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Conversations with Health Care Providers and Parents Before Autism Diagnosis: A Qualitative Study

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Abstract

Introduction

The purpose of this study was to explore communication with health care providers from the perceptions of parents before their child's diagnosis of autism spectrum disorder and provide some examples of how communication may contribute to the autism diagnosis.

Method

This study used a qualitative descriptive design with multiple individual structured in-person interviews.

Results

Three themes captured parents' ($n = 8$) descriptions of the phases of communication during their children's diagnoses including, (1) anguished questioning, (2) urgently seeking help, and (3) expecting a diagnosis. In addition, three themes characterized the communication style that parents needed, although not always received, in each of the periods of diagnosis including (1) compassionate curiosity, (2) acknowledgment and affirmation, and (3) engagement with parents.

Discussion

Results point to opportunities for pediatric providers to use a more empathic and engaging communication style during the diagnostic process with better identification of education and support needed by parents and families.

KEY WORDS

Autism spectrum disorder, communication, engagement, families

Autism spectrum disorder (ASD) is a lifelong neurodevelopmental condition that presents difficulties in socialization, communication, sensory processing, and repetitive behavior (American Psychiatric Association [APA], 2013). The prevalence of ASD is estimated at 1/59 people in the United States (approximately 5.5 million people; Centers for Disease Control and Prevention, National Center on Birth Defects and Developmental Disabilities Division of Birth Defects (CDC), 2018a). There is no identified cure for ASD, but early interventions can improve a child's expressive or receptive language, communication, maladaptive behaviors, social skills, cognitive skills, adaptive independence, social participation, psychological well-being and the possibility of future employment (Finke et al., 2019; Weitlauf, Sathe, McPheeters, & Warren, 2017). Health care providers (HCPs), including nurse practitioners, may struggle with communication with parents of children who are trying to determine whether or not their child has a developmental delay.

Even though the signs of ASD may be present in the first 2 years of life, most children are not diagnosed with ASD until 4–5 years of age (CDC, 2018b). The diagnosis of ASD is complex because it is based on the application of the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) criteria that is informed by developmental history and structured observation (APA, 2013). Although parents are often skilled at identifying differences in their child's development (Richards, Mossey, & Robins, 2016), recent research shows parents of children with ASD need time and

education to understand the ASD specific symptoms (Gentles, Nicholas, Jack, McKibbon, & Szatmari, 2020).

To improve early ASD identification, the American Academy of Pediatrics recommends the use of brief, formal ASD screening instruments at standardized intervals during routine primary care visits (Hyman, Levy, Myers, & Council on Children with Disabilities, Section on Developmental and Behavioral Pediatrics, 2020). In fact, the use of developmental screening tools rose from 21% in 2002 to 63% in 2016 ($p < .001$), with a reported 59% referral rate of at-risk patients to early intervention, up from 41% in 2002 ($p < .001$; Lipkin et al., 2020). However, some HCPs still only screen for ASD during primary care health visits when parents raise a developmental concern (Siu et al., 2016; Zwaigenbaum et al., 2015), which requires the parent to be able to both recognize a delay and feel comfortable communicating the concern to an HCP.

Lack of universal ASD screening by HCPs during primary care visits may contribute to a delay in ASD diagnosis, because many parents may not recognize more subtle signs of ASD (Weitlauf et al., 2017; Zwaigenbaum et al., 2015). Low rates of referrals and/or lack of follow-through on referrals (Zuckerman, Lindly, & Sinche, 2015) after positive ASD screens also appear to contribute to delays in children's receipt of ASD diagnoses. It is common for children with ASD to be receiving only speech and language therapy for developmental language disorder before being diagnosed with ASD because the two conditions often co-occur and speech delays may be more easily identified through routine screening and by caregivers (Herlihy, Knoch, Vibert, & Fein, 2015; Tomas & Visers, 2019).

In light of the low or inappropriate use of ASD screening tools, conversations between HCPs and parents about developmental concerns are vital to achieving the goal of early identification of ASD. Although previous studies included parents' experiences of receiving their child's ASD diagnosis ($n = 10$; Mulligan, MacCulloch, Good, & Nicholas, 2012), parents' perceptions of health care received by their children ($n = 11$; Russell & McCloskey, 2016), parents' perspectives of early intervention ($n = 14$ from 12 family units; Edwards, Brebner, McCormack, & MacDougall, 2017), parents' perception of autism from a cultural perspective ($n = 15$; Fox, Aabe, Turner, Redwood, & Rai, 2017), and the relationship between parents' affective experiences and their parenting behaviors ($n = 15$; Dieleman, Moyson, De Pauw, Prinzie, & Soenens, 2018), no other qualitative studies have explored phases of conversations about developmental concerns parents have with HCPs.

The purpose of this study was to explore communication phases with HCPs from the perceptions of parents before their child's diagnosis of ASD and provide some examples of how communication may contribute to the ASD diagnosis.

METHODS

Design

This study used a qualitative descriptive design. The findings in qualitative descriptive studies include rich data (i.e., quotations) that inform the understanding of phenomenon with less interpretation compared with other qualitative methods (Sandelowski, 2010). Approval was received from the University's institutional review board.

Participants

Participants were recruited from a speech therapy clinic in a large Midwestern U.S. city with no local autism center. All patients were approached to be in the study, and no incentives were provided. English speaking parents of minor children with ASD undergoing speech therapy in this clinic were eligible for participation. The children's diagnosis of ASD by local community providers, that is, clinical psychologists were recorded in the speech therapy clinic files. The time lapse between diagnosis and interview was not quantified for this study.

Data Collection

Data were gathered via individual, structured audiotaped interviews. Questions were developed to assess parents' thoughts and feelings about communication and types of support provided for families in the time before ASD diagnosis. Team members conducted the interviews, which were approximately 60 min long. Interviews were conducted in a private room. A structured interview guide was developed and used in the study. It is as follows.

- 1 Thinking back to before your child was diagnosed with autism, at what age did you first become concerned that there may be a problem with your child's development and behavior?
 - Can you tell me what you think may have led you to be concerned?
 - Who first noticed that something was concerning about your child's development?
 - Did other family members (extended family) notice anything?
 - Did friends or neighbors?
 - How did you feel about others' concerns and/or perceptions?
- 2 What made you first seek guidance or advice from a professional?
 - What type of health professional was the first professional that you asked about your concerns?
 - When was that (at what age)?
 - What was his and/or her response?
 - How did you feel at the time?
- 3 When was your child given a formal diagnosis of autism (at what age)?
 - By whom?
 - Can you describe that process?
 - Approximately how many visits were made to this professional before getting a diagnosis?
 - Approximately how many different professionals assessed your child before he was given a diagnosis?
- 4 Please describe the communication between the different professionals involved in the diagnostic process?
- 5 Please describe the communication between you and the professional who diagnosed your child?
- 6 What would you recommend to improve communication?
- 7 What information was provided to you upon receiving the diagnosis? How was this information provided, that is, verbally, written, etc.?
- 8 Knowing what you know now, is there any additional information that you would have found helpful at the time?
- 9 What types of support were provided or suggested to you upon receiving the diagnosis?
- 10 How was this provided, that is, verbally, written, etc.?
- 11 Are there any additional types of support or resources that you wish you would have received?
- 12 How did you feel that you and your child were treated during the diagnostic process?
- 13 Did you feel you were allowed to provide enough input?
- 14 Did you feel that your opinion and perspective were respected?
- 15 Did you feel that your family values and culture were recognized during the process?
- 16 Did you feel that your questions and concerns were adequately addressed?

- 17 Do you think your experience as a family going through the process of having their child diagnosed with autism was different from what other families might go through? If so, how?
- 18 How satisfied were you with the entire process from when you first expressed concerns to someone and when your child received the diagnosis of autism?
- 19 How stressful was the entire process for you?
- 20 How stressful was the process for your family?
- 21 What do you think would have improved the process of diagnosis?
- 22 Thinking about the professionals that have worked with your child over the years, through assessments and treatments, what attributes do you think were most helpful to promote communication between those professionals and your family?
- 23 Any additional attributes you think are important to make professionals most effective when working with children with autism and their families?
- 24 What attributes do you think were most helpful to promote good communication among different professionals working with your child?

The questions were designed to elicit information regarding (1) parents' perceptions of their communication with HCPs regarding their children's developmental concerns, (2) parents' satisfaction with provider communication during the diagnostic process for ASD, and (3) parents' perceptions of provider attributes that promoted communication.

Data Analysis

Data analysis occurred through an iterative, consensual process of group coding and thematic analysis (Braun & Clarke, 2006) across four research team members. Audiotaped interviews were transcribed by a research team member and entered into NVivo for Mac 11.1.1. (QSR International, 2018). The team created an initial codebook of five codes including first signs of ASD, seeking help, diagnostic experience, communication with providers, and parent involvement in the diagnosis process. Each team member coded the first transcript using the initial codebook. As a group, coding was compared in each passage to refine the codebook. With the revised codebook, the group recoded the first and subsequent transcripts. Differences of opinion were discussed until consensus was reached, and the final codebook included eight coding labels. The small, purposeful sample facilitated a deep exploration of the parents' perceptions. In qualitative studies, validity refers to how well the themes and findings represent the actual phenomenon (Morse, 2015). Rich and detailed descriptions of the themes with participants' quotes were included to establish validity. Research team members had different expertise and professional backgrounds, which helped with reflexivity, the practice of overtly examining one's own biases and preconceptions.

RESULTS

Eight parents participated in the study. Most parents were married with a college education (see Table 1). The characteristics of the children are noted in Table 2. Children were diagnosed at ages ranging from 24 months to 8 years.

TABLE 1. Parent demographics

| Demographic | <i>n</i> (%) |
|-------------|--------------|
| Sex | |
| Female | 6 (75.0) |

| | |
|--------------------|----------|
| Male | 2 (25.0) |
| Ethnicity | |
| Black | 2 (25.0) |
| White | 6 (75.0) |
| Marital status | |
| Married | 6 (75.0) |
| Divorced | 1 (12.5) |
| Never married | 1 (12.5) |
| Highest degree | |
| Associate's degree | 1 (12.5) |
| Bachelor's degree | 5 (62.5) |
| Missing | 2 (25.0) |

TABLE 2. Child characteristics

| Child | Sex | Age when parent suspected ASD (months) | Age at medical diagnosis ASD (months) |
|-------|--------|----------------------------------------|---------------------------------------|
| 1 | Male | 16 | 54 |
| 2 | Female | 20 | 31 |
| 3 | Male | 30 | 60 |
| 4 | Male | 18 | 36 |
| 5 | Male | 18–24 | 108 |
| 6 | Female | 48 | 60 |

Note. ASD, autism spectrum disorder.

Three themes captured parents' descriptions of the phases of their children's diagnoses, including (1) anguished questioning, (2) urgently seeking help, and (3) expecting a diagnosis (see Table 3). In addition, three themes characterized parents' desired communication style, although it was not always received, in each of the phases of the diagnostic process including (1) compassionate curiosity, (2) acknowledgment and affirmation, and (3) engagement with parents. Information from the transcripts was used to develop scripted responses for HCPs to improve engagement with parents (see Table 3).

TABLE 3. Phase of ASD diagnosis, needed communication, and scripted responses

| Phase | Needed provider style of communication | Example of a scripted response |
|-----------------------|----------------------------------------|------------------------------------------------------------------------------------------------------------------------------|
| Anguished questioning | Compassionate curiosity | Tell me about your concerns. What are you noticing? Are other people concerned? Tell me about what they are saying. |
| Urgently seeking help | Acknowledge and affirm | I am glad you told me about your concerns. I can (will) help you figure out what is going on with your child. |
| Expecting a diagnosis | Engagement | There are options regarding treatment for you child. Some things still are not known for sure. |

| | | |
|--|--|-----------------------------------------------------------------------------------------|
| | | Even though we don't know all the answers, lets you and I work together for your child. |
|--|--|-----------------------------------------------------------------------------------------|

Note. *ASD, autism spectrum disorder.*

Themes for Phases of Diagnosis and Desired Communication Style

Anguished questioning and parents' need for compassionate curiosity

Anguished questioning characterized the first phase of the diagnostic experience, which was the process of parents accepting that their children's development was atypical from other children. All interviewed parents described the period when they or others around them began noticing atypical development in their children. One father described his and his wife's reaction to their mothers' concerns about their child's development. He said,

At first, I was kind of offended...we both had really strong mothers that were pushing us to try to find out if there was anything wrong [with the child]. But being new parents, sometimes we looked at that as being too overly aggressive...So, there was a little denial between the both of us.

Two parents noted unusual behaviors in their children that they hoped were within the spectrum of typical. One mother said, "I may have been looking at him with, you know, a little more of a concerned lens, but not that much. I mean he just did things differently than my other children." In addition, one father said this about his son's behavior as a toddler, "He had some quirky behaviors but it was cute, it was interesting how he played and did other things. But you know he was talking and moving around and doing lots of other things [that were typical behaviors]." One parent described her struggle with her inner knowledge that her child had atypical development and others' opinions that he did have concerning behaviors. She explained not wanting to listen to her own concerns about her child because she wanted to believe she was wrong: "It was a constant emotional struggle to have someone tell you 'no' even though you knew it [presence of atypical behaviors] was true but you just kept wanting to believe them."

Parents explained away their concerns by countering their children's concerning behaviors with examples of typical behaviors. For example, one mother described how her child's verbal communication was evidence against the diagnosis of autism. She said, "I guess the big thing was that he was so verbal. It couldn't be autism, because he can talk right?" She described discussing her child's behaviors and development with the pediatrician and who never voiced autism as a possible diagnosis. HCPs also explained away parents' concerns by pointing out the children's typical behaviors. For example, one parent described when she asked the pediatrician to confirm the atypical behaviors that she had noted in her child. She said,

I said [to the doctor], "this is what I see, what do you think?" And he basically listed a few reason as to why he [the child] didn't have autism. One reason was, "look he can sit next to you and he doesn't shy away from you." He doesn't mind me touching him, which was true like a physical grasp or whatever, but there were other things that he didn't like.

Another approach taken by parents when first noting atypical development was to decide to "wait and see" if the child would grow out of it or develop more typical behaviors as they got older. One parent

said, "The irony of it is that when we first had the concern when he was about 16 months, but we didn't start looking for help until our son was about 3 years old."

The wait and see approach on whether the child had autism was also recommended by HCPs. For example, one parent recalled the following: "We talked about his speech development being a concern to us. She [the child's pediatrician] too was sort of in the mindset of 'he's young right now, let's just kind of wait for it a little bit.'"

The high frequency of anguished questioning during the first phase of their children's diagnosis necessitated a communication style that demonstrated compassionate curiosity, that is, HCPs asking questions with empathic concern and the desire to help (Ministero, Poulin, Buffone, & DeLury, 2018). Parents in the study "wanted to feel comfortable sharing concerns and asking questions." They wanted "providers to not be intimidating."

Parents needed others around them, such as friends, family, teachers, and HCPs, to listen to parents' concerns as well as to share their concerns with parents. One parent said,

It was a weird mix of emotion too because I was like "hey why didn't you say something earlier?" You know? And they were like "how do you say that?" And I was like yeah how do you say that I think there is something wrong with your kid?

Although she understood that it might be difficult for others to share their concerns with the parents, it still would be beneficial.

Select parents perceived that their HCPs were not attending to their concerns, and they felt that providers should "ask for, listen to, and value parents' information about their own children." For example, a parent suggested that providers gently explore parents' understandings of their children's development. Providers' curiosity about what parents know about child development and what they are observing in their children might help parents to accept that their child has atypical behaviors, so interventions could begin sooner. One father said,

[Parents should] mention it to the pediatrician, say "he's been doing this and that, and the other thing. He doesn't have as many words as some of the other kids, so is that something for me to be concerned about?" And kind of balance that with maybe some of the other things you're noticing you mention to your pediatrician.

Conversely, parents recommended that providers should take parents' concerns seriously, conduct more in-depth assessments of parents' concerns and use resources to formally assess and treat issues early in proximity to when parents expressed their concerns. One parent whose child's pediatrician recommended "wait and see" in response to her concerns about her child said, "I think that what would have improved the process was being given more of a push to pursue some things earlier on and being given more options as far as where we could've pursued help from."

Urgently seeking help, and parents' need for affirmation and acknowledgment

Once parents came through the phase of anguished questioning, they moved into the phase of seeking a diagnosis. This second phase was characterized by the theme "urgently seeking help." Once parents

began to seek diagnosis, they felt an urgency to have answers to stabilize their feelings and families and to begin helping their children as soon as possible.

Most parents started to seek diagnoses with their primary care providers (PCPs; e.g., pediatricians, physicians, and nurse practitioners). Diagnoses were delayed by PCPs in two ways: some providers were not willing to refer for evaluation, and some parsed delays into separate medical diagnoses and avoided a holistic assessment. Parents noted atypical behaviors in their children that were not recognized as atypical by professionals. For example, one mother described how PCPs at first would not confirm her concerns about her child's speech. She said,

He was always talking which was hard for anyone who met him. It was mostly echolalia. I think that is what confused so many people because he spoke clearly. I couldn't get him signed up for speech when he was little because he could talk. And he could talk to you clearly, so he had no speech impediment. So they would look at me too like, "well what do you want him to be here for?" And it was like, he was detached, I remember tucking him in at night and I remember the first time thinking like I am here and you are here and I'm looking at you but you're not with me. I had a daughter. She was talking at 13 months and he was too [although] it just it wasn't the same.

Once parents knew that their children were not developing typically, and they felt that their PCP was not meeting their needs, they looked for help outside of primary care. For example, after being told to continue to wait, parents of one child began to do their own research. On their own, they found an autism specialist who eventually diagnosed their son. The father of this child said,

The pediatrician that we initially consulted with said, "don't worry about it, kids develop at their own speed, give it another 18 months." And we said no, we are not going to wait awhile. We can't do that. If it comes to that [child does not have a developmental condition] then okay great, we were wrong and he [pediatrician] was right but in this case you know he pushed it off . . . so, we went after it more aggressively and that made a big difference.

Another mother described how she expressed her concerns to her child's pediatrician only to be given (false) reassurance that the child's development was typical. Her comments convey the urgency that parents felt once they knew that their children needed special services. She said,

To try to continually convince people that there is something majorly wrong with your child. It goes against every instinct you have. You hear good things and you are like ugh okay that's good, I'm just being crazy [or imagining something is wrong] you know? . . . As a mom, I wanted to believe that. And it felt hopeful to me. But, my professional experience as a social worker gave me some pause to say "this is not normal development." So, there was a bit of hope and there was denial around that.

This mother eventually asked her pediatrician to refer her child for evaluation.

Parents who were urgently seeking help expressed a desire for communication from providers that acknowledged and affirmed their concerns and their conviction that their children could benefit from assessment, diagnosis, and treatment. Parents felt alone; affirmation and acknowledgment of their concerns made them feel relieved and hopeful.

So he ended up going to 4K [kindergarten]. I walked in and the first day there his 4K teacher and I'm not kidding, I like grabbed her by the elbow and said, and I let him [her son] go and there he was making laps around the thing and I said, "please tell me you see what I see." And she said "I do. I know what you are saying." And I said, "please tell me that you think the same thing I think, he has autism." And she said, "I can't diagnose that. But I know what you're seeing is what I'm seeing . . . I will help you."

By contrast, the lack of affirmation caused parents to report feeling hurt and dismayed. One parent stated:

I don't understand, if he [PCP] would have diagnosed him with autism how would that have hurt him [her son] at all? I mean I wouldn't necessarily want him to give out the label if he didn't think it was so, but I don't understand if he wasn't sure about it, why he didn't have better answers of somewhere else to go.

Expecting a diagnosis and engagement with parents

Parents expected a diagnosis from the HCP and/or education professionals who cared for their children. In this phase, parents needed engagement with professionals to form a team. They expressed the desire for professionals to acknowledge and respect that they, as parents were the experts of their children.

You know, everyone's got an opinion about things and what you should do. It's stressful in the sense that family members may know your child and professionals only sort of have a snapshot of your child. It's like, I am with my child every day. I know what he will and won't respond to.

Parents expressed some frustration with partial, inconsistent, and unspoken diagnoses. They described a lack of ownership among health care and education professionals regarding who was responsible for making the diagnosis of ASD.

Parents in this study described a common approach to assessment by the participants' PCPs to parse out the delays individually rather than considering the whole picture of the child's development. For example, speech delays were investigated with a medical approach, and children were evaluated for secondary hearing issues such as fluid in the middle ear from enlarged adenoids. Children were referred to physical therapy for walking delays and orthopedic care for toe-walking. From the parent perspective, when issues were addressed individually, they were attributed to medical problems and/or viewed as possibly typical and not acted upon.

Parents felt that schools and therapists contributed to the delay in the ASD diagnosis by providing diagnoses such as academic autism, sensory integration disorder, and/or speech delay. This impacted parent satisfaction with the process of ASD diagnosis. One mother described frustration when providers offered her therapy options for her child without providing a diagnosis. She said,

They immediately said he needs speech therapy, and he needs early childhood, they right away said we can start working with him and gave me their break down of what it would cost and what they were going to do. But then I said to them, well what does he have? And they said, we can't diagnose anything... I tried to get it out of them, and they wouldn't say, they wouldn't even, they didn't use the word autism, they didn't use any developmental delay.

Once at the diagnostic phase of working through options, parents expressed a strong desire for providers to engage with them. This approach would allow parents to be involved in the diagnosis and creation of management plans. Parents felt strong desires to advocate for their children, but they did not always know how to accomplish that because of a lack of knowledge regarding autism and knowledge of resources: "It was a little bit scary, a little bit overwhelming. I feel like there was a lot of miscommunication . . . I kept feeling that I was not getting enough information that I needed for her." Parents did take on the responsibility to investigate options and to learn about autism on their own but still felt undereducated and overwhelmed with diagnosis and treatment options. One mother said, "I always felt like I wanted more education about autism and I don't think I got enough besides giving it myself."

Parents wanted to engage with knowledgeable providers. Parents worked to make themselves knowledgeable but still valued and needed professionals' input. They desired to be educated about autism, rather than just reach a diagnosis for their child. For example, one parent described how lack of engagement made her feel unsupported by the providers. She said,

She gave us a bunch of books and things, but when I said, well what do we do next? . . . She said here all these different options. And I'm like, "Isn't there something we're supposed to do first?" And she's like, "you have to read this stuff and pick something you want to do." So it was basically her saying here's your diagnosis, do whatever you want with it. And not knowing a single thing about autism, I was like what?

In contrast, another parent reported feeling supported through engagement with providers. This parent said,

I feel like with what we knew to ask, they were [questions and concerns adequately addressed]. So, you don't know what you don't know. I do feel like, again, people were open to our input and were sensitive to what we were going through as parents. Because it's difficult, regardless of whatever name that it may have been given to know that your child has a disability is difficult and people were sensitive to that.

Finally, parents wanted an individualized assessment of their children's strengths; they wanted acknowledgment of their children as multifaceted humans who were "more than autism symptoms." As one parent said,

Instead of just giving me numbers, give me, "okay, this is what your child can do, this is what your child can't do, and this is what your child possibly can do with a little bit more support." That gives parents an opportunity to . . . get the boots on the road . . . and say these are some things I can do tangibly right now.

DISCUSSION

In this study, parents of children who had a diagnosis of autism spoke about their experiences before their child was diagnosed with ASD. On the basis of their insights, we discerned three themes indicating they went through a process of anguished questioning with their PCPs, followed by urgently seeking help, and then expecting a diagnosis of ASD. Although this data does not describe the experiences of all families, it does provide examples of communication patterns that accompanied a

delayed diagnosis of autism. The perceptions of parents contributed to the identification of compassionate communication strategies to promote timely diagnosis.

In terms of context for parents realizing that their child had signs of ASD, parents in this study experienced anguished questioning in the early in conversations with others, before their children's diagnoses. Although they were trying to understand if their child's development was normal, parents reached beyond HCPs and asked questions of family and friends who were sometimes more aware of the abnormal development before the parent. Results match literature showing grandparents may notice ASD before parents (Sicherman, Loewenstein, Tavassoli, & Buxbaum, 2018). Parents noted that early on, they hoped that the abnormal behaviors were not real, and they tried to ignore others' concerns for their children. They were sometimes offended when friends or family mentioned their concern for the child's development. However, some parents reported that they wished others would have shared their concerns about their child's development delay earlier.

The theory of family self-management (FSM) provides a framework for understanding how communication between parents and HCPs can promote or delay the diagnosis of ASD among children. FSM predicts that individuals and families use condition-specific knowledge and beliefs, self-regulation skills, social facilitation, and negotiation to achieve proximal and distal health outcomes (Ryan & Sawin, 2009). Risk and protective factors form the context in which families engage in self-management of chronic conditions, such as ASD (Ryan & Sawin, 2009). In the context of ASD diagnosis, specific risk and protective factors include the parent or family member's perceptions of normal child development. Communication style and the interactions between the HCPs and the parents in health care appointments are processes that facilitate health outcomes. The proximal outcomes are the individual and FSM behaviors, such as voicing concerns for their child's development or parent satisfaction with their HCPs communication. Distal outcomes involve the health and quality of life of the children and families' quality of life after receiving an ASD diagnosis and securing appropriate interventions.

Informed by FSM theory, our results suggest that proximal outcomes such as individual and family self-management behaviors were influenced by HCP communication. Parents reported that the process of communication was sometimes difficult with HCPs and wished HCPs would have validated their concerns, often informed by their families, rather than offering "wait and see" advice. Thus, HCPs should act quickly on developmental concerns; a "wait and see approach" can potentially delay the diagnosis and frustrate concerned parents.

Parents noted that they needed communication that demonstrated compassionate curiosity on the part of HCPs, so they could explore the meaning of the child's atypical behaviors. All parents reported the desire for provider attributes that would promote communication during the diagnostic process. They preferred knowledgeable, kind providers who were "focused and warm at the same time," who make them feel comfortable to ask questions, not intimidated. This finding matches previous literature in which HCPs ask questions with empathic concern and the desire to help, which is appreciated by parents (Gentles et al., 2020; Ministero et al., 2018).

Past research shows that poor communication between parents and HCPs has been linked to barriers in access to care; parents have often felt left out of shared decision making and collaboration about

resources and next steps when children have signs of ASD (Levy et al., 2016; Magaña, Parish, & Son, 2015). The lack of HCP agreement with parents on the concerning child symptoms was likely exacerbated by the shortage of developmental-behavioral pediatricians, and advanced practice nurses with training in pediatric mental health in the study location (Bridgemohan et al., 2018) and the limited training pediatricians receive during training about ASD (Major, 2015). There are also very few advanced practice registered nurses and mental health professionals who specialize in children, which leads to the problems of finding experts in the complex differential diagnoses (Bridgemohan et al., 2018). Additional education of HCPs regarding the referral process after a positive ASD screening could help raise the referral rate (Monteiro, Dempsey, Berry, Voigt, & Goin-Kochel, 2019) and the selection of evidence-based and novel treatments, clinical practice guidelines, and community resources (Levy et al., 2016).

Past research shows that among children with ASD, those with more proactive provider responses to concerns had shorter delays in ASD diagnosis (Zuckerman et al., 2015). In contrast, children with ASD having passive and/or reassuring provider responses had longer delays (Zuckerman et al., 2015). Including the autism modules of (CDC, 2020) aimed at helping HCPs do a better job communicating abnormal screening results could also be helpful to improve communication and patient engagement.

Patient engagement is a strategy for countering the barriers in communication that could help parents feel comfortable communicating concerns about their child's development to HCPs (World Health Organization, 2016). Engagement is conceptualized as parents taking an active role interacting with HCPs and family members. The results of this study point to opportunities for pediatric providers to better identify ASD, enact more positive communication with parents, and provide education and support needed by parents and families. An improved understanding of how parents may respond to their child's atypical development informs the strategy of scripted responses that show affirmation of the anguish parents are going through. It also offers support for parents as HCPs engage with them to work together for solutions. The results of the study may inform future development of interdisciplinary intervention studies of communication with ASD parents and children with ASD undergoing diagnosis and speech therapy.

CONCLUSION

HCPs and nurses are challenged to facilitate access to early diagnosis and intervention, which may negatively affect health outcomes. The diagnostic process should be designed to allow parents to feel engaged and comfortable exploring their thoughts with knowledgeable HCPs and other professionals, which can be accomplished through specific communication styles. Interventions with scripted dialogue informed by parents' preferences may improve parent–HCP engagement.

The authors acknowledge that this study is exploratory in nature. Although this study included a small sample size of parents, their perceptions were based on many instances of communication with HCPs that occurred over several years. Because previous qualitative studies of individually interviewed parents of children with autism spectrum disorder (ASD) reached saturation of themes at 10–15 parents, this comprised our recruitment goal. The parents in the present study provided detailed accounts of their experiences, which we presented as examples of how communication with HCPs can delay or promote the diagnosis of autism among children. Participants represent a limited geographic

area, which may impact their experience. Replication of the study with participants of diverse ethnicity would be valuable.

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