



| Research Article / Araştırma Makalesi |

Speech, Language and Communication Differences before Autism Diagnosis: The Perspectives of Parents

Ebeveynlerin Gözünden Otizmde Tanı Öncesi Dil, Konuşma ve İletişim Gelişimindeki Farklılıklar¹

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Abstract

Purpose: Autism-specific behaviors begin with some preliminary symptoms and can be detected during the pre-verbal language stage or after diagnosis. Early diagnosis and early intervention can begin if caregivers or parents identify these precursors of behaviors during the pre-diagnostic period, and the person with autism can receive effective and timely training. The goal of this study was to find out what non-typical language and communication behavior parents or caregivers of children with autism might have noticed before they were diagnosed.

Design/Methodology/Approach: After applying exclusion criteria, fifty participants (47F, 3M) who are primary carers of 3-10-year-old children with autism were accepted into the study. Data was gathered using a two-part interview form with 37 questions. Face-to-face interviews were held.

Findings: Descriptive and situational analysis methods were used to analyze the data. Following the analysis of the findings, behaviors such as not making eye contact, not responding when their name is called, and indifference toward their parents were observed in the children of the participants who were diagnosed with autism till the age of 18 months.

Highlights: When the findings were evaluated, it was discovered that the individuals' issues began at an early age. In terms of autism suspicion, family observations are crucial; early symptoms are predictors of various developmental stages. Accordingly, families should follow their children more closely and they should be informed more by experts so that families can notice the differences in developmental areas.

Öz

Çalışmanın amacı: Otizmlili bireylerde gözlenebilen otizme özgü davranışlar söz öncesi dönemde ya da tanı öncesinde bazı ön belirtiler ile kendini ortaya koymaktadır. Bakım veren ya da ebeveynlerin bu davranış öncüllerini tanı öncesi dönemde fark etmeleri durumunda erken tanı ile erken müdahale süreci başlayabilmekte ve kişiye etkili ve zamanında eğitim sunulabilmektedir. Bu çalışmada otizmlili çocuğa sahip ebeveynlerin tanı öncesi dönemde gözlemiş olabilecekleri tipik olmayan dil ve iletişim davranışlarının belirlenmesi amaçlanmıştır.

Materyal ve Yöntem: Katılımcı grubunu 3-10 yaş arası otizmlili çocukların birincil bakım veren durumundaki 50 (47K, 3E) ebeveyn oluşturmaktadır. Veri toplamak için 2 bölüm ve 37 adet sorudan oluşan bir görüşme formu hazırlanmıştır. Görüşmeler yüz yüze gerçekleştirilmiştir. Veriler betimsel ve durum analiz yöntemleri kullanılarak analiz edilmiştir.

Bulgular: Bulguların analizi sonrasında katılımcıların otizm tanısı almış olan çocuklarında 18 aylık olana kadar geçen sürede gözlenen farklılıkların başında göz teması kurmama, ismi söylendiğinde tepki vermeme ve ebeveyne karşı ilgisizlik gibi davranışlar yer almaktadır. Bulgular incelendiğinde bireylerin yaşamış olduğu bu güçlüklerin yaşamın erken dönemlerinden itibaren kendini göstermekte olduğu saptanmıştır.

Önemli Vurgular: Erken dönemdeki göstergelerin çeşitli gelişim basamaklarının yordayıcıları olmaları sebebiyle ailelerin gözlemleri otizm şüphesi açısından önem arz etmektedir. Bu doğrultuda aileler çocuklarını daha yakından takip etmeli ve ailelerin gelişimsel alanlardaki farklılıkları görebilmeleri adına uzmanlar tarafından daha fazla bilgilendirilmelerinin önemli olduğu düşünülmektedir.

¹ The findings of the study were summarized in a poster presentation at the X. National Language and Speech Disorders Congress, which took place in Istanbul from April 28 to May 1, 2019.

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INTRODUCTION

Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder characterized by three core behaviors: inadequacy in social communication, inadequacy in social interaction, and finally limited/repetitive interest and behaviors, according to the Diagnostic and Statistical Manual of Mental Disorders-5 [DSM-5], published by the American Psychiatric Association in 2013. The presence of observable behavior and symptoms can help to diagnose ASD. Autism symptoms are said to appear over time, and some children's symptoms can be diagnosed as early as their first birthday (Ozonoff et al., 2009). Researchers who looked at video recordings of children before they were diagnosed (for example, movies taken on their first birthday) noticed that children tended to produce fewer sounds and they were limited in making eye contact, hugging adults, and smiling, all of which are crucial diagnostic criteria for autism (as cited in Aydın et al., 2017). Other studies (Gray and Tonge, 2001; Turan et al., 2020) state that most of the parents of children with autism notice problems with their children's development before the 24th month, while Servi and Baştuğ (2018) found that the difficulties related to ASD in the literature were noticed by the parents as early as the 24th month. According to studies, 31-55% of children with ASD exhibit symptoms in the first year of life, and 75-88 % of them display symptoms in the first two years of life (Volkmar et al., 1985; Loveland and Landry, 1986; Short and Schopler, 1988; Gray and Tonge, 2001). While Akkuş et al. (2020) reported that speech delay is the most common difference observed in children by 53% of parents, Crane et al. (2016) discovered that 82% of parents noticed a difference in the social development. According to the findings of the studies, these differences affect the communication abilities of children with autism and cause other issues in addition to communication challenges. These issues can also lead to behavioral problems like as tantrums, self-harm, and aggression. Studies by Webber and Scheuermann (2008), Hart and Banda (2009) and Ploog et al. (2013) revealed that inadequacy in functional communication skills causes individuals with autism to have difficulty expressing their preferences, wishes, and needs, as well as sharing their ideas. It is stated that these problems can also cause behavioral problems such as tantrums, self-harm and (as cited in Genç-Tosun and Kurt, 2017).

Typically developing children develop responsiveness to social interaction just a few hours after birth. Faces, rather than shapes, are preferred by typically developing children and they also prefer and show interest in their mother's face over strangers. Children follow the elements of attention with their gaze and gestures from the first years of life, but in varying degrees of quality and quantity. This tracking is done in a variety of ways by babies; babies as young as 6 months by scanning their visual fields with their gaze; 8 month-old babies by looking at auditory and visual objects and 20 months do it by turning their heads (Farroni et al., 2004; Brooks and Meltzoff, 2005; Mundy and Newell, 2007). Emotional reactions such as crying (from birth), social smiling (1-2 months), facial expressions also begin to demerge in the first months. Children with autism, on the other hand, do not complete these developmental phases in the same way. Comparative studies with children with typical development and children diagnosed with autism and/or not yet diagnosed with autism but in the risk group were conducted in order to study communicative intentions. Study findings reveal that during the 24-month developmental period, researchers noted poor coordination in pointing, restricted eye contact, and limited use of gestures in children with autism (Zwaigenbaum et al., 2005; Landa and Garrett-Mayer, 2006; Mitchell et al., 2006; Clifford and Dissanayake, 2008; Feldman et al., 2012). Children with autism have been seen to differ from typically developing children in areas such as interpersonal gaze shifting, eye contact to attract attention, and shared attention (Rozga et al. 2011). In their study, Ozonoff et al. (2011) investigated the social attention skills and found that there were significant limitations between groups of 12 month-old children (who were later diagnosed with ASD) with a sibling with autism (High-Risk Infant Siblings [HR-ASD]) and 12 month-old typically developing children with typically developing sibling (Low-Risk [LR Non-ASD]). Children who diagnosed with autism demonstrated less attention to faces, less directed vocalization, and limited social smiles at 36 months. Language development problems are also prevalent in children with autism, and there is a lot of heterogeneity in this instance. According to studies, some children with ASD acquire language in the same way as typically developing children do, while about a quarter of them never learn to communicate verbally and never acquire a functioning language ability (Tager-Flusberg, 2006; Luyster et al., 2007; as cited in Aydın et al., 2017). While some children with ASD are able to communicate verbally, others are unable to do so, according to Crais et al. (2009). While some children with ASD have completed their speech development, the reason why some of them lag behind in this development process is not yet known.

In children with ASD, problems with social communication and interaction skills also appear throughout the preverbal period of communication development (as cited in Akçamuş et al., 2019). Landa and Garrett-Mayer (2006) stated there are behaviors noticed in children with autism during the preverbal language period that are not seen in children with typical development. Atypical vocalization (including different vocalization limitations during crying), delaying or holding the parent's hand instead, not reacting to the name (appears 4-6 months in typical developing individuals), having problems with imaginary play, and less smile while interacting with the mother, limitation in intimacy, hugging, and imitation are examples of these behaviors. Smiles, limitations are examples of behaviors (Landa and Garrett-Mayer, 2006). Children with autism exhibit limited and decreased performance in imitating sounds and words at 12nd and 18th months. In studies comparing HR-ASD and LR-ASD children aged 12 and 24 months, functional and symbolic imitation skills were also found to be poorer in HR-ASD children. In a study by Loh et al. (2007), in terms of repeated activities, it has been suggested that *'arm waving'* (and its frequency) is the behavior that distinguishes those with autism from those with typical development at 18-24 months. Ozonoff et al. (2008) also reported that children with autism exhibit shaking, rocking, hitting, rolling, and atypical visual field scanning behaviors. For these reasons and based on the findings, it is critical for families to evaluate and consider the indicators in the preverbal stage in order to make an

early diagnosis. However, it is also known that early signs are difficult to detect by observers who have little knowledge (Ozonoff et al., 2009).

Gaze, gesture, joint attention, and interaction skills, which are also represented as non-verbal communication, should be taken into account when predicting the language competency potential of children with ASD in the future (Crais et al., 2009). In a study by Shumway and Wetherby (2009), it was revealed that limitations in the use of gestures are one of the early nonverbal communication issues in children diagnosed with autism. It is known that children's language development can be influenced by gesture skills (e.g., pointing with fingers, moving hands to mimic wings, nodding) (as cited in Aydın et al., 2017). Knowing the characteristics of the development of gestures and different types of gestures in children with typical development is extremely important for early diagnosis in children who may have with a possible developmental-linguistic or communicative disability. Individuals with autism's language skills have been demonstrated to be a predictor of future language ability levels in studies. Wetherby et al. (2007) conducted a study to confirm the given information, with the goal of evaluating the social communication profiles of children with autism. The receptive language skills of children with autism aged 18-24 months were found to be the most important predictor of their predicted verbal and nonverbal developmental language performances at the age of 3 years in the aforementioned study. Anderson et al. (2007), on the other hand, did a study that found that the language abilities of children with autism at the age of 18-24 months could help professionals predict the functional language development of children at the age of 5. These findings once again highlight the need of early intervention, which begins with early diagnosis. Because of these findings, it is believed that future linguistic gains can be attained with early intervention.

In the sibling studies, it was seen that siblings in the high-risk group performed differently on language assessments than siblings in the low-risk group. receptive language subscales of the Mullen Scales of Early Learning (Mullen, 1995 [MSEL]) and MacArthur-Bates Communicative Development Inventory (Fenson et al., 2007 [CDI]- Turkish version: Aksu Koç et al., 2019; Türkçe İletişim Gelişimi Envanteri [TiGE]) were used in sibling studies which were carried out to establish the determinants for early autism diagnosis and HR-ASD and LR Non-ASD groups were compared. It was concluded that the children in the HR-ASD group had lower receptive language scores (Lazenby et al., 2016). In their own study, Landa and Garrett-Mayer (2006) found similar results to those found in this one. Accordingly, 24 children in the HR-ASD group scored lower on the MSEL battery's receptive and expressive language subtests than children in the comparison group (LR Non-ASD vs Non-ASD). Ozonoff et al. (2014) found that 12-month-old HR-ASD children had lower MSEL battery receptive language scores than LR-ASD children in a study involving 420 children within the HR-ASD and LR-ASD groups. The receptive and expressive language scores of children diagnosed with autism or in the risk group were found to be lower than those of the control groups in assessments (Mitchell et al., 2006; Ventola et al., 2007; Luyster et al., 2008; Chawarska et al., 2009; Weismer, Lord, and Esler, 2010).

In addition to assessing language development in the preverbal period, the assessment of other developmental areas in children with autism has become more important in terms of early identification and determining predicting indicators. Landa and Garrett-Mayer (2006) assessed 6-24-month-old children in the domains of fine-gross motor skills and visual perception, and found no significant differences in visual perception across a 14-24-month period, but the HR-ASD infants got lower scores in fine-gross motor skills. In addition, HR-ASD children were found to differ from typically developing children in the areas of muscle control, delayed walking, and atypical postural control (incontinence, sitting without support, etc.).

Motor development deficits (fine and gross motor skills deficits) in individuals with autism appear to be deficiencies in the field of non-linguistic development, based on the findings of studies in the literature. As, given that developmental areas (motor and linguistic) develop in lockstep and at the same time, it's reasonable to conclude that deficiencies in these two areas have an impact on one another. When compared to those with typical development, those with autism show different developmental traits in the pre-linguistic stage.

Individuals with autism do not use deictic (pointing) and symbolic (pretend play with objects) expressions and they also do not perform well in areas such as *'establishing eye-contact, making requests, rejecting, dissatisfaction, disapproval and responding (communicative intentions-acts; Roth and Spekman, 1984)* particularly in the pragmatic developmental period. Limitations in vocalizations, atypical vocalizations, and the fact that wishes and discontents are not conveyed by different vocalization patterns are among the conditions that may indicate autism in the phonological development following motor development from birth. The absence of features indicating typical development in the motor, phonological (vocalizations), and pragmatic (communicative intentions) areas, particularly in the first 18 months, can directly suggest language delay-disorder and may indirectly suggest autism. Even when verbal language competence is demonstrated in children with autism, issues in the pragmatic field are still seen; the basis of these problems leads us to the preverbal pragmatic development period. The delay in producing the first words expected at 18 months and the lack of receptive language abilities may also lead to a developmental issue in infancy and maybe autism suspicion.

When the literature is examined, it is seen that the qualitative studies conducted in the field of autism in Turkey mostly focus on the problems experienced by the families (Top, 2009; Töret et al., 2014; Akkuş et al., 2020; Turan et al., 2020). While various studies in the worldwide literature have been undertaken to determine the differences experienced by families with children with ASD in the pre-diagnosis phase (Gray and Tonge 2001; Young, 2003; Guinchat, 2012; Crane et al., 2016; Sichertman et al., 2019), the quantity of qualitative studies on this topic in Turkey appears to be limited (Servi and Baştuğ, 2018). As a result, it is expected that this study will make a substantial contribution to the Turkish literature, or at the very least will direct researchers interested in the subject to conduct research on the subject.

Language is a tool that people use to express their wants, needs, thoughts, and feelings. Language skills at a young age serve as the foundation for future language abilities. Lack of linguistic abilities, or failure to acquire them effectively, can cause difficulty in communication, as well as a slew of other issues. As a result, early detection and treatment of language and speech impairments is critical. Family observations are vital for the diagnosis and suspicion of autism since language, speech, and communication indicators in the early period are predictors of various developmental stages. Accordingly, in this study, answers were sought to the following questions in order to determine the behaviors that parents observed in the pre-verbal and pre-diagnosis period:

1. Is there a difference between children diagnosed with autism and children who develop typically in terms of general developmental stages?
2. In terms of general developmental stages, what is the difference between children diagnosed with autism and children who develop typically?
2. What differences did parents notice in the first 18 months of their child's life?
3. What differences did parents observe prior to diagnosis?

METHOD/MATERIALS

Study Design

The case study design, one of the qualitative research approaches, was used to conduct the descriptive research. In phenomenological research, the interview is the primary data collection tool. The phenomenology approach was used in this study, and semi-structured face-to-face individual interviews were used to try to determine the differences in language-speech-communication development noted by families prior to diagnosis.

Participants

The study included 50 (47F, 3M) parents who were primary caregivers of children with autism, aged 3-10 (\bar{x} =6.54, SD =1.99), who were enrolled in rehabilitation centers in Istanbul

The goals of the study were explained to the participants, and their consent was obtained after they were given general information about the study. The participants all agreed to take part in the study. Inclusion criteria for the study were determined as follows:

- Their children have only been diagnosed with autism and do not have any other disabilities.
- The age range of children diagnosed with autism is 3-10 years.
- Being the primary caregiver of the child with autism.

Material

Semi-structured interview technique was used in this qualitative study, which was conducted to determine the differences observed by families with children with ASD in the pre-diagnosis period. Interview questions were prepared based on the relevant study findings (Brewer, Pattison, and Young, 2003; Zwaigenbaum et al., 2005; Landa and Garrett-Mayer, 2006; Ozonoff et al., 2009; Chamak et al., 2011; Crane et al., 2016; Sichertman et al., 2019), collected as a result of the researchers' literature review and a semi-structured interview form was created for individual interviews with the participants. A pilot interview with a participant who met the inclusion criteria was done to assess the clarity and clarity of the questions in the interview form. Following the pilot interview, the participant was questioned on the questions' clarity, difficulty, and clarity, and feedbacks were collected. The interview form was revised in response to the feedback. Questions that were difficult to understand were simplified, and the usage of domain-specific words was minimized.

The interview form is divided into two sections, one for '*general information*' and the other for '*language and communication*'. 17 questions were created in the first half to acquire demographic information about the participant and the child, and 20 questions were created in the second part to determine the language, speech, and communication behaviors seen in the participants' children. These questions were formatted as 'yes/no' and 'open-ended' questions.

Data Collection

Face-to-face semi-structured interviews with the participant who provides primary care to the child with autism were undertaken in order to collect data. Participants were interviewed in a quiet room at three special education and rehabilitation centers that had previously been agreed upon. Participants were informed about the subject and purpose of the planned research, that the research results would not be used for anything other than scientific purposes, and that their personal information would be kept confidential prior to these face-to-face interviews, and voluntary consent was obtained. The interviews lasted about 15-20 minutes on average. The responses of the participants were noted during the interview in detail. Additional questions were asked and the answers were discussed in cases where the participants' answers were not clear and understandable.

Data Analysis

The data obtained from the participants were analyzed using descriptive and situation analysis methods. Descriptive analysis is a type of qualitative data analysis that entails summarizing and analyzing data based on pre-specified themes. The primary purpose of this type of analysis is to present the findings to the reader in a summarized and interpreted form. The researchers analyzed the interview data and identified common themes in order to compile the participants' responses on the differences they noticed prior to diagnosis. 'General Development', 'First 18 Months', 'Before Diagnosis' and 'Problem Behaviors in Communication' are the themes found. The researchers agreed to conduct descriptive analyses of the data based on the themes they had developed.

FINDINGS

The findings of the data analysis obtained by using the appropriate approach for the study's principal aims are presented in this section.

The demographic and other associated information regarding the study participants and their children diagnosed with autism spectrum disorder is provided in Tables 1 and 2.

Table 1. Demographic information about participants

Demographic information		%	N (50)
Gender	Female	94	47
	Male	6	3
Education	Primary School	16	8
	High School	32	16
	University (College)	50	25
	Postgraduate	2	1
Education (Spouse)	Primary School	14	7
	High School	34	17
	University (College)	52	26
Income (by month)	1000-2000 TL	14	7
	2000-3500 TL	30	15
	3500-5000 TL	32	16
	5000 TL and above	24	12
	1	24	12
Number of children	2	64	32
	3	12	6
	Yes	18	9
History of speech and language disorders in family	No	82	41

80% (n=40) of the participants participated from Istanbul and 20% (n=10) participated from Kocaeli. The participants in the study ranged in age from 27 to 53 (\bar{x} =36.92, SD =5.10), while the age range of the spouses of the participants was 29-58 (\bar{x} =40.62, SD =5.98).

A total of 9 (18%) participants answered "Yes" to the question "Does anyone in your family have language and speech disorders?" Statements like 'My brother had delayed speech,' 'My brother's son also has autism', 'There is stuttering on the father's side,' and 'The mother has temporary stuttering,' were given in response to comprehensive questions about these conditions.

Table 2. Demographic information about participants' children with ASD

	\bar{x}	SD	Min	Max
Age	6,54	1,99	3	10
Age of 'difference' suspicion*	20,24	9,63	7	48
Age of 'ASD' diagnosis	2,86	1,05	1,5	6

* Indicated as month.

40% of the research participants' children are between the ages of 6-7. Of the children diagnosed with autism, 52% (n=26) were the second child, 44% (n=22) were the first child, and 4% (n=2) were the third child. The children were divided into two groups: boys (68%; n=34) and girls (32%; n=16). When asked when the differences in their children first became apparent, in response, 24% (n=12) of the participants said that their children were 1-year-old, 18% (n=9) said that they observed differences when their children were 1.5 years old, and 14% (n=7) said it was at 2 years old. The age at which children are diagnosed varies

significantly, as does the time it takes for individuals to notice differences. The vast majority of children are diagnosed between the ages of 2.6-3.0 (40%, n=20).

The table below shows the data of mean, minimum, maximum, and standard deviation (SD) derived from the language-speech-communication and general development questions (Table 3).

Table 3. Information about the development of children who have been diagnosed with autism

	\bar{x}	SD	Min	Max
Unsupported Sitting	7,42	2,03	4	12
Sitting	7,93	2,38	3	12
Crawling*	9,63	3,05	6	18
Walking	14,24	3,93	8	27
Babbling*	7,64	2,92	3	18
First Words	16,33	10,92	6	60

* Indicated as month.

** The numerical findings were organized in order of most marked and the first two responses were given.

According to the participants' responses, the age of onset of sitting without support in children diagnosed with autism is \bar{x} = 7.42 months; teething is \bar{x} = 7.93 months; crawling is \bar{x} = 9.63 months; walking is \bar{x} = 14.24 months; babbling is \bar{x} = 7.64 months; and the age of saying the first word is \bar{x} = 16.33 months. While 34% (n=17) of the participants gave the information that their children diagnosed with autism begin to sit without support in the 6th month; 12% (n=6) of the participants stated that they started to sit without support at the 7th month and 10% (n=5) of them expressed that it was at the 12th month. When asked when their children were teething, 20% (n=10) stated they were teething in the seventh month, and 16% (n=8) said they were teething in the ninth month. 16% (n=8) of the participants said that their children began crawling at the age of eight months, and 12% (n=6) stated that it was at the age of twelve months. When asked when their children first started walking, 12% (n=6) said they didn't crawl but instead started walking right away, 34% (n=17) said they started walking at 12 months, and 14% (n=7) said they started walking at 18 months.

When participants were asked about the babbling period, which is an important period in children's language development, 12% (n=6) of the participants stated that their children's babbling started at the 10th month, 8% (n=4) said that it was at the 8th month, and 8% (n=4) expressed that it started in the 7th month. In addition to these responses, 6% (n=3) of respondents said '*I don't recall*' and 4% (n=2) said '*there was no babbling.*' When it came to first word production, 34% (n=17) of the participants said their children started saying their first words at the age of 12 months, and 12% (n=6) stated that it was at the age of 18 months. The most common responses when asked what these first words were '*mother, father, grandfather, mama.*' The amount of families who are unable to recall when their children first spoke is likewise extremely significant (54%, n=27).

The open-ended question "*Did you observe any differences till your child was 18 months old?*" received 66% (n=33) positive responses(yes) and 34% (n=17) negative responses(no). Participants who said '*yes*' were asked what kinds of differences they noticed, and the results are listed in Table 4.

Table 4. The differences till the child was 18 months' old

	%	n
No eye contact	47,1	16
Not responding to the name	32,4	11
Indifference to parents	20,6	7
Sensory sensitivity	17,6	6
Sleeping problems	17,6	6
Excessive interest in rotating objects	17,6	6
Not responding to sounds	11,8	4
Not playing with toys	11,8	4
Obsession	11,8	4
Desire to be alone	11,8	4

	%	n
Excessive crying and discomfort	8,8	3
Feeding problems	8,8	3
Being calm compared to other children	5,9	2
Selective perception	5,9	2
No babbling	2,9	1
Trembling (Shaking) behavior	2,9	1
Excessive interest in English words	2,9	1
Poor perception	2,9	1
Atypical behaviors	2,9	1

When looking at Table 4, the behavior of 'not making eye contact' comes out on top with a rate of 47.1 % (n=16) among the behaviors that parents see as a difference in their children before the age of 18 months. This behavior is followed by 'not responding when their name is called' (32.4%; n=11) and 'indifference towards parents' (20.6%; n=7). "We experienced difficulty during the complementary meal time," "my child was picky about every food, my child did not take it into his mouth", and "My child was celiac" were among the statements given by individuals who observed their children having feeding challenges in the first 18 months. "My child was screaming and crying while washing hands with cold water," one participant responded, indicating that her child showed sensory sensitivity. Another participant said, "my child would focus on the washing machine for a long time" and "my child would repeatedly rotate the objects that he could turn with his hands," referring to her child's extreme interest in rotating objects. In addition, some participants stated that "my child would be more interested in the tiny features of toys than playing with them" and "my child would use toys out of the purpose."

Table 5. Differences before the diagnosis

	YES		NO	
	%	n	%	n
Having problems in taking and trying foods after 6 months	40	20	60	30
Exhibiting differences in the first 18 months	66	33	34	17
Cooing in the first 2-3 months	74	37	26	13
Babbling similar to typically developing children*	78	39	12	6
Difference in vegetative sounds (crying, sneezing, coughing, laughing etc.)	18	9	82	41
Interest in other adults or other children	40	20	60	30
Making eye contact or pointing to initiate communication	66	33	34	17
Exhibiting stereotypical behaviors (shaking, etc.)	60	30	40	20
Showing intimacy (hugging, kissing, smiling) to family members	82	41	18	9
Enjoying hugs from family members	88	44	12	6
Being happy to be hugged by other people*	26	13	52	26
Reacting when name is called *	68	34	28	14
Imitating the sounds heard in the environment (animal, vehicle, etc.)*	26	13	72	36
Playing with toys (with family members)	62	31	36	18
Playing with toys (with other people)*	10	5	78	39

* Items from the participants with the response "I don't remember"

Each item in Table 5 about the behaviors noticed prior to the diagnosis was offered to the participants with a 'Yes' or 'No' choice, and the results are shown in the table as percentages and numbers. After the first six months, 40% of the participants (n=20) said they had difficulty taking and trying foods other than breast milk. Some of the participants answered this question with the "my child was vomiting frequently, then we discovered he had celiac", 'Only breastfed until 2 years old', 'After 8 months, the issues began', They also gave the answers of "We were force-feeding" and "my child vomited often, my child always ate in the form of puree" statements as additional information.

The sounds described as cooing were heard by 74% (n=37) of those who took part in the interview. 78% (n=39) of participants said "Yes" to the question "Was your child's babbling normal/typical?" while 12% (n=6) said "No." 8% (n=4) of the participants stated that they had no idea and 2% (n=1) stated that their babbling stopped following the febrile convulsion. There is a difference in the natural sounds of their children such as crying, sneezing, coughing, and laughing, according to 18% (n=9) of the participants. When asked what these differences were, the participants gave the following responses: 'my child had strange and illogical laughter', 'my child had an uncontrollable cry', 'my child was sobbing all the time', 'my child didn't seem to be laughing, even though my child was smiling', 'my child didn't seem to be laughing at the proper thing', 'my child was crying for no apparent reason'. 66% (n=33) of the participants indicated their children communicate with them through making eye contact or pointing to items. When asked if their child reacts when their name is called, 68% (n=34) responded 'Yes', 28% (n=14) said 'No', and 4% (n=2) said 'Sometimes'. 72% of the participants (n=36) stated that their children could not imitate the sounds of cats, dogs and cars they heard in the surroundings. Only 2% (n=1) indicated her child could imitate on occasion.

The majority of the study group's participants (60%, n=30) reported seeing stereotyped behaviors in their children. 'Swinging, hand obsession, trembling, flapping their hands like butterflies, opening and closing their hands, waving rope, shaking hands' were the most common responses when questioned about the observed behavior. 82% (n=41) of the participants said their children demonstrate affection for family members by smiling and hugging them. When the question "Was your child happy to be hugged by family members?", 88% (n=44) answered "Yes"; when asked "Was your child happy to be hugged by other people?" This percentage dropped to 26% (n=13). Furthermore, 22% (n=11) of the participants said that their children were occasionally glad to be embraced/hugged by strangers. 62% of the participants (n=31) stated that they try to pick up their children's toys and play with them, however, when the participants were asked the question 'Did your child try to play with other people?', this rate decreased to 10% (n=5). In addition, it was discovered that 12% (n=6) of the participants answered "Sometimes" to this question.

Table 6. Behaviors of the child when the child cannot explain himself

	%	n
Behavioral problems (crying, hitting to him/herself etc.)	64	32
Using gestures	30	15
Guidance by holding the parent's hand	14	7
Staying silent	6	3
Repeating what he/she says	2	1

'What was your child doing when he couldn't explain himself?' and "How did he behave?" questions were presented to the participant. They responded differently. 'Behavioral problems' was the most commonly given response. One of the participants answered this question as "My child already explains him/herself very well and expresses his/her wishes". Table 6 contains detailed information about the responses.

DISCUSSION

In this study, data were collected to determine the atypical language and communication behaviors that parents of children with autism may have observed/noticed in the pre-diagnosis period.

According to the literature, people with language issues have a higher prevalence of language and speech disorders in their family history (Koyuncu and Mercan, 2019), the first child is more likely to be diagnosed with autism (Balkır, 2019; Ünver and Memik, 2019; Doğan, 2019), and boys have a higher risk of developing autism (Töret and Özkubat, 2013; Aslan, Cihan and Altın, 2014; Selimoğlu, Özdemir and Şekeroğlu, 2018). Unlike previous research findings, the majority of the participants in this study (n=41, 82%) did not have language or speech impairments in their families, and the children identified with autism were typically the second child (n=26, 52%). The fact that the majority of the children diagnosed in the present study are male (68%; n=34) is consistent with the findings of the literature. At 12 months, 24% (n=12) of participants noticed differences in their children's development for the first time, 18% (n=9) of them noticed at 18 months, and 14% (n=7) of them noticed them at 24 months, according to this study. Many other studies have also found that parents detect the first indicators of autism in their children before they reach the age of 24 months (Zwaigenbaum, 2001; Prater and Zylstra, 2002; Bıçak, 2009; Guinchat et al., 2012; Selimoğlu et al., 2013; Turan et al., 2020). The age of diagnosis of autism is found to be 2.6-3.0 in this study (40%). This conclusion is supported by numerous research in the literature (Brewer et al., 2003; Top, 2009; Selimoğlu et al., 2013; Aslan, Cihan and Altın, 2014; Servi and Baştuğ, 2018; Akkuş et al., 2020).

It is expected that a child with typical development begins to sit without support when he/she is 9-10 months old (Tekin, 2016), crawl in 8-10 months, and walk in 12-18 months (Kahriman, 2007). Individual variances, on the other hand, can cause variations in these stages. Some babies begin walking at the age of eight months, while others may not begin walking until they are eighteen months old (Ergin and Yıldız, 2017). In children with typical development, tooth eruption generally begins at 5-10 months (Arikan and Bekar, 2020). The first words emerge between 8 and 18 months in children with typical development, and on average in the 12th month (Karacan, 2020). In our study, as a result of the analysis of the answers given to the general development questions asked to the participants about the children diagnosed with autism, the age of onset of sitting without support was found to be \bar{x}

= 7.42 months; teething age was found to be \bar{x} = 7.93 months; crawling age was found to be \bar{x} = 9.63 months; walking age was found to be \bar{x} = 14.24 months; the age of babbling was found to be \bar{x} = 7.64 months and finally the age of saying the first word was found to be \bar{x} = 16.33 months. 12 months for unsupported sitting, 12 months for teething, 18 months for crawling, 27 months for walking, 18 months for babbling, and 60 months for first words are the maximum values. The first words in the children of the study participants come on average at the age of 16 months, with a range of 6 to 60 months. The values in the literature regarding the months and the findings obtained in the research differ at some points. Individual differences can explain this condition, but according to the literature, it is assumed that it is primarily due to the fact that autism produces variances in general development.

According to published research, the time for parents to notice changes in their children varies greatly. According to Crane et al. (2016), 17% of parents noticed autism symptoms in their child's first year of life, 34% in the second year, and 33% of them noticed between the ages of 2 and 5, while in the study of Bonniau et al. (2011), 82% of parents noticed autism symptoms before their child turned two. According to another study conducted in Turkey, the age to observe these differences has been estimated to vary between 1.5 and 4 years old (Selimoğlu et al., 2013). The times of observing the differences in each participant's children differed in this study.

Single words such as "mama," "dad," "grandfather," "bye bye" and "mama" are among the child's first meaningful productions. (Baytar, 2014). This and other related information in the literature, as well as the results of our study, are all in agreement. Babbling appears about the middle of the sixth month, according to Charlier and Juhem (2007), although Alam Samsul (1998) claims that babies less than six months do not have substantial babbling and that the best babbling period is between 6 and 12 months (as cited in Tarcan, 2019). Based on the information gathered from the study's participants, it can be concluded that the onset of babbling in children with autism, which occurs at an average of 7 months, is relatively similar to typical development. Despite the fact that babbling occurs at a normal pace in this study, there is evidence in the literature that the development and patterns of babbling in children with autism differ from those in typically developing children (Landa and Garrett-Mayer, 2006; Ozonoff et al., 2011). However, just a few of the participants claimed that their children's babbling has various productions. The production of first words in children with autism was likewise observed to be considerably delayed (\bar{x} = 16.33, SD = 10.92) in this study. The minimum and maximum values were found to be quite diverse according to the typical developmental stages, despite the mean values being similar to the literature findings. The minimum values, in particular, show exceptionally early onset values when compared to typical developmental phases. This has led to the conclusion that families are in a complex situation in terms of remembering or general development awareness. The age of the child with autism, as well as the child's birth order and the participant's emotional condition, are likely to have contributed to this conclusion.

Bonniau et al. (2011) reported that the majority of parents observed deficiencies in social and communication skills well as numerous behavioral issues in their children as the first differences. The most noticeable difference that parents noted was that their children did not make eye contact and did not react when their names were called. Parents began to observe some certain differences in their children at the age of 9 months in another study by Brewsee, Pattison, and Young (2003). The first observed differences are avoidance of eye contact and indifference towards toys. Individuals diagnosed with autism have trouble making eye contact and display stereotypical behaviors, according to practically all autism studies. The primary difference noted by families in children with autism up to 18 months of age is not making eye contact, according to the associated replies in this study. Furthermore, in terms of language development, it was discovered that the production of first words was the most differentiated and delayed developmental stage before first 18 months. However, despite the fact that the production of first words was delayed, it was discovered that the first words were words like 'mother, father, grandfather', and 'mama' in this study, which was similar to the literature findings. Because habits like not establishing eye contact, acting stereotypically, and indifference are associated with autism and can be witnessed in a concrete sense, it's simpler to detect them. Information about autism on various platforms is also shaped within the framework of these behaviors. As indicated in the introduction, several studies have found that, in addition to behaviors like 'not making eye contact' and 'indifference', there are other less concrete behaviors such 'unusual vocalizations' and 'the lack of typical development of turn-taking abilities'. The information given on various platforms should be integrated with given findings.

Various research has indicated that children with autism spectrum disorder experience dietary/feeding issues such as food selectivity and food rejection (Schreck, Smithin, and Williams, 2004; Sarı and Bahçeci, 2012). In this study, parents reported that their children had some feeding issues. This condition may have arisen as a result of sensory sensitivity or other factors in individual with autism. According to the responses, the families were aware of the condition but did not take any precautions or seek help from a professional until the diagnosis was made. Behaviors observed by parents such as disinterested behavior towards toys and the environment, improper use of toys, excessive attention to certain objects or toys (for example, high intensity or focus) are also consistent with the findings of the research (Gillberg et al., 1990; Guinchat et al., 2012; Selimoğlu et al., 2013; Sichertman et al., 2019).

Finally, a review of the literature reveals that the symptoms experienced by families in their children span a wide range of developmental areas. In some research, the first symptom noticed by parents in their children was about language and speech development (De Giacomo and Fombonne 1998; Selimoğlu et al., 2013), whereas Crane et al. (2016) discovered these variations

in the area of social interaction. The differences seen by the families were in the area of social contact, according to the findings of this study. Families noticed changes in language and speech development later in development, according to the findings.

The results of the open-ended questions and the results of the item-by-item yes-no questions differed. As a result, parents who indicated there was little difference before the diagnosis when asked an open-ended question said they noticed significant differences when answered yes-no questions. Both sorts of questions elicited contradictory responses. This is assumed to be owing to a lack of understanding of general developmental phases.

CONCLUSION AND RECOMMENDATIONS

With the discovery that the pre-verbal stage is actually extremely essential, the focus on exclusively verbal activities for autism diagnosis has shifted. According to the findings of this study, the majority of families did not notice any notable variations in their children's development throughout the preverbal stage, and reported that their children's development developed in a comparable manner to that of children with typical development. While they assumed their children were developing typically, their families were shocked and upset when they were diagnosed with autism.

The lack of observation of differences in elements such as gesture, joint attention, game ability, and social orientation during the preverbal period of language development is assumed to be attributable to a lack of awareness. Parents who know when their children crawled and walked are often unable to recall when they said their first words. This result could have been influenced by the fact that concrete behaviors are more persistent and observable. However, it may be important to bring attention to the lack of interest in language development as well as knowledge of the subject. As a result, it is suggested that language and related factors be studied more closely and that awareness-raising research be conducted to gather understanding.

Many projects to inform people have been launched as a result of today's technology advancements, and these activities are continuously growing. Informative sharing and online meetings are held by various professionals (doctors, speech and language therapists, teachers, special education specialists, psychologists, child development specialists, etc.) and organizations-communities (about general development: *Anne-Baba-Çocuk Eğitim Projesi, Kadın Emeğini Değerlendirme Vakfı (KEDV), Ana Baba Okulu, Benim Ailem Projesi, Mobil Anaokulu Projesi, Aile Mektupları Projesi, e-Bebek Uzman Bilgisi, KU Dil ve İletişim Gelişimi Laboratuvarı, BOUN Bebek ve Çocuk Gelişimi Laboratuvarı*; about autism: *Tohum Otizm, İstanbul Otizm Gönüllüleri Derneği, Otizm Vakfı vb.*) in different platforms and also training programs (*FLOORTIME, MEB Otistik Çocuklar Eğitim Programı, Otistik Çocuklar için Davranışsal Eğitimi Programı [OÇİDEP]* etc.) on the subject are also being offered at the same time. Guidance to these information events and activities is regarded to be effective in raising family awareness and knowledge about language development. Professionals who work with families bear a significant amount of responsibility in this regard. Professionals may inform families themselves about the developmental areas or inform them about the programs and social media profiles listed, as well as promote and propose activities that assist language development that parents can perform with their children at home. As understanding grows, early detection and intervention may become possible. In addition, efforts can be done to address future possible behavioral issues caused by the child's failure to meet his or her growing communication needs.

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The author(s) hereby declare that the study has not unethical issues and that research and publication ethics have been observed carefully.

Researchers' contribution rate

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Literature Search: Ö.O., A.Ş., B.Ç.; Writing: Ö.O., A.Ş., B.Ç.; Translation: Ö.O.; Review: Ö.O.

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Ethics committee approval for the study, dated 27/05/2020 and numbered 61351342/2020-271, was obtained from the Üsküdar University Non-Interventional Research Ethics Committee.

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