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A Voice and a Vote: The Advisory Board Experiences of Spanish-Speaking Latina Mothers

Lisa Ross DeCamp, MD, MSPH,
Johns Hopkins University School of Medicine, Baltimore, Maryland

Johns Hopkins Bayview Medical Center, Baltimore, Maryland

Emily Gregory, MD,
Department of Pediatrics, Perelman School of Medicine at the University of Pennsylvania, Philadelphia, PA

Sarah Polk, MD, ScM,
Johns Hopkins University School of Medicine, Baltimore, Maryland

Johns Hopkins Bayview Medical Center, Baltimore, Maryland

Marilyn Camacho Chrismer, BS,
Kennedy Krieger Institute, Baltimore, Maryland

Flor Giusti, LSCSW,
Johns Hopkins Bayview Medical Center, Baltimore, Maryland

Darcy A. Thompson, MD, MPH, and
University of Colorado School of Medicine, Aurora, Colorado

Erica Sibinga, MD, MHS
Johns Hopkins University School of Medicine, Baltimore, Maryland Johns Hopkins Bayview Medical Center, Baltimore, Maryland

Abstract

Latino children experience disparities in health care access and quality. Family advisory groups for clinics and hospitals may be one way to address disparities. We implemented and sustained an advisory board whose parent participants were exclusively limited-English proficient Latina mothers. As part of the board evaluation, we conducted semistructured individual interviews with parent participants during initial participation and after the final board meeting of the year. Members were satisfied with their board participation in both initial and follow-up interviews. They reported that board membership was an important way to improve clinic services and a unique opportunity for Latinos in the community. Experiences of discrimination and marginalization in health care settings were a theme across interviews. Members reported board membership countered these negative experiences. An advisory board including Spanish-speaking parents is an opportunity to engage vulnerable populations, which may result in broader impact on health care disparities.

Correspondence regarding this article should be directed to Lisa Ross DeCamp, MD, MSPH, Johns Hopkins University School of Medicine, Baltimore, MD. ldecamp1@jhmi.edu.

Los niños latinos experimentan disparidad en el acceso y calidad del cuidado de salud. Grupos de familias asesoras para clínicas y hospitales pueden ser una forma de hacer frente a las disparidades. Nosotros implementamos y sostuvimos un consejo asesor cuyos participantes fueron exclusivamente madres latinas con dominio limitado del inglés. Como parte de la evaluación del consejo, condujimos entrevistas semi-estructuradas individuales con las madres participantes durante la participación inicial y después de la última reunión del año del consejo. Los miembros estaban satisfechas con su participación en el consejo en ambas entrevistas, la inicial y la de seguimiento. Ellas reportaron que ser miembros del consejo era una forma importante para mejorar los servicios de la clínica y una oportunidad única para los latinos en la comunidad. Las experiencias de discriminación y marginalización en las instalaciones de cuidado de salud eran un tema a lo largo de las entrevistas. Los miembros reportaron que ser miembros del consejo contrarrestó estas experiencias negativas. Un consejo asesor incluyendo padres que hablan español es una oportunidad para involucrar a poblaciones vulnerables, las cuales pueden resultar en un impacto más amplio en las disparidades del cuidado de salud.

Keywords

Patient engagement; Hispanic/Latino; immigrants; limited English proficiency; pediatrics; primary care

Latino children in Spanish-speaking families experience disparities in primary care access and quality (Flores, 2010; Flores, Olson, & Tomany-Korman, 2005; Flores & Tomany-Korman, 2008). The disparities experienced by these children indicate that pediatric primary care often does not meet Latino families' needs and expectations. Using parental self-report measures of health care attributes, only about one-quarter of Spanish-speaking parents report care consistent with a medical home (DeCamp, Choi, & Davis, 2011). Satisfaction with health care among Spanish-speaking Latino parents is lower than that of English-speaking Latino parents or non-Hispanic White parents (Halfon, Inkelas, Mistry, & Olson, 2004; Ngui & Flores, 2006; Weech-Maldonado, Morales, Spritzer, Elliott, & Hays, 2001). To reduce health care disparities for Latino children, we need to implement changes to pediatric primary care based on an improved understanding of their needs and expectations.

Patient engagement may be a way to shape health system changes to better match patients' and families' health care needs and expectations and address health care disparities for Latino children with parents with limited English proficiency (LEP). Patient engagement refers to collaborative partnerships between patients, families, and health care providers to improve health and health care across the health system (Carman et al., 2013; Chu & O'Brien, 2012; Danis & Solomon, 2013; Maurer, Dardess, Carman, Frazier, & Smeeding, 2012). Patient engagement is of increasing value to our health system and reflects the broader vision of patient- and family-centered health care fundamental to the medical home (Medical Home Initiatives for Children With Special Needs Project Advisory Committee, 2002; Patient-Centered Primary Care Collaborative, 2014). The National Committee for Quality Assurance (NCQA) now includes patient engagement activities as part of medical home designation (NCQA, 2011).

A patient or family advisory group, whereby patients/families from a practice meet on a recurring basis with clinical leaders to identify and address areas for improvement, is one format for engagement. Among NCQA-designated medical home practices, only about one-third has implemented such groups (Han, Hudson Scholle, Morton, Bechtel, & Kessler, 2013). Family advisory groups are not well-described in the literature perhaps because, when they are established, they are viewed as an important core practice activity, as opposed to a topic of study (Scholle, Torda, Peikes, Han, & Genevro, 2010). Understanding their potential to meaningfully engage families and contribute to improved health care access and quality. This requires understanding of the perspectives of the families who participate in these groups.

We recently established a family advisory group for an urban, pediatric primary care clinic to engage these families in health care improvement. Parent participants were exclusively LEP Latina mothers. To our knowledge, there are no reports describing the experiences of Spanish-speaking Latino families in advisory groups focused on ambulatory care. As interest in patient engagement increases, and promising programs emerge, it is critical to include vulnerable patient populations in patient engagement activities to prevent increased health care disparities resulting from health system changes that do not reflect the values of diverse populations. Accordingly, patient engagement in the pediatric setting must extend to Latino families and include Spanish-speaking LEP parents; Latinos are the largest U.S. minority (U.S. Census Bureau, 2013a) and comprise the majority of LEP persons in the United States (U.S. Census Bureau, 2013b).

The purpose of this study was to inform increased engagement of LEP Latino families in health care improvement by (a) describing the initial experiences and expectations for advisory board participation of low-income LEP Latina women who participated in the first year of a family advisory board for a pediatric primary care clinic and (b) describing the assessment these mothers made of board activities and impact after their first year of board participation.

METHOD

Study Design and Sample

In this qualitative study, we conducted 20 semistructured interviews with 10 LEP Latina mothers who participated in the initial year of a family advisory board for an urban, hospital-based pediatric primary care practice located in Baltimore, Maryland. The clinic's majority patient population is Latino children with LEP immigrant parents (approximately 75% of annual clinic visits), although the clinic serves a racially and ethnically diverse patient population in both immigrant and nonimmigrant families. In addition to Latino immigrant families, other immigrant families primarily come from Africa and the Middle East and have entered the United States with refugee status. The clinic serves primarily publically insured children. About 10% of patients have private insurance, and a small minority of patients are uninsured Latino immigrant siblings of insured children.

During the initial year of the Latino Family Advisory Board/*Consejo de Familias Latinas* (LFAB), seven meetings were held from September 2011 to June 2012. Evaluation interviews with board members were completed after initial meetings of the family advisory board and again after the final meeting of the first year. Board development was guided by community-based participatory research (CBPR) principles in which board members helped to determine the structure, function, and tasks of the board. All meetings were conducted in Spanish and cofacilitated by a clinic provider and a licensed clinical social worker affiliated with the clinic. Childcare and a meal were provided at each 90-minute evening meeting, and board members received $30 per meeting for time and travel.

Clinic providers and staff recommended families for board participation. Criteria for recommendations included parent-preferred health care language of Spanish and perceived interest in participation. We specifically asked for recommendations of families who both did and did not face challenges using the health care system and of families who had generally well children and children with special health care needs. The names of 29 families were provided to the LFAB coordinator. Successful phone contact was made with 20 of 29 families. Seventeen families agreed to come to the first meeting and 12 mothers attended. Reasons cited for not wanting to come or not coming to the first meeting included lack of time, working at the time of the meeting, or lack of interest. Although we invited all caregivers, only mothers attended.

During the initial year, 13 LEP Latina mothers participated in at least one board meeting. Average meeting attendance was nine mothers (range: 6–12) and three clinic staff, including the clinic medical director. Nine parent board members attended at least five of seven meetings. Subsequently, the term *board members* refers to parent board members, unless otherwise specified. At the initial meeting, board members prioritized areas for improvement and additional supports needed for families at the clinic. These priorities were used to determine further meeting topics. Topics discussed at subsequent meetings included feedback on community pharmacy experiences with a medication dosing activity, development of low-literacy Spanish language oral health brochure, and feedback on clinic family support services brochure and screening form. The oral health brochure and family support services materials are now in use at the clinic.

Interview Design

All parents who attended an LFAB meeting (*n* = 13) were invited to participate in the interviews. In keeping with the application of CBPR principles in board development, among the expected outcomes of the interviews was information to be used to shape subsequent structure and functioning of the board. Initial interviews took place between October 2011 and January 2012. Topics covered included why they decided to participate, their perceptions of the clinic, their assessment of the positive and negative aspects of the board, what they hoped the board could accomplish, what they personally might gain from participation, their relationship with other board members, and their experiences with participation in other community groups.

Follow-up interviews took place in June and July 2012 after the conclusion of the first year of the board. Topics covered included reflections on their board participation over the past year (e.g., what they had liked and disliked, group dynamics), changes in the clinic that may have resulted from the board, priorities for future clinic improvements, what they had learned by participating, what they hoped the board would accomplish in the future, and their desire to continue participation.

A bilingual Latina of Cuban descent, with significant prior experience working with the local Latino immigrant community, conducted the interviews in the participants' homes. Initial and follow-up interviews lasted 25–50 minutes. Participants signed separate informed consents for each interview after the consent form was orally read to them and received $25 per interview for participation. This study was approved by the Johns Hopkins Medicine Institutional Review Board.

Data Analysis

Interviews were digitally audio-recorded and transcribed into Spanish and subsequently translated into English by a commercial transcription and translation service. Prior to data analysis, study staff and investigators (Rubi Luna, MC, LRD) refined translations to better reflect meanings as understood by Spanish speakers in the community and de-identified transcripts. Transcripts used for analysis included both Spanish and English text to allow for data coding and analysis by study team members not proficient in Spanish and review in the original language by those proficient in Spanish.

All authors participated in development of a preliminary codebook and through an iterative consensus process, the three authors responsible for coding (LRD, MC, EG) refined codes and determined that they were clearly defined and could be consistently applied. During early application of the codebook, some interview transcripts were coded by all three coding authors (five initial interviews and two follow-up interviews). Two of these three study team members then coded each of the remaining transcripts. Rather than employing a measure of intercoder reliability, we addressed all coding difference by reconciling them through discussion and consensus (Barbour, 2001; DeCamp et al., 2013; Heisler et al., 2009; Patton, 2002). We used ATLAS.ti version 5.7.1 to apply codes to the transcripts and organize text segments and relevant quotes abstracted during analysis. Board members provided feedback on findings and interpretation periodically during second year board meetings.

RESULTS

Of the 13 eligible board members, three board members did not participate because of a lack of time and conflicts with family responsibilities or work. Nine of the 10 interview participants attended at least five meetings during the first year and continued with the board the next year. One attended only two meetings and elected not to continue on the board because of family commitments. Participants had attended one to three board meetings at the time of the initial interview, and all initial interview participants completed a follow-up interview. Interview participants were immigrants from five different Latin American countries, most had less than a high school education and had two to three children, most of whom were U.S.-born. Table 1 displays characteristics of these board members. Interview participant characteristics are similar to nonparticipant board members, new board members in subsequent years, and that of other Latino immigrant families who use the clinic.

Reasons for Joining the Board and Initial Board Assessments

Members reported joining the board to contribute to improving services at the clinic. Some expressed that they felt it was part of their duty as mothers to participate in activities to improve services for their children.

> … y yo le dije a mi mamá: "eso está bien, porque no cualquiera le hace plática sobre nuestros hijos, que a nadie le va a interesar, solamente a nosotras" y pues a quién más, entonces uno tiene que tratar de hacer cambios, ayudar a hacer cambios porque eso está bien para ellos. [… I told my mother, "That's a good thing, because not everyone talks to us about our children, and who's going to be more interested in our children than ourselves." So, we have to try to help make those changes which are beneficial for them.]

Some members reported that they did not know what to expect but attended simply because they were asked by a trusted clinic team member. For some participants, the board appeared to be a welcome opportunity to have a new and different experience, "es bonito ir a otro lado a participar" [it's nice to go to different places and participate].

Board members assessed their initial board experiences positively. They reported enjoying the interaction with staff–participant board members during meetings, learning more about the clinic and the services it offers, sharing their experiences, and hearing others' stories. They also appreciated having a place to voice their opinions about the clinic, which some previously thought was not possible. Members perceived it beneficial to have a diverse group of women providing opinions.

> Bueno, no me imaginaba que ahí podíamos … expresar todo lo que … nos había pasado anteriormente acerca de la clínica … con las enfermeras, las doctoras, los personales … no, no me imaginaba … [Well, I never imagined that we would be able to express everything that had happened to us before in the clinic … with the nurses, the doctors, the personnel … no, no I could not have imagined …]

In general, board members assessed the initial group dynamics positively. Some board members reported that they felt somewhat reluctant to speak up because of shyness, but that this barrier decreased with time, "Bueno, pues, yo creo que al principio siempre uno tiene nervios porque uno nunca ha estado con tanta gente" [I think that you're always nervous in the beginning because one has never been with so many people]. A few board members did perceive some interactions more negatively, as when discussion focused on a specific staff member. Overall, they reported feeling they could speak up and that differences of opinion were handled respectfully.

> Hubo un día que alguien no le pareció la - alguien de la misma persona que íbamos no le pareció la opinión que yo di, entonces tu sabes que no todo el mundo tiene la misma mentalidad … Pero es una opinión que cada quien da. [There was this one time that someone from my group didn't agree with my opinion, and you know not everyone has that same mentality … But it's an opinion that each person gives.]

No member expressed concerns about privacy, although some mentioned they valued the request to maintain confidentiality of any personal information that might be shared during meetings. Members generally did not know other board members, except "by face" from interactions in the clinic or the community, although two board members were relatives. Members reported getting to know other board members as a potential positive aspect of board participation.

Board members expressed confidence about the validity and importance of their opinion in clinic improvement.

> Por eso hacen el grupo y están pidiendo las opiniones de las personas que realmente están viviendo lo que está pasando en la clínica. [That's why they have this group, and they are asking for opinions from those persons that truly know what goes on in the clinic.]

They also possessed a sense of optimism about what the board could accomplish. Members felt the board could make a positive difference at the clinic and for Latino children in general in the community.

> … hablamos en ese día que, de que hicieran ese … para los niños, podemos pensar que tal vez los hispanos tenemos una esperanza en este [consejo] … pues mejor, nunca sabemos, a veces nosotros tenemos miedo de ir a un hospital, que por la asistencia, sí nos atienden pero hay que pagar y a veces los sueldos son bien bajos, ¿me entiende? Muchas cosas que pienso que puede mejorar algo. [… that day we talked about … for the children, the Hispanic community could have a hope in this (board) … sometimes we don't know all the information and are afraid of going to the hospital, because of the assistance, they do take care of us, but we have to pay, and with a low income, it's very difficult, do you understand? I think this project could improve a lot of things.]

Members did not generally provide specific descriptions of what the board could do, and most did not have prior experience with a similar community group. Two members reported being involved with parent groups at their child's school focused on improvement. Many members expressed that just forming the board was an accomplishment and that working together the board could go on to make positive change at the clinic.

> [Trabajadores en la clínica] Saben un poquito y nosotros, todo lo que saben ellos y lo que sabemos nosotros, nos va a unir y de ahí va a salir algo bueno. [(Clinic staff members) know a little, and we know something, so what they know together with what we know is going to unite us, and something good is going to come out from that.]

Overall at the time of the initial interviews, board members were still somewhat uncertain about the purpose and the potential activities of the board but had enjoyed their early experiences, felt this was a unique opportunity, and wanted to continue their participation.

During initial interviews, we also asked members about their clinic experiences to provide additional context for their board participation. No member brought up concerns about the clinic during interviews that were distinct from those discussed in board meetings. Members reported variation in wait times, availability of sick care, and interactions with staff as compared to anecdotes shared during meetings but agreed that improvements were needed in those areas at the clinic. Most of the members had previously used other community clinics. In general, they reported longer wait times and fewer Spanish-speaking providers and staff at other clinics that prompted a change to the current clinic. The most prominent positive attribute of the clinic discussed by members was the clinic providers. In addition to the providers' manner, access to Spanish-speaking providers was an important reason for members' positive regard for the clinic.

> … Pues los que están enfrente, los que atienden, son personas que son … se comportan bien, respetuosas para nosotros, los hispanos y entonces por eso y porque también las doctoras … hablan español y ya no necesitas intérprete. [The staff, the ones from the reception area are, well, they are … they're very nice … they respect us Hispanics, but also because the doctors … speak Spanish and you don't need an interpreter.]

Negative aspects of the clinic cited by members were long waits, variable availability of prompt sick care, difficulty using the clinic phone system, and a waiting room that lacked child-friendly amenities.

> Cuando yo llamé entonces me dijeron, "no tenemos chance para eso. Tenemos para tal día." Yo les dije, "no, gracias pero yo no puedo' porque me lo llevé para emergencias." [When I called they said, "We don't have any appointments. We can schedule an appointment on this day." I said, "No, thank you, I can't wait" because (of that) I took him to the emergency room.]

Some members were reluctant to provide negative feedback about the clinic during the interview, which seemed to stem from a desire not to undermine their appreciation for the care received in the clinic.

> Que no me gusta esperar, pero … si también hay mucha gente yo creo que uno no puede tampoco exigir mucho. Lo importante es que los atienden. [I don't like waiting, but if they have a lot of people, I suppose you can't get too demanding. The important thing is that they take care of them.]

In board meetings, reluctance to provide negative feedback was also noticed in early meetings, but this diminished over time.

Assessment of Board After the First Year of Participation

During follow-up interviews, board members reported that they continued to be satisfied with their board participation. Reasons for their satisfaction reflected their assessment of the positive aspects of the board during initial interviews. Members continued to value the opportunity to participate in clinic improvement and to learn about child health topics and clinic and community resources.

> El tiempo que estuve ahí, conocí a muchas personas, mucha gente que no había visto y me gustó mucho también porque así podíamos discutir nuestras opiniones, ya que muy poco se ve este tipo de reuniones para un hispano. [During my time there, I met many, many people who I had not seen, and I liked it a lot because we could also discuss our views, since there aren't these types of meetings for Hispanic people.]

Board members often mentioned that the information provided during board meetings was especially important because language barriers resulted in them lacking basic information about clinic and community resources. Several board members reported that they had been able to secure assistance they needed for health and social services related tasks (e.g., requesting a medication refill or help with a school form) through contact with clinic staff during meetings. Although board members reported this as an advantage of board participation, they recognized that this was not the principal intent of the board.

> Pero no, no es que te digan: “Si tu vienes todo el tiempo y todo el tiempo te van a dar,” no, simplemente ellos te dicen: “bien, si tú vienes, pues también hay una ayudita” y pues está bien. [It’s not like they tell you, “If you come all the time, every time they’re going to give you something,” No, they’ll just say, “Well, if you come, there is also a little bit of help” and that’s fine.]

Board members’ positive assessment of group dynamics was consistent across initial and follow-up interviews, but the language used to describe the group changed between the two interviews. During initial interviews, board members often referred to other board members as “mujeres”(women) or “los otros miembros” (the other members); however, during follow-up interviews, they often referred to other board members as “compañeras” (meaning friend, partner, or colleague) or like family members:

> Siento que somos como compañeras ya de un grupo, o sea que queremos luchar por algo juntas todas para que nuestros hijos, o sea, lleguen mejor, o tal vez nosotras aprendamos cosas nuevas, experiencias nuevas para ayudarlos a ellos mismos. [I feel that we’re like partners of a group, I mean, that we want to fight for something together so that our children achieve more, or we may learn new things, new experiences to help them.]

These feelings seemed to stem from feelings of increased trust among board members. In addition to positive regard for other board members, members reported positive interactions with and trust of clinic staff participating on the board. As with the initial interviews, some negative group dynamics were discussed, but no member reported this would affect her decision to continue board participation.

Board members did not identify any particular needs for improvements to board functioning. They affirmed that evening meeting times and the availability of food and childcare at meetings were important features of the meetings that allowed them to participate.

> Y pues muchas cosas que a mí me gustan [del consejo] … a veces quieres participar en otras cosas pero no se puede porque no quieren a los niños, y ahí sí, eso es lo que me gusta. Me divierto yo y se divierten ellos. [There are a lot of things that I like (about the board) … sometimes you want to participate in something else but you can’t because they don’t want [you to bring] the children, and here they do, that’s what I’ve liked. I have fun and they have fun as well.]

Board members expressed appreciation for monetary compensation but stated they would continue attending should it not be available in the future. In general, board members looked forward to continued participation and were willing to have new members join.

When board members were asked about board achievements, their responses focused on the unique opportunity to voice their opinions about the clinic and contribute to clinic programs. Several members highlighted the opportunity to provide feedback without any adverse consequences as an important board achievement: “Nunca me había expresado a hablar y ahí usted puede expresar su opiniones y no hay problema.” [I had never expressed myself to talk; and there, you can express your opinions and there is no trouble.] Board members also identified their work on the clinic oral health brochure as an important achievement and many thought that the board may have contributed to positive changes in the phone service or wait times they had noted over the year.

> Está un poquito mejor la cosa de la espera … Como de un 10, es un 6 ó 7 … cada día uno va informando de todas las cosas que se necesitan y ellos, y cómo se llama, grano a grano uno va llenando el vaso … Entonces poco a poco se puede poner bastante bien … antes no tenía voz ni voto … y ya ahora tenemos la oportunidad. [The waiting has improved a little bit … Like out of 10, it’s a 6 or 7 … Every day, one informs about everything that is needed and they, how do you say, grain by grain one fills the vase … so little by little it can get better … before we had neither voice nor vote … and now we have the opportunity.]

In contrast, a few board members felt that not enough clinic improvement had taken place. Some members expressed concern about whether clinic leaders could, themselves, affect change given they also had supervisors who may have other priorities:

> Es una pregunta algo difícil porque yo no sé realmente si ellos [los líderes de la clínica] puedan lograr hacer un cambio de esos. Porque si estuviera en las manos de ellos posiblemente uno diría que sí, pero ellos también necesitan permiso de otras personas que no sé quiénes sean, pero … [It’s a difficult question because I don’t know really if they (clinic leaders) can make a change like that … Because if it were in their hands, possibly one would say yes, but they also need permission from other people and I don’t know who they are, but …]

Board members consistently identified positive personal changes they attributed to their board participation. As in the initial interviews, board members valued learning about the health care system. They felt they had gained increased skills and confidence speaking in group settings.

> Cada reunión uno aprende algo nuevo, como … a veces uno tiene temor a tantas cosas, cómo aprender a comunicarse. Entonces, sí ellos dicen “no, que todo mundo tiene que ser respetado y no tengan miedo, exprésense, están en un país libre.” [Every meeting, one learns something new like … sometimes one is afraid of so many things, like learning how to communicate. So, if they say “no, everyone has to be respected and don’t be afraid, express yourselves, you’re in a free country.”]

Board members also valued the opportunity to interact with women from varied Latin American countries and learn about different cultural practices within Latin America.

Perceived Marginalization and Discrimination in Health Care

Board members' perceptions of marginalization and discrimination of their families in the health care setting was a cross-cutting theme across initial and follow-up interviews. Discussion of discrimination did occur during board meetings, but discussions of discrimination and marginalization were notably more prevalent during interviews. Members described marginalization and discrimination both in interactions with the health care system overall and in the clinic. They described believing that certain physicians did not want to touch them and that "Americans" were allowed to jump the queue and be seen more quickly.

> Yo les dije: "oye, pero si yo llegué primero, ¿Qué es lo que pasa?" … Que la gente americana, 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 told them, "Hey, I arrived first. What's going on?" … 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 to treat us that way.]

Members described the board as an experience that countered these perceptions of discrimination and allowed Latinos to participate more fully in the health care system. One member noted that it was an achievement just for Hispanics "to be taken into account." Some members described how participating on the board influenced their perspective of the clinic and adjacent hospital. One indicated that the most important accomplishment of the board was its ability to counter the "harsh" treatment of herself and her peers.

> Nunca iba; y diciendo "no voy a ir, ahí no me pueden atender, yo no puedo ir ahí." El miedo siempre, temor" … Yo hace poco estuve enferma, yo fui al hospital y me atendieron muy bien… . Pues que yo escuchaba a muchas personas decir "ay, que ir a ese hospital yo me muero, y que ahí no me atienden"; pero no sé, yo viví una experiencia diferente. [I would never go (to that hospital), and I would say, "I'm not going to go, they can't see me there, I can't go there." Always with fear, worry … I was sick a little while ago, I went to the hospital and they treated me very well … I hear many people say "ah, going to that hospital I will die, and that there they don't treat me," but I don't know, (having participated in the board) I lived a different experience.]

> Yo creo que, puede ser que llevar lo que nos ha pasado (en el consejo), las experiencias que hemos tenido a una reunión, no sé cómo decirlo … Para que se enteraran de lo que uno estaba pasando o estuviese viviendo … Sí, o que sean un poco más, que no seamos tratados tan duro se podría decir. [I believe the most important thing (the board) has done is the experiences that we have had at the meetings, I don't know how to express it. So they know what people are going through and experiencing. Yes, or maybe so that they can be a little more, so that we are no longer treated so harshly, one could say.]

DISCUSSION

Patient engagement is a critical component of creating a patient/family-centered health system. Patient engagement programs, however, may face challenges including a diverse range of patient populations, such as those with language barriers. In this study, we offer the perspectives of LEP Latina mothers who were members of a Spanish language advisory board for a pediatric primary care clinic. LEP Latina mothers on the board expressed a high level of satisfaction with their participation, both during initial participation and after 1 year. Their satisfaction resulted from feeling that they provided valued and necessary feedback to the clinic, positive interactions with other members during board meetings, and regard for the board as a unique opportunity for Hispanics in the community. The board contributed to improved clinic educational materials, improvements in the clinic physical space, and raised awareness of the health care experiences and needs of local Latino families among clinic/hospital administrators. Participation on the board also led to feelings of increased confidence and increased health care knowledge among board members. Positive benefits for both the health care system and participants suggest that efforts to expand advisory group programming to include LEP populations could be of benefit to pediatric primary care clinics in other communities.

Although we present findings specific to a single advisory board in one community, much of the information from our qualitative evaluation could benefit similar advisory groups in other settings. We found that members had an intrinsic desire to participate in the group, from a sense of motherhood duty, or simply to get out of the house. However, they could act on their desire to participate because of the supports put in place such as childcare and food during meetings and a small amount of financial support for meeting attendance. Other advisory groups have found providing some compensation, such as reimbursing for transportation or childcare, and providing meals or snacks at meetings sustains engagement in patient advisory groups (Aligning Forces for Quality [AF4Q], 2013; Johnson et al., 2008; National Initiative for Children's Healthcare Quality [NICHQ], 2013; Roseman, Osborne-Stafsnes, Amy, Boslaugh, & Slate-Miller, 2013). In addition to supports for participation, we sustained engagement of board members because they enjoyed the meetings. Finally, board members' satisfaction was related to feelings of trust and partnership among parent- and staff-participant board members. We were intentional about creating a space of trust and partnership through use of CBPR principles to guide board development. The link between CBPR and successful patient engagement is nascent. However, information discussing frameworks for patient engagement reflect many concepts fundamental to CBPR underscoring the importance of dedicating effort to a partnership building when forming an advisory group (Carman et al., 2013; Chu & O'Brien, 2012; Danis & Solomon, 2013; Johnson et al., 2008; NICHQ, 2013; Patient-Centered Outcomes Research Institute, 2014).

In addition to providing additional evidence of satisfaction with board participation, interviews provided important evidence in support of the negative effects of discrimination and marginalization on health care experiences for board members. Although some discussions of incidents where members felt discriminated against occurred during board meetings, discussion of discrimination and marginalization during the interviews was notably more prominent. In quantitative studies, perceived discrimination in health care among Latinos has been associated with lower health care satisfaction and reports of worse doctor–patient communication (López-Cevallos, Harvey, & Warren, 2014; Perez, Sribney, & Rodríguez, 2009; Shavers et al., 2012). Parental report of a medical home in national surveys often depends on positive responses to questions that deal with satisfaction with care and doctor–patient communication. Perceived discrimination may result in more negative responses to these types of questions but has yet to be explored as a contributor to the lower medical home prevalence for Latino children. Prior quantitative research focused on experiences of discrimination have found foreign-born, Spanish-speaking Latinos are less likely to report discrimination in health care than nonimmigrants or English speakers (López-Cevallos et al., 2014; Perez et al., 2009; Shavers et al., 2012). The poignant and prevalent discrimination described by board members contrasts with these quantitative findings. Another qualitative study including immigrant Latino parents also found they perceived discrimination in the care of their child (Davies, Larson, Contro, & Cabrera, 2011). This suggests that existing quantitative measures may not be suitable for capturing Spanish-speaking immigrants' experiences of discrimination. It is also possible, however, that participating on the board increased members' awareness of their general societal marginalization and resulted in increased characterization of negative health care experiences as discriminatory. Regardless, it appears that discrimination in health care experienced by Latinos merits further investigation as the focus on patient satisfaction and engagement increases.

LIMITATIONS

This study has certain limitations. First, we report the views of a small, nonrepresentative sample of mothers who participate on an advisory board for a single pediatric clinic. Participant characteristics, however, match that of the larger clinic population, and these mothers, although perhaps distinct in their ability to commit to meeting attendance, are low-income, immigrant women who do not speak English well and in general have limited education. Board members report similar values for pediatric primary care as LEP Latina mothers in prior research and the improvements suggested for the clinic are also similar to reported shortcomings of pediatric primary care for this population in other settings (Arauz Boudreau et al., 2010; Brousseau, Hoffmann, Yauck, Nattinger, & Flores, 2005; Clark, 2002; Clark & Redman, 2007; Coker, Chung, Cowgill, Chen, & Rodriguez, 2009; DeCamp et al., 2013; Sobo, Seid, & Reyes Gelhard, 2006). Thus, the pediatric primary care experiences of board members may reflect that of other LEP Latina parents at the clinic and across the United States. In addition, our advisory board outcome appears similar to that of other ambulatory advisory groups. Achievements of other ambulatory care advisory groups often included improvements to the clinic physical space and contributions to educational materials that were among the projects completed by the board (AF4Q, 2013; Johnson et al., 2008; Roseman et al., 2013). Second, we did not include the views of parents using the clinic who did not participate in the advisory board. Among the expected impact of patient advisory groups is improvement in the patient experience for all patients. Perspectives of nonparticipating parents could also offer important insight into the clinic impact of the board that is not biased by board participation. This is an area for future study. Finally, the qualitative analysis of board evaluation data included staff participants on the board, although one of the primary coders was not a board member. Qualitative research methodology calls for the researcher to have continual awareness of and address the biases one brings to the analysis, but there remains a potential for a biased interpretation of the data.

CONCLUSIONS

Despite these limitations, our findings offer important insights on patient/family advisory groups from the perspective of patient participants. Because these patient advisory groups are relatively new in many clinical settings, it is important to understand not only how these groups impact the health care sytem but also how they impact participants as well. We found that participation on the board was overall a positive experience for members and that feedback in a group setting mirrored concerns elicited in individual interviews. We also found our board members viewed their board participation in a context broader than just health care. Their poignant descriptions of the board as a way to counter societal marginalization and discrimination highlight that family advisory groups composed of vulnerable patients and families could create opportunities for community impact beyond health care. The challenge of eliminating health and health care disparities is significant, but inclusion of diverse patient populations in patient engagement programs offers a promising opportunity to advance patient/family-centered care and to foster partnerships that may have impact outside the walls of the clinic.

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TABLE 1

Characteristics of Latino Family Advisory Board Mothers (*n* = 10) and Their Children (*n* = 26)

Characteristic	
Maternal age, mean (years)	34 (range: 22–42)
Country of origin—Mexico, %	50
Other countries of origin	Honduras, El Salvador, Argentina, Dominican Republic
Length of stay in the United States, mean (years)	10 (range: 3–21)
Maternal education	
Sixth grade or less, %	40
Some high school, %	30
High school or more, %	30
Annual household income	
<$20,000, %	80
Mother lives with husband/ partner, %	70
Mother’s health status fair/ poor, %	20
Mean number of children	2.6 (range: 2–5)
Age of children, mean (years)	7.4 (median: 4.9)
U.S.-born children, %	81
Children’s health insurance status	
Medicaid, %	81
Uninsured, %	19
Children’s health status fair/ poor, %	7.7