at length about their experiences and expectations and then analyzing the findings in the context of the medical home. The voices of the Latina mothers in this study highlight that current efforts to improve primary care quality through application of the medical home model are highly relevant to this population despite cultural and linguistic barriers. Efforts to employ this model in clinics serving Latino families should recognize the fundamental importance of the parent/provider relationship to the primary care experience of these families. Practice improvements that reduce wait times, improve care coordination, expand hours, and increase availability of phone care must occur in concert with facilitating relationship-building between LEP parents and providers. Future research should explore how Latino families would prioritize the care improvements identified in this study and evaluate the impact of medical home implementation on health care quality and parental satisfaction for Latino children in LEP families.

While the challenge of confronting health care disparities remains, our study offers evidence that meeting this challenge does not require discovering novel ways to deliver care. Rather, focusing implementation of the medical home model on changes most desired by families has the potential to significantly improve the pediatric primary care experiences of Latino children in Spanish-speaking families. Effectively addressing these priorities will be central to meeting the promise of the medical home, high-quality primary care for all children.

Acknowledgments

This work was funded by Robert Wood Johnson Foundation Clinical Scholars Program.

Appendix: Interview Guide

Section A: Primary Care Clinic and Providers

1. Tell me more about the place where you take your child/children for check-ups.
2. What made you decide to take your child/children to that clinic?

(If they use different clinics for each child begin focus on youngest child here.)

- **Recommendation from:** Nursery staff, OB, friends/family, Insurance list, Phonebook
 - **Clinic Features:** Location, hours of the clinic, wait time for appointments, appointments available when you need them, after-hours line (ability to contact clinic/doctors after the clinic closed), friendliness of the staff and doctors, reputation in the community, Spanish speaking doctors/staff, Latino doctors/staff
 - Explore what things were most important to them when choosing a clinic and why
 - If they use different clinics for different children, explore why
- 3 Have you always taken your child to this clinic for check-ups?
 - Explore why they decided to leave the other clinic(s)/switch to the current clinic.
 - 4 Explore what they like and dislike about their current primary care clinic and why.
 - 5 Explore providers that see the child for appointments.
 - Do they have a usual provider or many different providers?
 - How did they choose the usual provider?
 - What are the things that you like about the provider(s)?
 - Manner or style of provider practice
 - Personality of provider
 - Perceived time spent with the family
 - Type of advice they give the family

- Any negatives?
- 6 If they describe continuity with a provider, explore their opinion about having continuity with one provider. If they don't have continuity explore why they do not have continuity and any potential benefits of continuity. Probes for benefits of continuity. Provider...
- Knows the child
 - Knows the child's health problems
 - Knows the family and their situations
 - Understands the mother better
 - Treats the mother with more kindness or more respect
 - Any negatives?
- 7 Tell me about the last check-up for your youngest child. (Define check-up- “physical”, “shots”, “appointment when the child is not sick”)
- Explore what takes place and topics discussed during check-ups
 - Vaccines
 - Physical Exam
 - Advice about: Growth, Development, Behavior, Sleep habits, Nutrition, Parenting
 - What are some other things that you would like to know about taking care of your child/children's health?
 - Besides your child's health care providers, where else do you get advice/ information about your child/children's health?
 - People (Friends, Relatives, Child Care Providers)
 - Media (TV, Books, Internet, Radio, Pamphlets)
 - Explore what kind of advice/information that they obtain from these other sources.
 - Advice about *what to do when child is sick*
 - Advice about *feeding/nutrition*
 - Advice about *development*
 - Advice about *discipline*
 - Explore if they receive different advice from different sources and which advice they follow/trust the most when the advice/information is different?
- 8 Tell me about how important it is to you to have a provider that speaks Spanish.

- Explore the differences between having a provider that speaks Spanish and having an interpreter.
 - Ask for stories about problems they have faced because they need/prefer services in Spanish
 - Explore whether or not it is important to them to have a provider that is Latino.
 - Understands your culture/religion/beliefs
 - Speaks Spanish the same way you do
- 9 Explore what other services are offered by the clinic beside appointments.
- WIC
 - Laboratory
 - Nutritionist
 - Social Worker
 - Child development/behavior specialist
 - Explore how often and why they use these services.
 - Explore what other services they think the clinic should offer and why they might beneficial

Section B: Health Care During Illnesses

1. When your child is sick how do you decide where to go for health care?
 - Explore the process of getting sick care at the primary care clinic
 - Call in or walk-in for appointment
 - Availability of same day appointments
 - Wait time for appointments once they arrive
 - Understands your culture/religion/beliefs
 - Speaks Spanish the same way you do
 - Explore whether barriers to getting sick care at the primary clinic have caused them to go other places for sick care
 - Explore where they chose to go and why
 - **Places:** Emergency room, urgent care, drugstore/pharmacy, chiropractor, hospital, traditional healer
 - **Reasons to go:** Felt the problem was too urgent to arrange an appointment at the clinic, could not get an appointment at the clinic, would have had to wait too long for an appointment at the clinic, clinic was not open

2. Has your child needed to see a specialist? How has it been taking your child to an appointment with a specialist?
 - How did they arrange the appointment with the specialist (Did they call to make appt or did clinic call?)
 - Was transportation to get to the specialist a problem?
 - Was there an interpreter available to them?
 - Did the specialist know why they had the appointment?
 - Explore if the primary doctor knew what happened at the specialist appointment
 - If they report care with many different doctors explore how they keep track of the appointments and what each doctor asks them to do
 - Explore if they would like someone from the clinic or community help them managing the health care of their child.
 - What should this person do to help?

Section C: CHASS (Only If Families Do Not Go to CHASS)

1. Did you consider using CHASS for check-ups for your child?
 - Explore why they decided not to use CHASS
 - Explore what changes CHASS would have to make to be a place they would want to use for health care for their child/children

Section D: Conclusion Questions

1. Describe the perfect pediatric clinic for their children and family.
 - What would the building look like (waiting room etc.)
 - Hours
 - How would you make appointments
 - Kinds of providers
 - Services
 - What would they use it for...appointments, education, parent groups?
 - Would it serve the whole family or just kids
2. Is there anything else that you can think of that clinics and doctors could do to help families take care of their children's health?

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Table 1

Characteristics of sample mothers and their children

Characteristic	
Maternal age, mean, years	31 (range: 20-44)
Foreign-born mother, %	97
Country of origin-Mexico, %	95
Length of stay in US, mean, years	9 (range: 2-20)
Limited English proficiency [*] , %	97
Maternal education	
Less than high school, %	71
High school graduate, %	11
More than high school, & Annual household income	18
<\$20,000, %	82
\$20,000-\$30,000, %	16
Mother lives with husband/partner, %	87
Mother's health status fair/poor, %	26
Mean number of children	2.7 (range: 1-6)
Age of children, mean, years	5.9 (range: 2 months-19 years)
US-born children, %	83
Children's health insurance status	
Public insurance ^{**} , %	81
Private insurance, %	5
Uninsured, %	15
Children's health status fair/poor, %	12

^{*} Participants classified as LEP using US census definition (self-report of speaking English less than "very well")

^{**} Includes children with coverage from either Medicaid or the State Children's Health Insurance Program

Table 2

Participant experience with, and expectations for, the parent/provider relationship

Good providers are “worth the wait”

Quote 1

Foreign-born mother, %

Había un doctor antes que era tan bueno, se tomaba el tiempo a pesar de que estaba llena la clínica, esperaba uno un poco más pero valía la pena. Porque se tomaba la molestia de checar bien a los niños, de preguntarle cómo se sentían, de preguntarte a ti, este...si tenías alguna duda o algo, pero se sentía que realmente tenía interés en la salud de los niños

They used to have a doctor that was very good, he used to take his time even though the clinic was full, it was a longer wait but it was worth it. He took the trouble to examine the children well, to ask them how they were feeling, to ask me...if I had any questions or concerns, but you could tell he was genuinely concerned about the children's health

Quote 2

Es un doctor muy paciente. No, no, también se tarda mucho uno, casi como dos horas, aunque tengas la cita a cierta hora te tardas como dos horas, pero es muy bueno el doctor, o sea, vale la pena. He is a very patient doctor. No, no it takes a lot of time as well, almost 2 h, although you have a scheduled appointment at a certain time it always takes about 2 h, but the doctor is very good, it is worth it

A caring, attentive provider was more important than a bilingual provider

Quote 3

Qué importa, que no, que [el médico] no sea bilingüe pero es atento...Y de buen trato más que nada. What is important, not that [the doctor] is bilingual, but that he is attentive...and more than anything [the doctor] should treat you well

Knowing the child's name and relating positively with the mother were markers of a caring provider. They were also an important factor in a mother's assessment of her relationship with the provider

Quote 4

Pues, era agradable, era...no te sentías así como con miedo o que...ay, no porque llegaba y saludaba y muy amigable, y a los niños los saludaba.....Por su nombre, y eso es lo que a mí me gusta...y que me conoce a mí. Well, he was kind...and you didn't feel afraid with him or...because whenever he came in, he would greet you and was very friendly, he also greeted the children...he called them by their names, and I liked that...and that he knows me

Quote 5

Sí. Dice, “¿cómo estás?”[a la madre] O, dice, te veo cansada y...pero es muy platicador, y te platica, o sea que trata de hacerte reír y todo...hay dos doctores pero me gusta más el Doctor J. Yes. He says, “how are you?”[to the mother]? Or, he says, you look tired...He is very talkative, and talks to you. He tries to make you laugh...there are two doctors, but I like Doctor J more

Quote 6

Ella[La doctora] me dice cuando estoy mal, o cuando no estoy mal. Cuando estoy mal, por ejemplo si yo le pido una medicina que no la necesita, me dice claramente no porque no la necesita esa....O sea, ella me entiende como mamá y yo la entiendo como profesional. O sea, que no le puedes dar más de eso, y me dice “no, ese tratamiento es así, se sigue así y si no se le quita llámame.”

She [the doctor] tells me when I'm wrong or when I'm not. When I am wrong, for example, is when I ask for a medicine he doesn't need, she tells me why he doesn't need it...Well, she understands me as a mother and I understand her as a professional. I mean, [she tells you] if you can't give him any more of that [medication], and she tells me “no, the treatment works like this, you have to follow it this way, and if he doesn't get better, call me”

The assessment of the provider relationship also depended on the provider's ability to relate to and engage the child

Quote 7

Es que los niños como con la gente extraña son como... así como que se como que no quieren ni que los toquen, pero pues él les empieza a hablar bien, bien...[Child 1] se siente... cómodo con él With children when people are strangers they are like... like as if they as if they don't even want to be touched, but then he begins speaking well with them... [Child 1] feels...comfortable with him

A thorough physical exam was important to fulfilling mothers' expectations for providers to "take time" with their child

Quote 8

Mira cuando llego digo lo que tiene o aunque no esté mala, que sea un chequeo, me dice que le quite la ropa, la pesa, la mide, le oye su espaldita, su corazón, le checa los oídos, los ojos, la boca, todo le checa. Y los demás doctores no

Look, when I get there, I tell him what she has, but even if she is not sick and it is only a check-up, he tells me to take her clothes off. He takes her weight and he measures her, he listens to her back, her heart, he checks her ears, her eyes, her mouth. He checks everything, but the other doctors don't

Quote 9

O sea cuando estaba un doctor, él sí lo revisa pues de todo. Y cuando está, pues una doctora no... no lo revisa pues no más como que anda a la carrera y... no más lo... de lo que está, de lo que le dice pues uno que está enfermo, es de lo que... de lo que lo revisa

Well there used to be a doctor that would examine everything. And when the lady doctor is there...she only examines them in a rush, she only examines what we tell her they are sick with

Sincere eliciting and answering of questions, and providing detailed explanations, also fulfilled mothers' expectations that the provider "take time" with their child

Quote 10

Porque nada más tienen una doctora... y tienen mucha gente, entonces la doctora te atiende cinco minutos y ya estás afuera. Y a mí me gustaría que tuvieran más tiempo para checar bien a los niños, para preguntarte... sí te dicen si tienes preguntas o algo, pero...como nada más por rutina, no porque sienta yo que realmente les interesa

Because they only have one doctor ... and they have a lot of patients, and so the doctor will treat you for five minutes and then you're out. And I would like them to have more time to check my children better, so I can ask, they do ask you if you have any questions or something, but...it's more like a routine, not because they are really interested [in your questions]

Quote 11

La doctora que está ahorita toma su tiempo, te dice si tienes algunas preguntas, y luego a los bebés los revisa bien...aparte de eso se ve bien cariñosa y bien amable con ellos, y toma todo su tiempo para... hacerte las preguntas que tú necesitas. Y entonces yo he escuchado en otras personas que dicen no, dicen no, ni siquiera los checan, no más dicen que tiene esto y ya. Y bueno yo, para mí la doctora ha sido así, y este... a mí me parece bien

The lady doctor that's there right now takes her time and asks you if you have any questions, and she examines the babies well... and she also looks like she is very caring and nice to them, she takes all her time...to answer the questions that you need answered. And then, I have also heard other people saying that other doctors don't even check their kids, they only tell them what they have and that's it. But well, the lady doctor has been like that to me...and I think that's good

Mothers' assessments of the provider were related to their perception of effective diagnosis and treatment

Quote 12

Me dijo que era buen pediatra y pues yo quise ir allá, y ya conocí pues, sí me gustó cómo los atendió y aparte de la medicina que les mandaba, luego, luego se aliviaban los niños

She told me that he was a good pediatrician, and so I wanted to go there, when I met him, I liked how he treated them, and with the medication he would prescribe, the children would get better right away

Quote 13

Pero yo creo que la doctora que la atendió...no sé qué le pasaba porque le recetaba medicamento y medicamento y mi niña no se componía... Y sí la cambié de doctor

I think the female doctor that treated her...I don't know what was wrong with her because she would prescribe medicine after medicine, and my daughter would not get better...and so I changed doctors

Even though there was a strong desire for providers to prescribe medications for illnesses, mothers acknowledged that medications were not always necessary, or could have harmful effects

Quote 14

Porque a veces, cuando uno los lleva, le dan, otra... otro... otra medicina u otro... le dan tanta medicina que a veces uno no sabe qué, qué medicina le puede afectar, le puede hacer mal...

Because sometimes when we take them in they give them a medicine...and they give them so much medicine that sometimes we don't know which one is affecting them, or if it's going to make them sick...

A provider who met mothers' expectations for a high-quality parent/provider relationship could temper mothers' expectations for prescription of medication for illnesses

Quote 15

El doctor va que, desde la cabeza a la punta de los pies me revisó a mi bebé. Mi niña cuando nació tenía una infección en sus ojitos, que le producía mucha secreción, lagunita verde... cuando fui con [El Doctor] él me hizo hasta un croquis del ojo y me explicó que...por qué la secreción de los ojitos de mi niña y me dijo qué era lo que le tenía que hacer, no me dio medicamento al momento porque me dijo que era algo de ...natural, como un, digamos, por lo...de la nariz y los ojos. So, me dijo qué hacer y me explicó a qué se debía. ...yo quedé maravillada

The doctor examined the baby, from the head to the tip of her toes. When my daughter was born she had an infection in her eyes, and it was producing a lot of secretion. green discharge...when I went to see [the doctor] he even drew a sketch of the eye and explained that...why she had the secretion coming out of her eyes and he showed me what I needed to do, he didn't give me any medication that day because he told me it was something...natural, like a, let's say, coming out of...her nose and eyes. So, he told me what to do and explained to me what it was due to...I was so impressed

While continuity with one provider was preferred, seeing different providers at a clinic was not always a problem

Quote 16

Pues porque ya el, el doctor ya conoce al niño ya sabe qué es que es lo que tiene, qué es lo que le puede recetar, si no es alérgico a una medicina, o, no sé...tú llevas a tu niño con un doctor y ése es el que ya, ya sabe qué es lo que tiene el niño

Because [if you only have one doctor] the doctor already knows the child and understands what he has. He would know what to prescribe, if the child is allergic to certain medicine or something...you take your kid to the doctor, and he already knows what is wrong with your child

Quote 17

Sí, o sea, para mí es lo mismo, por lo que yo voy a esa clínica, o sea, ya, yo sé que están ellos dos y cualquiera de ellos pues me va a dar buena medicina, o esto. Para mí está bien, que los dos [atienden a mi niño] para mí está bien

Yes, I mean, [both doctors] are the same for me, I am going to that clinic, I mean, already I know they are both there and either one will prescribe a good medicine, or things like that. That's fine with me, that they both [see my son] that's fine with me

A change in provider at a clinic could negatively impact a mother's assessment of care at a clinic

Quote 18

Si [la doctora] se tomara más tiempo en verte, porque casi, creo que ni te, checan así a los niños...pero sí que te conociera a ti, que conociera a tus niños, te digo el doctor que estaba antes, él sabía el nombre de la niña a pesar de que a la niña casi no la había llevado ahí, llegaba... cosas así que hacen la diferencia, porque los niños ya los van conociendo y ya tienen más confianza con ellos. Y jugaba con ellos, y así para que se dejaran checar, porque...algo, no, nada más a lo que van y ya

Let me tell you, if [the doctor] could take a little more time seeing them, because she hardly, I don't think she even, examines them...that she would at least get to know you, your children, the previous doctor, he knew my daughter's name even though I hardly ever brought her there ... things like that make a difference, because the children get to know them and they feel more comfortable around them. And he used to play with them, and, so they would let him examine them.... now, they only come in do it and that's it

The quotations selected for presentation in Tables 2 and 3 serve as examples for the complete set of statements from which the identified themes emerged

Table 3

Participant descriptions of their experiences with services at pediatric primary care clinics

Participants preferred a walk-in system for care due to the unpredictability of children's illnesses

Quote 19

La verdad, sin cita, porque hay veces que pues los niños son, ahora son niños, y agarran todo y todo se echan a la boca y si le cae algo mal, imagínese si me pongo a hacer una cita, y le cae algo mal antes de que le toca la cita, y vomitadera o diarrea y... este... eso que asusta se deshidrata y... uno qué puede hacer, mejor va uno con el doctor y ya

The truth [I prefer] to walk-in, kids will be kids and they put everything in their mouths and if something happens to them, imagine that I make an appointment and something is wrong with them before their appointment and they have vomiting and diarrhea? That would be scary, they would get dehydrated and what could you do? Better to go right away to see the doctor

They used to have a doctor that was very good, he used to take his time even though the clinic was full, it was a longer wait but it was worth it. He took the trouble to examine the children well, to ask them how they were feeling, to ask me...if I had any questions or concerns, but you could tell he was genuinely concerned about the children's health

Quote 20

La mayoría de los niños chiquitos constantemente están enfermos. Ahorita ya mis niños gracias a Dios que ya no, pero chiquitos sí se enferman más seguido, seguido, y que no tengas a dónde llevarlos[sin cita], eso es frustrante. A mí eso me desespera

The majority of young children are constantly getting sick. Thank God at the moment my children are not, but when they're younger they do get sick more often, and having nowhere to take them [as a walk-in], it's very frustrating. That really frustrates me

Participants expressed frustration with long wait times to be seen at clinics

Quote 21

Cuando llegas al consultorio ya lo que quieres es salir, o sea, tanto que esperar, que los niños están que...los checan de llorar y tengo que llevarlos, a veces sí me vengo y digo, "ay no, ya no quiero preguntar, ya me voy"

When you get to the office all you want to do is leave, in other words, you wait so long, the children are up to a point that...they examine them they start to cry and I have to take them, sometimes I do go and think, "no more, I don't feel like asking any more questions, I'm leaving"

Quote 22

El tiempo es oro, entonces como que duramos más tiempo esperando, a que nos atiendan, entonces podemos durar hasta una hora sentadas y quince minutos en el chequeo en la revisión así de que dices, "ay, no," y luego los niños inquietos y empiezan a llorar, y la tensión crece y se desespera uno y ...

Time is gold, but we spend more time waiting than being seen, so we may be sitting there almost up to an hour, and 15 min in the examination so you think "oh, no" and then the children are restless and they start to cry, and tension grows and you start to feel desperate...

Both walk-in and appointment-based systems had advantages and disadvantages

Quote 23

Pues no me gusta que sea con cita porque... se tardan mucho también aquí, te la dan retirada, pero por eso me cambié allá, porque decía pues, voy cuando yo quiera, pero me salió peor porque, cuando yo los llevaba...Y no me lo atendían porque ya estaban llenos! ...Digo pues me quedo acá con la cita

Well, I don't like it when it is by appointment...because here they take too long. They give them to you way far out, that's why I switched to over there because I thought that in that way I could go anytime I wanted, but then it ended up being worse. When I would take them... they wouldn't treat him because they were full...I thought, well, I better stay over here with appointments

Quote 24

Pues ahí tenemos que esperar tal vez más, pues tiene sus desventajas y ventajas porque, la desventaja es que uno...llega y no tiene cita, ¿verdad, así como va, tiene que esperar seguro. Y, pues la ventaja es que...que si uno no puede un día ir...sabe uno que lo van a atender otro día

Well, over there we have to wait maybe more, but it has its advantages and disadvantages. The disadvantage is...that we get there without an appointment, right? So we will have to wait for sure. And, the advantage...is that if we cannot make it 1 day...we know we'll be seen another day

Limited clinic hours meant mothers had to use the emergency room for illnesses

Quote 25

Pues el horario está bien, pero...no sé a lo mejor que tuvieran unas cuantas horas...el fin de semana porque toca la suerte que muchas mamás se nos enferman el fin de semana y no hay dónde llevarlas, más que el hospital...

Well the hours are fine, but...I don't know maybe they should open for a few hours on...weekends because it's just the luck of many moms that our children tend to get sick on the weekend and we have nowhere to take them, except the hospital...

Families expected friendly clinic staff and valued nurses that could calm and comfort their child

Quote 26

Oyy... pues un mejor trato de las enfermeras...que estén conscientes de que están brindando un servicio y es el trabajo aparte de ellas, porque... este... uno no va...porque no más por fastidiarlas a ellas o porque tengan más trabajo. Uno va porque necesita ir ahí...Pero sí un mejor trato, ese sería lo primero, un mejor trato

Oh...well a better interaction with the nurses...they should be aware that they are providing a service and that it is their job. We don't go there....just to bother them or to make them busier. We go there because we need to...This would be the main thing, to treat people better.

Quote 27

Les hacen cosquillas y luego esconden la aguja cuando las van a picar. Y ya cuando los pican les ponen curitas del, de los personajes que les gustan.... Sí, son muy buenas las que están ahí

They tickle them. They hide the needles before they pinch them. Then they put band aids of characters that they like...Yes, the nurses there are very good

Assistance by phone, when available, was variably helpful

Quote 28

Aunque sea por teléfono, pero me atendía, me decía qué le hiciera a la niña, o que... pero sí, sí, me gustó mucho el trato de esa doctora

Even over the phone, she would still help me, and she would tell me what to do with my daughter...so yes, yes I did really like the treatment of that doctor

Quote 29

Y este, y le hablaba y "no señora, es que es normal, es normal" ..., así como si me estuviera diciendo enojada...Sí, y le dije...ya no la voy a llamar, mejor lo vamos a llevar al Hospital, porque me da no sé qué estar hablando y como que se enoja o no sé qué

I would call and she would say, "No, ma'am, it's normal, it's normal." ...She would say it like she was mad at me...Yes, I said...I am not going to call anymore, better to take him to the hospital because they won't act like they don't know what I am saying and they won't get mad about I don't know what

Language services were often inadequate leading to both misinformation and frustration

Quote 30

Sí había enfermeras que hablaban español, este... y ellas nos interpretaban pero había veces que ellas se salían a atender a... al otro paciente, y nos quedábamos esperando al doctor, y a veces llegaba el doctor primero que la enfermera y nos empezaba a decir y... pues se quedaba uno... con cara de, "what?", hasta que llegaba la enfermera, y pos yo me imaginé que se desesperaba el doctor pues se desesperaba uno que no entendía y él nos decía y pos no sabíamos ni qué, y este...y hasta que llegaba la enfermera otra vez pátras y ya...nos decía, el doctor volvía a decirle lo que tenía el niño, y este...y pos es que sí se siente uno incómodo porque no sabe uno el, el idioma pues y qué hace

They had Spanish-speaking nurses there...and they would be our interpreters, but sometimes they had to go...see another patient and we would sit there waiting for the doctor and sometimes the doctor would get there before the nurse and he would start saying things, and we were there...with our faces like, "What?" ...until the nurse arrived, and I imagine the doctor was frustrated because we were frustrated not understanding him and he would say something and we wouldn't understand anything...we would stay like that until the nurse was back in the room...and the doctor had to tell her what was wrong with the child all over again...we were very uncomfortable because we didn't know the language and we didn't know what to do

Quote 31

Pues, poco en inglés y poco en español. Porque como [el doctor] no sabía mucho cómo hablar español pero yo le entendía así más o menos porque me lo revolvía e inglés y en el español, me decía algo en inglés y luego en español y ya sabía de lo que me hablaba...

Well, a little bit in English and a little bit in Spanish because [the doctor] couldn't speak a lot of Spanish, but I would understand more or less because he would mix both English and Spanish, he would say something in English and then in Spanish, so I would know what he was talking about

Quote 32

Pues mi esposo habla más inglés que yo, pero sí es difícil porque no entiendes cien por ciento lo que te están diciendo. Y también del niño nos pasó que, que se supone que le van a quitar las anginas pero nunca nos explicaron que iban a poner los tubos, so, yo no sabía

Well my husband can speak English better than me, but yes, it's hard because you can't understand one hundred percent what they're saying. And also what happened with our son that, they were supposed to remove his tonsils but they never told us that they were going to insert [ear] tubes, so, I didn't know

Lack of care coordination reduced access to specialty care and needed services and may have negatively impacted communication between providers

Quote 33

Ayer y hoy he tratado de comunicarme, porque el lunes tengo otra cita allá...Y no, no me pueden, les digo que sí hay ahí alguien que hable español y no, no lo pueden hacer la cita, porque quieren que les deletree el nombre de la niña, el nombre de la pediatra...

Yesterday and today I've been trying to communicate because on Monday I have another appointment over there...and they can't, I ask them if there is anybody who can speak Spanish, but there isn't; they cannot make the appointment because they want me to spell out my daughter's name, the name of the pediatrician...

Quote 34

No, tenía que explicar que porque llegaba y era como que así que, porque también el papel que mandaban de aquí no pasó bien, no se veía casi nada, y tenía que explicarle, a lo que iba y lo que la niña tenía, el diagnóstico que había tenido...

No, I had to explain why I was there and it was like, because the paper that they faxed from here didn't go through, you couldn't read it, and I had to explain, what I was there for and what my daughter had, her diagnosis and ...

Quote 35

Sí. Si me había dicho de que ya debería estar hablando como... frases, como oraciones de tres palabras y él no hacía eso, no más que decía una palabra...Ella me dio el teléfono que yo hablara...Hablé, pero...Tenía que esperar al... a que hubiera un lugar...Unos tres meses y que ellos me hablaban y nunca me hablaban

Yes, She told me that he should be talking like...phrases, like three word sentences and he did not do that, he would only say one word...She gave me the telephone number for me to call...I called but...I had to wait for space to become available...3 months I waited for them to call and they never called me