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Pediatricians' role in healthcare for Latino autistic children: Shared decision-making versus "You've got to do everything on your own"

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Despite recent evidence of a reduction in some racial disparities in autism rates, Latino children continue to be under-identified with autism compared to non-Latino children (Maenner et al., 2021). Once identified, Latino children receive poorer autism-related healthcare compared to non-Latino children (Magaña et al., 2012). In addition to language barriers, Latino parents report that the stigma of an autism diagnosis makes it difficult to seek help from providers (Zuckerman et al., 2013, 2016, 2017; Zuckerman, Sinche, Cobian, et al., 2014; Zuckerman, Sinche, Mejia, et al., 2014). Other barriers to a timely autism diagnosis and services are Latino parents' lack of access to autism information and pediatricians' bias toward them as less knowledgeable about autism than White parents (Lajonchere et al., 2016; Zuckerman et al., 2017; Zuckerman, Sinche, Mejia, et al., 2014). Despite these documented disparities, little is known about how Latino families experience the process of obtaining an autism diagnosis and services (Gordillo et al., 2022), referred to as the 'diagnostic odyssey' because of its complex and circuitous nature (Lappé et al., 2018).

Pediatricians' Role in Autism Diagnosis and Care

Pediatric primary care providers are key players in the autism 'diagnostic odyssey' (Lappé et al., 2018; see also Barnard-Brak et al., 2017; Zuckerman et al., 2015). The American Academy of Pediatrics (AAP) describes pediatricians' critical role in identifying and

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responding to ‘early signs’ of autism, guiding families through the diagnostic process and educating caregivers about treatments and services (Hyman et al., 2020). Pediatricians also have an important role in caring for autistic children, who often have co-occurring medical concerns that require more than standard pediatric healthcare (Angell et al., 2021; Hyman et al., 2020). Despite their position as gatekeepers to a diagnosis and services, and an increasing likelihood that they will encounter autistic children in their practice, pediatricians report feeling unprepared to care for them (Levy et al., 2016). This mirrors parents’ accounts that their autistic children’s healthcare needs are not being met, with the greatest unmet healthcare needs reported by Latino parents (Carbone et al., 2013; Magaña et al., 2012).

Complementary Health Approaches for Autistic Children

After a long and frustrating diagnostic process and realization that autism services are limited and difficult to access, some parents of autistic children turn to complementary health approaches (CHA),[i] such as special diets, supplements, and mind-body practices (Höfer et al., 2017; Hopf et al., 2016; Lindly et al., 2017a). Although less is known about Latino parents’ CHA use (cf. Zuckerman et al., 2017), parents generally may choose CHA for their autistic children when they feel that conventional care does not adequately address their concerns, e.g., children’s sleep problems or self-injurious behavior; because they deem CHA safer than prescription drugs; or because CHA is congruent with their personal or cultural beliefs (Lindly et al., 2017a, 2018; Perrin et al., 2012).

The AAP recommends that pediatricians educate families about CHA treatments, which can vary widely in efficacy and safety (Hyman et al., 2020). However, parents may not disclose CHA use to their pediatrician due to anticipated judgment or disapproval (Levy et al., 2016; Lindly et al., 2017b, 2018). This, along with limited data on CHA efficacy, and providers’ self-disclosed shortcomings in autism knowledge, create barriers to shared decision-making (Levy et al., 2016; National Center for Complementary and Integrative Health, 2021b).

Shared Decision-Making in Healthcare for Autistic Children

Shared decision-making is a process wherein healthcare providers and families engage in reciprocal communication and information exchange in order to come to mutual agreement about treatment options (Charles et al., 1997). Key features are: 1) at least two parties are involved, 2) information exchange occurs in all directions, 3) all parties are aware of treatment options, and 4) all parties bring their knowledge, values, and priorities equally into the decision-making process (Adams et al., 2017). Shared decision-making is particularly useful when multiple treatment options exist, and when parents and providers disagree about treatments; and it ensures that care is consistent with family preferences and values (Levy et al., 2016).

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[i] We use the National Center for Complementary and Integrative Health (NCCIH) terminology complementary health approaches (CHA), formerly known as complementary and alternative medicine (CAM). The NCCIH defines CHA as non-mainstream practice used *together with* conventional medicine, while alternative approaches are non-mainstream practice used *in place of* conventional medicine (https://nccih.nih.gov/health/integrative-health).

Shared decision-making is therefore particularly appropriate in healthcare for autistic children, whose parents face the difficult task of determining which of hundreds of ‘treatments’ described online are safe and effective (Fleury et al., 2019). There is insufficient research about shared decision-making among Latino parents of autistic children, but Latino parents are generally less likely than White parents to report that they experienced shared decision-making in healthcare encounters, especially lower-income Latino parents or those from non-English primary language households (Smalley et al., 2014).

Shared decision-making may have *greater* benefit for groups that are *most* disadvantaged, such as those with lower literacy, education, and income, via improved knowledge and self-efficacy and less conflict with providers (Durand et al., 2014). It is reasonable to anticipate that shared decision-making may reduce healthcare disparities among Latino autistic children. However, research on shared decision-making with Latino families of autistic children is lacking.

In our ethnographic study with 12 Latino families of autistic children, we sought to understand the families’ healthcare experiences related to their child’s autism diagnosis and care, and if shared decision-making was involved. The overarching purpose of our study was to understand Latino families’ experiences obtaining an autism diagnosis and services for their children, focusing broadly on all service systems. We have previously reported findings about the families’ experiences with home- (Angell et al., 2016) and school-based services (Angell & Solomon, 2017, 2018). In this article, we present findings related to the families’ healthcare experiences, both conventional and CHA, for their autistic children. The primary question for this analysis was: 1) How were healthcare providers involved in the Latino families’ ‘diagnostic odyssey’? Our iterative qualitative design yielded an additional question that we did not initially set out to answer: 2) Did families’ healthcare experiences reflect shared decision-making about treatments for their children, both conventional and CHA?

Methods

This article presents findings from a 12-month ethnographic study with 12 Latino families of autistic children living in Los Angeles County. Ethnography, a qualitative method which focuses on everyday lived experiences and the contexts in which they occur, utilizes in-depth investigation of multiple data types, including interviews, observations in natural settings, and review of cultural artifacts. We chose this approach because 1) it “can enable a deeper understanding of certain processes in humans” (Bolte, 2014, p. 67) and therefore provides an ‘experience-near’ understanding of the autism ‘diagnostic odyssey’ (Lappé et al., 2018) for an underserved group (Bernard, 2012); and 2) it situates us closely to the lived experiences of underrepresented families of autistic children, centering their emic perspectives (Markee, 2012).

Participants

The University of Southern IRB approved the study. A Los Angeles County regional center[ii] sent recruitment letters to randomly selected families in their database who met eligibility criteria: 1) Participating children were 8 years or younger, in alignment with the Centers for

Disease Control and Prevention (CDC) autism surveillance age (Maenner et al., 2020) and in order to collect data on more recent diagnostic practices and experiences; and 2) At least one parent self-identified as Latino or Hispanic and was bilingual (English/Spanish). While recruiting bilingual parents limits our understanding, as parents who speak only Spanish will have different healthcare experiences, our focus on bilingual and bicultural parents enabled understanding of barriers not attributable to language, and captured their unique perspectives from having roles and identities in two cultures (O'Brien & Shea, 2011).

The final sample is described in Table 1; all caregivers identified as Latino, Hispanic, or Mexican. Twelve families participated: 12 mothers, 8 fathers/stepfathers, 13 autistic children, and 1 grandmother. Two service providers also participated (1 behavior therapist, 1 physician).[iii] All participants signed informed consent; parents provided consent for their children. We did not collect data on family income, but the average household size and median income of the cities where the families lived indicate that all but one would be considered in "low-income tier" areas.[iv]

Procedures

Modeled from two large federally-funded ethnographic studies[v] (Lawlor & Mattingly, 2001; Mattingly & Lawlor, 2000; Solomon & Lawlor, 2013), this ethnographic approach utilizes a "relatively unstructured" interview and observation style to "facilitate the telling of the story" (Brinkmann, 2018, p. 579). The first author, trained didactically and through immersion on one of those federally-funded studies (Angell & Solomon, 2014; Solomon et al., 2015), collected all data.

The study had two phases; participants received stipends for participation in both phases. In Phase 1 (3 months), the first author conducted two audio-recorded narrative interviews (lasting approximately 1-2.5 hours each) with 12 families to learn about their experiences obtaining an autism diagnosis and services for their children. To enhance validity, in Phase 1 we developed visual timelines, chronologies of events related to the children's diagnosis and services, and used them for member-checking.

After Phase 1, 6 families were recruited to continue to the next phase using heterogeneity sampling.[vi] In Phase 2 (9 months), we conducted audio-recorded narrative interviews and video-recorded participant observations (with fieldnotes recorded immediately after each observation), and collected health records from the 6 families from the original cohort who

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[ii] California Department of Developmental Services funds are distributed through 21 regional centers, non-profit agencies that provide case management and fund services for people with disabilities in their catchment areas.

[iii] See Angell (2016) for details about study design and challenges in recruiting more service providers.

[iv] See the Pew Research Center definitions of U.S. lower-, middle-, and upper-income tiers using 2016 data (http://www.pewresearch.org/fact-tank/2016/05/11/are-you-in-the-american-middle-class/). One family's city median household income was US$80,000; the others were between US$30,000 and $60,000. City average household sizes were slightly larger than the Los Angeles County average.

[v] "Autism in Urban Context: Linking Heterogeneity with Health and Service Disparities," National Institute for Mental Health, National Institutes of Health (R01 MH089474, 2009–2012, O. Solomon, PI); and "Boundary Crossings," Maternal and Child Health, Department of Health and Human Service (1997-2000; M. Lawlor and C. Mattingly, PIs); National Institute for Child Health and Human Development, National Institutes of Health (2000-2004, R01HD38878; 2001-2003, R01HD38878-02S2; 2001-2004, R01HD38878-01A1S1; 2005–2011,R01HD38878; M. Lawlor and C. Mattingly, PIs).

[vi] Heterogeneity sampling was based on 15 factors drawn from autism disparities literature, e.g., the child's age at 'first signs,' whether a pediatrician's response facilitated or delayed an assessment, what services the child received, etc.

continued to Phase 2. Interviews and observations took place in home, clinic, school, and community settings. Audio and video data were transcribed verbatim and pseudonyms were used for all identifiable information.

Analysis

We constructed visual ‘diagnostic odyssey’ timelines from families’ initial interviews (24 interviews, 24 fieldnotes), with close attention to how pediatricians were involved. We then analyzed a subcorpus of data about specific healthcare encounters (10 interviews, 2 observations in pediatricians’ offices (one lasted the entire medical visit; the other observation was limited to the family’s wait in the exam room before the physician arrived because once he arrived he declined to participate in the study), and 2 fieldnotes). Two authors independently coded the subcorpus using Braun and Clarke’s (2006) approach: 1) theoretical thematic analysis, wherein a pre-determined theoretical framework (characteristics of shared decision-making) drives analysis; 2) analysis at the latent level, to identify underlying assumptions and meanings (i.e., not descriptive but interpretive); and 3) analysis with a constructionist perspective, attempting to understand how sociocultural contexts shape individual accounts from participants. Children’s health records (333 total records from 6 families in Phase 2) were also used to triangulate findings, e.g., comparing parents’ accounts with clinical narratives. For example, caregivers’ memoires of age at autism diagnosis were cross-referenced with documentation, when available; the “~” sign in Table 1 indicates an approximate age that could not be cross-referenced.

Trustworthiness

To build credibility and trustworthiness, we used prolonged field engagement, triangulation of multiple data sources, reflective fieldnotes, member checking with visual timelines, and multiple perspectives/peer debriefing with coauthors who were not involved with data collection (Letts et al., 2007).

Community Involvement and Author Positionality Statement

A Latina “autistic lived experience collaborator”[vii] on our team (3rd author) participated in iterative data interpretation processes and critical revision of the manuscript. Her contributions, along with another Latina researcher’s (4th author), included reframing analytic and interpretive choices to include Latino/a and autistic perspectives and raising critical questions about word choice and accessibility. The rest of the authors are non-Latino neurotypical academic researchers; two are also practicing pediatricians. Our multi-disciplinary backgrounds in general pediatrics, developmental behavioral pediatrics, public health, sociolinguistics, and occupational science, and our on-going research collaborations as well as clinical practice and lived experiences as parents, influenced our interest in and framing of our research questions and interpretation of our findings.

[vii] The first author’s lab uses “autistic lived experience collaborator” to refer to autistic lab members who have traditionally been called “stakeholders.” We avoid the term “stakeholder” here due to violent connotations among some tribes and tribal members (see https://www.cdc.gov/healthcommunication/Preferred_Terms.html).

Results

Pediatricians' Roles in the Children's 'Diagnostic Odyssey'

For most families, their pediatrician was involved early in the 'diagnostic odyssey,' with the parents' identification of 'first concerns' about potential developmental delay in their children, but they were mostly absent from the process after that, when families sought to understand autism and possible treatments or services that could support their children's development. Supplemental Table 1 describes each family's trajectory, starting with the 'first concerns,' which were sometimes identified by the parents and expressed to their pediatrician, and other times identified by the pediatrician, such as during a well-child visit. After the concerns were identified, in some cases pediatricians then showed a proactive response, i.e., facilitating a referral for an assessment; and in other cases, they delayed the process with a 'wait and see' approach. In only two cases (Gabriela and Isabella), pediatricians did not factor at all into the families' diagnostic process. Gabriela's preschool teacher identified her developmental challenges; Isabella's mother, familiar with the process because of Isabella's older brother Mateo Jr., went straight to the regional center, bypassing the pediatrician.

The pediatricians remained relatively absent from the families' stories related to the next phase of the 'diagnostic odyssey,' as parents sought to learn about autism and autism-related treatments and services. Nine of the 12 families (parents of Olivia, Rafael, Tanok, Mateo Jr. and Isabella, Ben, Salvador, Mikey, Jayden, Luke) described their child's pediatrician as uninvolved with their child's autism. The parents of Mateo Jr. and Isabella (siblings) and Ben found new pediatricians (both stories are described below); in those cases, here the dissatisfaction refers to the initial pediatrician that parents sought support from around the time of diagnosis.

Of the other three families, Elijah's pediatrician is absent from his caregivers' narratives after his referral to the regional center. Gabriela's mother never attempted to raise her concerns with her pediatrician, and at the time of data collection Gabriela had just been diagnosed, so any later potential interactions with their pediatrician about autism or services are unknown. Ricky's parents stayed with his first pediatrician, attempting to teach him about autism and coach him to provide support they needed such as referrals for services. This story is described below as an exemplar of successful parent/provider partnership and shared decision-making.

These early experiences with pediatricians gave the families an important signal about their pediatrician's potential role related to their child's autism. Although some pediatricians were proactive in identifying developmental delay and/or referring families to the regional center, none remained involved with the process after that. As described below, the families came to understand their child's pediatrician as only a source of information and support about their child's physical health; none found their pediatrician knowledgeable about autism services.

Conventional Healthcare Satisfactory for Physical Health, but not Developmental, Issues

Most families were satisfied with the care they received from their pediatricians for the children's physical health issues, e.g., vaccinations or ear infections; but many were upset to discover that their pediatrician would not be a source of information or assistance related to their child’s autism or development. For parents who initially expected to get guidance from their child’s pediatrician, the lack of involvement was particularly upsetting. The following two stories illustrate this phenomenon.

“It was kind of disappointing. We loved her.”—When Ben required emergency surgery as a baby for a ‘lump in his throat,’ his parents were grateful for their pediatrician’s quick action and expertise. Later, however, when they told the pediatrician they were concerned that Ben’s speech appeared to be far behind his peers, her response was not only disappointing but even offensive. This was because of assumptions they believed the pediatrician had about them vis-à-vis their Latino ethnicity. The parents, Lydia and Edward (who lived in a city with the highest median income, see Methods), told the story:

Lydia The doctor would just prescribe the medication, treat the ear infection. I told her, “I′m kind of concerned, he′s not saying very much.” And his pediatrician was like, “Well maybe” – which kind of turned me off after she said it – “A lot of the kids I work with, the parents take them to Mexico, they′re around other family and they′ll start talking.” (…) That didn′t sit right with me. (…) And then for hearing or testing, [the pediatrician] referred me – not that there′s anything wrong with a county agency, you know, but I′m thinking, “We have private insurance. We can afford to take him to a specialist. Why won′t you refer?” (…) She was really a great pediatrician. She was very great with Ben, but at that point I just kind of turned off and I was like, “I think we need to find another pediatrician.”

The parents found another pediatrician, who immediately referred them to an ear, nose, and throat specialist. After seeing the specialist, Ben got tubes in his ears. A few months later, the new pediatrician asked about Ben’s language. The parents reported that it had not improved, so they were referred to their Regional Center. The parents recalled:

Lydia I really think his first pediatrician, I don′t know if it was lack of education or just, like my husband said, the [low-income] population she was working with, [but] I think she probably should have gone the next step.

Edward : […] ***It was kind of disappointing. We loved her***. We were grateful for her. It′s just that when it came to [the autism] part of it, I think she sort of took it as, wait and see, you know, send him to Mexico to play with his cousins or something.

Lydia and Edward had had trusted the first pediatrician for her knowledge, quick action, and being “there every step of the way” for Ben’s medical issue in infancy. The parents were therefore particularly disappointed when the pediatrician failed to take action on their developmental concerns; her recommendation to take him to Mexico to address his speech concerns seemed in sharp contrast to her recommendation, and expertise, for his physical health.

“For my little special needs guy, I wish we had a better pediatrician.”—Sabine and Kyle began to see changes in their 5-year-old son Jayden after they started giving him vitamins, probiotics, and enzymes. They said:

Kyle And that´s around the time that we first started getting some eye contact.

Sabine […] We were at Smart & Final, and there were [stacks of] products […] I did the whole peek-a-boo thing with him, you know, I ducked down and went up. That was the first time that he actually smiled at me (begins to cry). […] So after that, we realized that vitamins are very necessary for him […] We asked the pediatrician, I think after we had already done it, and she goes, “Well, you know, there´s no studies.” Something like, “I wouldn´t do it. I don´t know enough of it, with kids with autism and these medicines.” ***I love her, if I had a [typically-developing] kid. But you know, for my little special needs guy, I wish we had a better pediatrician***.

These parents, when asked about successful partnerships with their child’s service providers, described a school-based speech therapist who previously worked with Jayden:

Sabine She’s amazing. I learned so much from her. You know, we’ve always considered alternative medicine for Jayden’s autism, and she’s the one that taught us about all of that […] B12 shots and additional vitamins that can help him, enzymes, probiotics.

Kyle pH balance. All kinds of different interesting things. Although they’re all theories, you know, I think we’re just willing to try anything and see where it goes.

While their willingness to “try anything” may be alarming to a healthcare provider who is considering the costs, lack of documented benefit, and/or potential harm of certain CHA, our analysis here links CHA to the parents’ desire to use multiple approaches to support their child’s development. The families felt compelled to try anything that might help facilitate their child’s development, making them less risk averse than healthcare providers. Further, the parents did not see the treatments they were using as potentially harmful, perhaps because of the notion that ‘natural’ was thought to be ‘safer’ than prescription drugs. Our analysis, however, focuses on Sabine’s recounting of the conversation with the pediatrician, which she experienced as a ‘closed door,’ i.e., a response that ended the conversation rather than facilitating a back-and-forth dialogue characteristic of shared decision-making. The conversation with the pediatrician could have promoted further discussion and parent education about the evidence, or lack thereof, and potential risks and benefits of the supplements that Sabine and Kyle were trying; their reasons for pursuing these supplements; and ways to systematically monitor the safety and effectiveness of these treatments. Sabine admitted that she and Kyle had already begun using the supplements before the conversation, which could have left the pediatrician feeling excluded from making this decision, with nothing more to discuss. The conversation seemed to have signaled to Sabine, however, that the pediatrician was not willing to engage in discussions about these types of treatments, which ultimately became a missed opportunity to ‘partner up’ (Lawlor & Mattingly, 1998) with parents in the context of disagreement about treatment, a situation when shared decision-making is *most* useful (Levy et al., 2016).

Parents Who Used CHA Were Most Frustrated About the Lack of Autism Treatment Information

While all the families reported that the conventional healthcare system was not a source of information about autism, the frustration about this lack of information was voiced most strongly from the six families who reported using CHA to address their child's behavioral, developmental, or sleep challenges. Their CHA use ranged from occasionally trying a special diet, to seeking the services of practitioners like DAN! doctors[viii] None of the families who were interested in DAN! doctors were able to regularly afford office visit fees, so many created their own regimen of vitamins, probiotics, oils, enzymes, and other supplements, attempting to mimic the DAN! protocol. They purchased these supplements at a local grocery store or online; one family found a provider who prescribed them vitamin B12 shots, which the parents administered to their child at home while he was sleeping, using numbing cream first so that it would not wake him up. These parents felt that they finally had answers from CHA providers or sources, or at least some ideas about how to better support and facilitate their child's development.

Pediatricians' reticence about certain CHA treatments is warranted, as some are ineffective or even extremely harmful (Akins et al., 2010). With regards to shared decision-making, however, our analysis focuses on the ways in which these parents interpreted their pediatrician's lack of treatment recommendations, or discussion about autism at all, as a failure to provide any support, or even an avoidance of their responsibility as the child's doctor. These parents reported a lack of information from their pediatricians about *any* autism-related services, even those that fall within a conventional medicine paradigm. The following two stories illustrate these parents' frustrations.

"Pediatricians, they don't help you at all."—In the following data excerpt, Miriam and Marcos described their frustration about the lack of information from their 3-year-old daughter Olivia's pediatrician about autism-related treatments:

Miriam [The pediatrician is] more like if they're sick, it's very generic. That's what I feel. Like they haven't said, "You should go to this person, I'll have you check into this," it's not like that. (…) I would research on the internet, and I started reading about how kids with autism have stims. I kind of figured it out myself.

Marcos Yeah, the research kind of had to come from our own -

Miriam ***And the doctors were worse, like pediatricians, they don't help you at all*** (laughs). They just told us, "Oh, go here," it wasn't like, "Well you should check her diet, you should do this." No guidance at all, it was just, "Send them to the Regional Center."

Marcos "They'll figure it out" kind of thing. They'd always try to pass the buck when it came to that.

[viii] The term DAN! doctor, or "defeat autism now!," originated with the Autism Research Institute (ARI; https://www.autism.com/ed_movingforward). The DAN! protocol included special diets, supplements, chelation, and hyperbaric oxygen treatment. In a 2011 press release, the ARI announced it would discontinue the DAN! protocol due to advocacy from autistic self-advocates who contested the name, as well as a lack of uniformity and quality control measures for natural practitioners claiming to use the protocol.

Miriam Because I think it has a lot to do with food and our environment, why kids are getting [autism], personally, so then I thought it was weird how there was no guidance on how to change that. Or that there wasn't even options – like, "She has it, she´s going to have it forever." But to me, it's like, I always tell my husband, "She´s going to have it for now, but I don´t think she´s going to have it forever." She's, you know, she's very [high] functioning, um, the biggest part is her speech, and socially, you could tell she likes to be on her own more and do things more by herself. But lately she's been playing with her brother more, or like –

Marcos Year, she's been more active with her brother and friends and cousins and stuff like that.

Miriam and Marcos's narrative reveals the challenges that parents face in sorting through massive amounts of information from various sources, e.g., social media and parent memoirs, and discerning what is true. The parents attempted to synthesize information with varying degrees of evidence, such as a research study about living near a freeway as raising the likelihood of autism; and other sources claiming environmental (i.e., food, vaccines) factors causing autism or exacerbating core challenges. While vaccines and food are perhaps most commonly linked to autism by CHA providers or users, the study referring to freeway proximity and increased likelihood of autism was published in an academic journal (Volk et al., 2011). Their house, at the end of a cul-de-sac, backed up to a busy freeway. When asked where they got information about autism, they said:

Miriam I just started googling "autism." I have like a little library in there, I started reading, they were like all Jenny McCarthy´s books, and then I just would get books on what [autism] was like, how to play with autistic kids, or I was just trying to get different ideas on what to do with her. And then like when studies come out, we´ll read them, like there was one about the rise of autism and living next to a freeway. […]

Marcos Whatever the variables are, we just didn't know. So what now we´re trying to do is just make sure that [Olivia] can move forward with [the support] she is receiving, and what we´re doing, and hopefully that it´s enough.

These data excerpts reflect the parents' uncertainty, as well as their optimism about Olivia's capabilities and motivation to continue to support her, with an apparent emphasis on her social engagement with family and friends. What is clear, however, is their disappointment that their pediatrician had not been one of their sources of information about autism or autism-related resources.

"It's like you've got to do everything on your own."—Another family that was vocal about their exasperation with conventional healthcare for failing to provide autism information was the family of 6-year-old Mikey. The parents, Michael and Jessica, searched online for information about supplements, vitamins, and special diets. They viewed the CHA providers, like DAN! doctors who they had seen a few times, as having a proactive "treatment plan" to address the child's development:

Michael ***It's just frustrating because it's like you've got to do everything on your own.*** I think we've explored every avenue. I wish the hospital (Jessica: the insurances) would acknowledge it.

Researcher: And what would that look like?

Michael: Start a treatment plan, immediately -

Jessica: Like the DAN! doctors.

Michael: I wish my insurance company would hire DAN! doctors to do that (…) [We were] fighting with our own doctor, who's supposed to take care of us. You know, having a shouting match with him down the hallway at the hospital to get what we needed.

The "shouting match" is a conflict between the parents and their pediatrician when they requested a speech therapy evaluation for Mikey when he was 19 months old. While this kind of conflict was not common in the data, the overall experience, of the healthcare system *not* being a place where the parents found answers about autism, was a pattern. The parents felt that they were left to "do everything on their own" in identifying and selecting treatments for their children.

Shared Decision-Making Examples: Respect for Parents' Values and Expertise

In contrast with the previous data excerpts, two families told stories about times they felt supported by their child's pediatrician. In both cases, the family context and parents' values and expertise were respected; both reflected ongoing discussions rather than a single conversation.

"He's trying to adapt and change, and he's been cooperative with us."—Sofia and Ricardo described their 6-year-old son Ricky's pediatrician, Dr. S., as supportive of the parents' efforts to support Ricky's development. The first author, who attended Ricky's six-year well-child visit, recorded the following fieldnote:

> After a physical exam, Dr. S. turned away from his laptop where he'd been taking notes and asked the parents a string of questions [about school and autism therapies]. Ricardo said, "Well, there's a big gap in terms of what he can do at home and what he can do at school." Dr. S. responded, "So he's catching more from his education at home than in the classroom? I think some children with autism get affected by crowds." The parents nodded vigorously […] Dr S. said, "Very good. So you'll probably have to compensate for the somewhat disturbing environment at school by doing extra work with him at home." The parents agreed.

The previous interaction took just several minutes. In an interview after the visit, the parents told the study team that Dr. S. had initially seemed dismissive about their concerns about Ricky's development when he was around 18-months-old. The parents said they had learned all they knew about autism on their own, and believed they knew more than the pediatrician about autism; for example, he gave them a fact sheet about autism that they found to be very basic compared to the information they had learned through books, articles, conferences, and support groups. However, Dr. S.'s awareness of and interest in Ricky's services – and the work the parents did to manage them – was enough to make them feel supported, and to facilitate open communication and trust. After the visit, Ricardo said, "***He's a little behind, but he's trying to adapt to the time and change, and he's been cooperative with us. That's why we choose him***."

"I just wanted to be heard."—Fabiana was a mother in the study who had three children under the age of five, two of whom were autistic. Fabiana generally preferred supplements, which she viewed as more "natural" and therefore "safer" than prescription drugs like Ritalin. The following story about melatonin[ix] illustrates a lack of shared decision-making with one pediatrician, and engagement in shared decision-making with another. Isabella, Fabiana's middle child, had significant sleep challenges and was at risk of wandering away from the house during the night. Fabiana recounted:

> When Isabella was diagnosed [with autism], we were at our wits end because she didn´t sleep. She´s a wanderer and gets into things, so I would be up with her, and then I wouldn´t sleep […]. Finally, I broke down and asked the pediatrician, "I know melatonin is something that we produce in our bodies, and I want to get your input on that. Is it safe? Is it not?" And she says, "Well, she just has autism, you need to deal with it." ***And I just felt so defeated. I felt like, "I´m not being heard. And I can´t function anymore***." […] I found this new pediatrician [who was] *wonderful*. I was up front, I said, "Look. My kids have autism." […] I remember [her] taking time, we were probably there for like an hour. I was crying with her, and she´s like, "You´re so overwhelmed, mom." I said, "I *am*." (…) I asked her about melatonin and she says, "Let's try it." […] I put [Isabella] on it and it was a godsend, it was awesome. [The new pediatrician also] said, "Let's refer her to an ENT [ear, nose, and throat specialist]." We did [a sleep study] at home, and [Isabella] had sleep apnea. So [the ENT] scheduled her for a tonsillectomy, and ever since then she´s been sleeping *so* good.

Fabiana, with a new baby and a history of postpartum depression, was caring for three young children with little help from extended family members, who thought the autistic children simply needed discipline. While the first pediatrician, who had been their provider since the first child's birth, may not have known all that was contributing to Fabiana's desperate need for sleep and support, Fabiana felt judged when she asked about melatonin. Conversely, Fabiana felt heard and supported by the second pediatrician. This facilitated information exchange, mutual agreement, and ultimately shared decision-making around the safe use of melatonin for Isabella's sleep challenges. In addition to facilitating shared decision-making, this may have even contributed to improved conventional treatment of Isabella's sleep problems, as it also led to her tonsillectomy.

[ix] This story, told by Fabiana, took place in 2013 and 2014. Although melatonin was shown to be safe and effective for children with autism as early as 2012 (e.g., Malow et al., 2012), we include it here because it was previously considered an alternative treatment for autistic children. The first pediatrician in the story appeared unaware of its efficacy and safety for autistic children, further illustrating the problem of a lack of knowledge about evidence-based treatments for autistic children among pediatricians.

Discussion

This article presents an ethnographic perspective on how Latino families of autistic children experience making decisions about healthcare for their children. Our research questions investigated 1) the families' experiences with both conventional healthcare and CHA related to their child's autism, and 2) whether and how these encounters reflected shared decision-making.

Our analysis examined the pediatrician's roles in the children's trajectories to an autism diagnosis. The families all found that their pediatricians, even if involved proactively in identification and response to the 'early signs' of developmental delay in the children, were entirely uninvolved with the next steps in the process, i.e., in parents' efforts to learn about autism and to determine which treatments or services were appropriate to address their children's developmental challenges. This is in sharp contrast to the AAP recommendations (Hyman et al., 2020) and confirms previous findings that pediatricians report low levels of autism knowledge (Levy et al., 2016), pointing to the need to better equip pediatricians to speak with parents about autism and evidence-based treatments and services.

Our analysis also provides a nuanced view of Latino parents' experiences of shared decision-making, including the role of conventional and CHA provider relationships. For half of the families in this study, consideration of CHA for their autistic child was a central issue in the treatment decision-making process. Previous research examining families' CHA use has been conducted primarily with White families or fails to report race/ethnicity (cf. Broder-Fingert et al., 2017). One early study found that Latino ethnicity was associated with CHA use (Levy et al., 2003), but subsequent studies have found that higher-income, non-Latino, formally-educated, U.S.-born mothers are most likely to use CHA for their autistic children (Lindly et al., 2018; Perrin et al., 2012; Valicenti-McDermott et al., 2014). It could be that Latino parents (of different societal and educational backgrounds) come to CHA for different reasons than their non-Latino counterparts. A recent study showed that Latino families with limited English proficiency were the least likely to use CHA for their autistic child compared to English-proficient families, both Latino and non-Latino (Zuckerman et al., 2017). This could be related to cost, as CHA treatments are not usually covered by insurance. The families in our study aspired to give their children the types of CHA that are reported in studies with well-resourced families, but it could be that less-acculturated Latino families prefer different types of CHA, e.g., natural remedies from their countries of origin. More research is needed to understand CHA use in Latino subgroups, including acculturation and place of origin.

Our findings align with prior shared decision-making research conducted mostly with White, English-speaking families of autistic children. Specifically, they align with Levy et al.'s (2016) findings that parents and providers are uncertain about the pediatrician's role in autism treatments; and Lindly et al.'s (2017b) findings that parents perceive their child's pediatrician to be lacking in autism knowledge, particularly regarding CHA, affecting parental disclosure of CHA use. Our findings also echo previous studies showing parents' general preference for 'natural' treatments over prescription drugs, and parent report of differences in their child's behavior after starting CHA (Lindly et al., 2017b, 2018). Our findings underscore a dilemma for shared decision-making in autism care: If pediatricians are unable to speak to parents about CHA use, whether due to parents' failure to disclose, or pediatricians' lack of time or knowledge, shared decision-making cannot occur. If parents do disclose information about CHA use, and pediatricians appear uninformed or uncaring, the result will similarly fail to support shared decision-making.

When conflict arises between conventional providers and parents around treatment decisions for autistic children, it is important to recognize that pediatricians, CHA providers, and parents may not be operating from the same epistemological paradigms about autism, impacting what each view as the goal(s) of treatment and potentially creating a dilemma for shared decision-making. Pediatricians may operate from a 'biomedical' paradigm, viewing autism as a neurological disorder (American Psychiatric Association, 2022), and/or from a or 'biopsychosocial' paradigm, viewing autism as a "behaviorally defined disorder with a biological basis" (Lind & Williams, 2011, p. 99). Either way, pediatricians likely see the immediate goal of treatment as ameliorating impairments and maximizing functioning. This might include attention to not only biological but also psychological and social factors that influence the child's development and any possible changes in core autistic traits (Bolton, 2022). CHA providers who align with DAN! doctor protocols also appear to view autism as having biological origins, but, similar to other non-mainstream medicine principles, believe that this biology is inextricably intertwined with the rest of the child's body systems and their environment. This is represented by the concept of 'ecological physiology:' "A physiology that does not stop at the skin, but which is closely interactive, to varying degrees, with anything from the immediately surrounding environment to the distant planets and stars" (Bates, 2000, p. 506). In Traditional Chinese Medicine, for example, "the entirety of the body is taken into consideration when interpreting problematic behavior" (Sobrino, 2015, p. 55). However, DAN! doctor protocols differ from other CHA such as Traditional Chinese Medicine because they focus on "recovery or near recovery" (Ravindran & Myers, 2012, p. 316) versus restoring an individualized, 'natural' 'balance,' "nourishing the entire body, not isolating autism as a target for elimination" in the child (Sobrino, 2015, p. 56).

However, parents of autistic children often simultaneously take up biomedical and biopsychosocial approaches, along with either type of CHA, without apparent contradiction (Ravindran & Myers, 2012; Shyu et al., 2010). In order to better understand these differences ethnographically, we take yet another epistemological stance, of autism as a sociocultural phenomenon, a "personal, family, and community/social group experience as evidenced through the analysis of social interactions, narrative accounts, and participation and engagement in activities in the home and educational, clinical, and other institutional settings" (Solomon, 2010, p. 242). The value of taking this stance is that we can see the 'taken for grantedness' of all paradigms, viewing them as situated in specific socio-historic, cultural, and temporal contexts. Perhaps more importantly, this lens allows us to understand 'what is at stake' for parents (Lawlor & Mattingly, 1998), whose choices may be difficult for pediatricians and other medical providers to understand. For example, parents' treatment choices that are based on seemingly blurred biomedical/biopsychosocial and CHA paradigms may come across as "far more emotive and individualistic than the more logical and rational decisions" outlined in 'western' biomedical models (An et al., 2020, p. 1826), leading those who operate within a biomedical/biopsychosocial paradigm to conclude that "empirical evidence is not of primary importance to parents when choosing treatments for their [autistic] children" (Bowker et al., 2011, p. 1380). Put in perhaps more neutral terms, "What is very clear at this point is that how parents select treatment is vastly different from how researchers in the field rank treatments by evaluation of effectiveness" (Matson & Williams, 2015, p. 23).

This difference, in how one evaluates treatment effectiveness, appears to be at the root of the dissatisfaction underscoring some of the narratives in our study. Conventional providers use standard scientific criteria to evaluate the effectiveness of treatments, and they may not discuss CHA with families because some have been shown to be harmful and most have not been scientifically evaluated at the level necessary for clinical guidelines (Akins et al., 2010). Parents, like the Latino parents in our study who used CHA, are not only willing to try a range of approaches as part of their pursuit of positive and hopeful outcomes for their children (cf. An et al., 2020), they may even view the inclusion of CHA as part of their "parental responsibility" (Hebert, 2014, p. 119) to explore alternative treatments, particularly when conventional care does not address their concerns. Hebert (2014) argues that the autistic parents in their study who used CHA were not motivated by desperation or hopelessness and were not "looking for a cure;" rather, Hebert argued that their CHA use reflected the parents' commitment to help their children reach their full potential and achieve the highest possible quality of life (2014, p. 119).

While these differences in treatment goals, choices, and evaluation may create challenges, or even conflict, between parents of autistic children and conventional healthcare providers, our ethnographic lens once again points to disagreement as the context in which shared decision-making is *most* appropriate. While conventional healthcare providers are right to be concerned with the safety of CHA approaches, these examples, along with previous research, indicate that parents want to have conversations with their child's pediatrician about autism-related treatments.

Clinical Implications

From the primary care perspective, a trusting relationship in which shared decision-making can occur will only be possible if providers are knowledgeable about both conventional and CHA treatments for autistic children. Physicians desire more training in both CHA and best practices for treating autistic children (Levy et al., 2016), and there is some evidence that certain CHA (e.g., melatonin, music therapy) are effective and safe (National Center for Complementary and Integrative Health, 2021a). Likewise, spending time to hear parents' concerns, priorities, and goals for their children may help providers better understand why parents want to use CHA, allowing them to serve as partners in problem-solving in a holistic sense, offering solutions that might include but are not limited to CHA. Ultimately, while we may lack sufficient evidence about the safety of many CHA treatments, we do know that some are dangerous (e.g., U. S. Food and Drug Administration, 2019), and open communication and trust are essential for pediatricians to be able to have conversations with families about the dangers of some CHA treatments.

In our study, the pediatricians who were most successful were not necessarily those who were most knowledgeable about CHA, but rather those who were able to 'meet parents where they were at' and work collaboratively toward goals. This aligns with AAP best-practice guidelines about caring for autistic children: "Families should be involved in the selection of intervention approaches and remain an involved participant in subsequent educational and therapeutic decisions" (Hyman et al., 2020, p. 21). In our clinical practice as general pediatricians (6th and 7th authors), we have attempted to apply what we have learned from this analysis of Latino families' experiences in several ways. First, we intentionally use the term "treatment plan" (e.g., "I think what you need is a treatment plan for your child's autism"), to make clear to families that we, as allopathic physicians, have a plan (just as CHA providers do). To support shared decision making, we encourage parents to disclose all the CHA therapies they are using for their autistic children. (When families use CHA treatments we are unfamiliar with, often purchased from small shops around the city or in Mexico, we use google "picture search" to help identify whether it is dangerous; we feel it is incumbent on pediatricians to know what is being sold and used in their local communities.) We then go through the list with the family, asking of each treatment: 1) What are you using this for? 2) Do you think it is working? 3) How much does it cost? We then discuss which CHA therapies are dangerous; and which ones, particularly if expensive, that parents are not seeing clear benefits from. We suggest evidence-based alternatives to the treatments that may be dangerous, expensive, and/or ineffective. We then discuss the pros and cons of continuing versus discontinuing; if they are considering discontinuing something, we suggest an "n-of-1" trial, i.e., stop it for a week or two, collect data, restart, and collect data. We also discuss evidence-based treatments they are using, to monitor and dose-adjust where necessary (e.g., often families are using very high doses of melatonin, and a lower dose will be effective). We then write this plan in the after-visit summary and send it to the family. In doing so, we aim to follow the AAP guidelines (Hyman et al., 2020) about family involvement in treatment decisions, even – or especially – in the context of disagreement, focusing on the child's safety while also attempting to keep the communication with the parents open (Levy et al., 2016; Lindly et al., 2017b, 2018).

Policy Implications

From a policy standpoint, our findings suggest that the structure of primary care visits may be an impediment to shared decision-making, since it leads pediatricians to focus on acute illness and well-child care for children with typical development. Shared decision-making for children with complex conditions is difficult to carry out during short office visits with much to accomplish. Our findings raise questions for further investigation; for example, does improved reimbursement for longer office visits improve shared decision-making, family and pediatrician satisfaction, and parental disclosure of CHA use? Alternatively, using other healthcare providers, e.g., nurses, medical assistants, community health workers, to provide more face-to-face time with families, may also improve outcomes. Reimbursement for non-office-based time spent communicating with parents via telemedicine, telephone, or email might also improve bidirectional communication and reduce disparities.

Future Research

This study also has implications for future research. More research is needed to determine whether increasing pediatricians' autism knowledge improves shared decision-making; and whether particular strategies such as pediatrician language choice or questions (e.g., Dr.

S.'s questions about Ricky's services) could improve parent/provider communication and trust (e.g., Heritage et al., 2007). This would go beyond a safety and efficacy model for discussing and evaluating CHA use with families of autistic children, giving providers more concrete and standard guidance on how to discuss CHA in this context. For instance, our findings suggest that conventional providers offer families of autistic children a "treatment plan" that considers multiple areas of need (e.g., Antonelli & Lind, n.d.). Our findings also confirm the need for parent education programs about autism treatments that are accessible and culturally appropriate, (e.g., Magaña et al., 2017), and training for pediatricians, to facilitate communication and shared decision-making.

Limitations

Our study has several limitations. First, although the study design included interviews and observations with pediatricians, we were only able to observe one interaction between parents and a pediatrician, limiting our findings largely to the perspectives of caregivers, rather than also gaining child and provider perspectives. Although this study is one of the first to deeply explore the experiences Latino autistic children and their families have with the health system, including conventional care and CHA, we narrowed the heterogeneity of our sample by recruiting only bilingual, bicultural Latinx families, in an urban area. The findings therefore may not be applicable to other Latino subgroups, e.g., those with limited English proficiency or in rural areas. Additionally, the original study was about access to autism care and not about shared decision-making or CHA specifically; it is possible that more focused interviews on this topic would have yielded additional information.

Conclusion

The shared decision-making model can reduce healthcare disparities for autistic individuals, but there is a need for more research to investigate the motivations, priorities, and decision-making processes of underserved families of autistic children. This study aimed to fill this gap by providing an in-depth qualitative investigation of the experiences of bilingual, bicultural Latino families of autistic children, revealing the role of CHA in families' treatment decision making processes and factors that facilitated or hindered shared decision-making.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Conflicts of Interests and Source of Funding:

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Table 1:

Description of Participants

Focal Child[1]	Child's Sex/ Gender	Participating Caregiver(s)[1]	Child's Age at First Interview	Child's Age at Autism Diagnosis
Mateo Jr	Male	Fabiana and Mateo Sr.	5 yrs 0 mos	4 yrs 1 mo
Isabella	Female		3 yrs 10 mos	2 yrs 11 mos
Olivia	Female	Miriam and Marcos	3 yrs 8 mos	~2 yrs 9 mos
Ricky	Male	Sofia and Ricardo	5 yrs 7 mos	2 yrs 8 mos
Mikey	Male	Jessica and Michael Sr.	6 yrs 6 mos	3 yrs 0 mos
Ben	Male	Lydia and Edward	4 yrs 8 mos	2 yrs 3 mos
Luke	Male	Julia	5 yrs 5 mos	~2 yrs
Jayden	Male	Sabine and Kyle	5 yrs 5 mos	2 yrs 7 mos
Elijah	Male	Laura and Maria[2]	6 yrs 4 mos	~3 yrs
Tanok	Male	Elizabeth	5 yrs 0 mos	~2 yrs 11 mos
Rafael	Male	Nicole and Rafael Sr.	6 yrs 7 mos	2 yrs 7 mos
Salvador	Male	Christina	8 yrs 1 mo	~4 yrs 2 mos
Gabriela	Female	Sarah	3 yrs 4 mos	3 yrs 1 mo

Abbreviations: yrs=years; mos = months

[1] Pseudonyms

[2] Grandmother; all other caregivers are mothers and fathers/stepfathers