



ISSN: 1999-5601 (Print) 2663-5836 (online)

Lark Journal

Available online at: <https://lark.uowasit.edu.iq>

*Corresponding author:

**Assit. Lecturer. Amani
Noori Saeed Mulla Khassaf
Dr. Alaa Ashour Khalaf Al-
Hussein**

University: University of Basrah
College: College of Arts
Email:

amani.saeed@uobasrah.edu.iq
: alaa.khalaf@uobasrah.edu.iq

Keywords:

Autism; early predictors of
autism; autism awareness;
communication impairments;
developmental milestones.

ARTICLE INFO**Article history:**

Received 24 Feb 2023
Accepted 21 Sep 2023
Available online 1 Oct 2023



The Lack of Awareness of Early Predictors of Autism by Iraqi Parents: A Qualitative Approach

A B S T R A C T

Autism is a worrisome, growing worldwide phenomenon. The awareness of early signs of autism by parents, being the primary caregivers, is of paramount significance in early identification, diagnosis, and intervention. This study is conducted to assess Iraqi parents' lack of awareness of autism and its negative effects on the prevalence of autism in Iraq. It might represent the first study reporting the lack of awareness of the basic features of autism among Iraqi parents whose children are late diagnosed as autistic. A self-designed online questionnaire was launched to parents of autistic children from different Iraqi regions to collect data on their perception and awareness of the initial signs of autism. The questionnaire aims to evaluate the parents' recognition of early developmental abnormalities, including interaction, behaviours, and verbal and non-verbal communication. The results show that very little is known and thus observed about the early symptoms and behaviours of autism by Iraqi parents. Therefore, unfortunately, mostly months or even years often elapse between the time the child starts manifesting signs of autism and the time of his/her diagnosis and treatment. This delay in the parent's concerns, awareness of their autistic children's abnormalities, and medical consultation contributes to the late diagnosis and consequently to the prevalence of autism. The researchers posit that this lack of awareness of autism can be due to the poor knowledge of the basic child developmental milestones among Iraqi parents, the deficient educational media coverage, and the scarcity, if any, of on-ground courses about autism in Iraq.

© 2023 LARK, College of Art, Wasit University

DOI: <https://doi.org/10.31185/lark.Vol3.Iss51.2991>

ندرة الوعي بالمشورات المبكرة للتوحد من قبل الآباء العراقيين: مقارنة نوعية

أماني نوري سعيد ملا خصاصف/جامعة البصرة / كلية الاداب
علاء عاشور خلف الحسين (دكتوراه)/ جامعة البصرة / كلية الاداب

الخلاصة:

يعد التوحد ظاهرة مقلقة وسريعة الانتشار في جميع انحاء العالم. إلا أن معرفة الوالدين بالعلامات المبكرة لهذا الاعتلال له أثر كبير في التشخيص والتدخل العلاجي المبكر. لذا جاءت هذه الدراسة لتقييم مدى وعي الوالدين باضطراب طيف التوحد وتأثير غياب هذا الوعي على ارتفاع حالات التوحد في العراق. وقد تعتبر

هذه الدراسة الأولى من نوعها من حيث أنها ترصد حالة غياب المعرفة باضطراب طيف التوحد من قبل الآباء العراقيين الذين تم تشخيص ابنائهم بالتوحد في وقت متأخر. وقد أعد الباحثان استبانة عبر الانترنت، لمخاطبة آباء الاطفال المصابين بالتوحد، المنتمين الى مناطق عراقية مختلفة، لجمع البيانات المتعلقة بإدراكهم ووعيهم بالعلامات الاولية للتوحد. كما وتهدف هذه الاستبانة أيضا الى تقييم وعي الآباء باضطرابات النمو المبكرة لدى أطفال التوحد مثل القدرة التفاعلية، والأنماط السلوكية، والتواصل اللفظي وغير اللفظي. إن معظم الأطفال المعنيين في هذه الدراسة لم يتلقوا التشخيص حتى بلوغهم سن دخولهم المدرسة، أي حوالي خمس إلى ست سنوات، وهذه مرحلة متأخرة جدا في التشخيص. وقد أظهرت نتائج البحث أن معرفة الآباء العراقيين بالمؤشرات المبكرة للتوحد عند أبنائهم ضئيلة جدا، لذلك، ولسوء الحظ، غالبًا ما تنقضي الأشهر وربما السنوات بين الوقت الذي تظهر فيه علامات التوحد والوقت الذي يتم فيه التشخيص والعلاج. ولقد أثر هذا النقص المعرفي لدى الآباء سلبا على الأطفال المصابين بالتوحد، وذلك لتأخر الآباء في اللجوء إلى الاستشارة الطبية وبالتالي تأخر التشخيص وتفشي الحالات. ويفترض الباحثان أن أسباب هذا النقص في الوعي باضطراب طيف التوحد من قبل الآباء يمكن أن يرجع الى ضعف المعرفة بالمراحل الأساسية الطبيعية لنمو الطفل عموما، ونقص التغطية الإعلامية التربوية، وندرة الدورات الميدانية التوعوية حول هذا الاضطراب في العراق.

الكلمات المفتاح: التوحد، المؤشرات المبكرة للتوحد، الوعي بالتوحد، اضطرابات التواصل، مراحل النمو الأساسية.

1. Introduction

Autism is a set of complicated neurodevelopmental disorders that usually emerges in the first two years of a child's life. It affects the child's ability to communicate and behave normally. The National Institute of Child Health and Human Development (2001) reports a prevalence rate of 91 per 10,000, with boys being more likely affected than girls. Early childhood, which includes the period from birth to eight years, is the basic developmental stage throughout the child's lifespan. Among the first and most important of all child developmental phases are the sensory processing skills. Sensory processing refers to "the child's ability to feel, understand and organize sensory information from his body and environment" (Emmons and Anderson, 2006, p. 14). Usually, sensory integration occurs naturally in most children, where they receive

information from their five senses, organize it, and respond accordingly. Studies report that most children, by the first year of age, can join attention with people and things and make interactional communication through sounds and gestures (Bates, O'Connell, & Shore, 1987). Locke (1978) similarly suggests that joint attention usually appears early in the first year of the child's life and forms the core ground for later communicative skills. It can be initiated by "deictic gestures" such as showing, pointing, and using demonstratives and personal pronouns (Clark, 1977). Thus, with the increased prevalence of autism among children worldwide, it becomes crucial that parents should have sufficient knowledge of the child's normal developmental milestones; the behaviour or an absence of it may appear at a certain period of time, then its persistence or otherwise regression at a later time can signal a developmental disorder. Moreover, knowledge of early signs of autism by parents is of an outstanding effect on its early diagnosis and treatment. Retrospective reports by parents of autistic children on the recognition of developmental impairments in autism propose that nearly 30% to 50% of parents notice developmental abnormalities as early as 8-12 months, while approximately 80% - 90% recognize such impairments by 24 months and more (De Giacomo & Fombonne, 1998). This delay in recognition of developmental impairments has adverse effects on the child's status and the therapeutic process. Research, based on parents' retrospective reports as well as prospective studies, has sought to identify the early signs that help in the prediction of early diagnosis of autism. For example, Zwaigenbaum (2010) lists a group of changes in various developmental aspects that could distinguish the onset of autism at 18 months. These are atypical eye gazing, inability to orient to names, poor imitation, feeble smiling, atypical reactivity, and abnormal social and emotional responses, in addition to motor, communication, and cognitive delays problems. Early recognition and detection of autism would be of great importance as it would allow for early treatment that aims at minimizing or even avoiding secondary developmental disturbances that appear as sequelae to the disorder, such as atypical behavioural and/or cognitive development (Mundy and Neal, 2001).

Autism, then is believed to be multifactorial, meaning that several risk factors work together to result in the condition. For example, MRI (magnetic resonance imaging) studies have shown abnormal brain structure, function, and development in autistic children that could be attributed to defective genes (Belmonte et al., 2004; Verhoeven et al., 2010). However, no matter what the cause is, the probable effective remedy and cure for autism so far is early diagnosis, followed by continuous and intensive special education and rehabilitation. The study, therefore, adds to the

limited literature of studies about autism in Iraq as regards parents' lack of awareness of early signs of autism and its negative impact on their autistic children's early diagnosis and treatment.

2. Prevalence of Autism

Autism has been described as the largest growing disability reported by school personnel (A report by US Department of Education, 1999). Reported prevalence rates have increased steadily over the past four decades. In 1978, the estimated number of children diagnosed with autism was 4 in 10,000 (Rutter, 1978). The California Department of Health and Human Services (1999) declared a 273% increase in the estimated number of children with autism from 1987 to 1998. From 1996 to 2004, the prevalence of school-aged children diagnosed with autism in Canadian British Columbia increased from 1.2 per 1,000 to 4.5 per 1,000 (Coo et al., 2008). Baron-Cohen et al. (2009) also recorded that the estimated rate of autism prevalence in UK primary school children is 157 per 10,000. In 2014, however, The Centre for Disease Control (CDC) (2020) reported autism prevalence in the US as nearly 68 per 10,000, while the National Autistic Society accounts for a prevalence of 91 per 10,000. Furthermore, it has been noted that the annual economic cost of autism care in the United States and the UK was very high (Knapp, Romeo, & Beecham, 2007). These alarming data have caught the attention of researchers and practitioners to view autism as an "epidemic" (Murray and Silverman, 2012; Isaksen et al., 2013).

Unfortunately, very little attention has been paid to the study of autism and its epidemiology in developing countries. In Iran, for example, Ghanizadeh (2008) reported a rate of 190 per 10,000 autistic disorders in school children; a number that exceeds the registered rates across the world. In Iraq, however, there is a severe lack of reliable statistical methods and systematic data concerning the prevalence of autism spectrum disorders. These variations in number are mostly caused by variations in the age of persons, diagnostic tools and criteria, parents' lack of awareness, and the unawareness of medical institutions and clinical professionals, especially in developing countries.

3. Early Manifestations of Autism in Children

The International Classification of Diseases (1992) proposes that the early signs of autism must appear before 36 months of age. Even earlier, studies point out that autistic children manifest behavioural and developmental impairments from 12 months of age (Rogers & Di Lalla, 1990;

De Giacomo & Fombonne, 1998; Beshalova & Buxbaum, 2003; among others). The impairment manifestation patterns, however, vary extensively, from one person to another. For example, some autistic children show aspects of developmental deviations from birth. In contrast, other children develop normally during the first year of age but exhibit speech and language disorders in the second year (Goin & Myers, 2004). Regardless of the onset of the deficits, research confirms that the majority of autistic children show early signs of developmental impairments before year 2, which means that a reliable diagnosis of autism on the second birthday is definitely possible (Charman & Baird, 2002; Lord et al., 2006).

The core features of autism can be categorized into three main types: Communication delay and/or disorders, social unrelatedness, and repetitive/stereotyped behaviours.

3.1 Communication Impairments (speech and language)

Among the basic and most noticeable features of autism are communication impairments (American Psychiatric Association (APA), 2014). Knowledge about the normal developmental milestones of speech and language is vital theoretically and practically in the field of autism. Speech and language developmental milestones, as shown in **table 1**, progress from the early stages of cooing, babbling and producing some words and word combinations, toward normal language usage and understanding. It is necessary that parents have the knowledge and understanding of these milestones to be able to recognize if their children exhibit speech and language delays. Usually, parents of autistic children are the first to recognize if something goes wrong with their child and thus refer him/her to evaluation due to speech delays or regressions in communication development (Short & Schopler, 1988). The presence of speech and/or language deficit or delay is a clear indicator of developmental impairments. Szatmari et al. (1995) also point out that autism symptoms can clearly be predicted in children by language milestones in less than 4 years of age. These language milestones include atypical vocalizations, speech delay, persistent echolalia, and pronoun reversal. For example, typical children learn only a few words between 12 and 16 months and usually produce an average of 4 new words per day between 2:5 and 6 years (Fenson et al., 1994). Therefore, a clear delay in language acquisition in autistic children can be diagnosed when first words are mostly produced at later stages of age compared to typically developing children who normally produce few words between 8 and 14 months. Thus, waiting until the age of 38 months to produce a few basic words is marked as a speech delay impairment (Howlin, 2003).

In addition, it has been noted that nearly one-quarter to one-third of the parents of children with autism report that their children appeared to be developing normally during the first year of age and then experienced a regression in certain aspects of development at 13 to 24 months of age. Lord et al. (2004), for instance, confirm that there is an absence of single words production in nearly 50% of children with autism. Moreover, new words may be used by a child a few times and then disappear. This phenomenon of word regression and loss seems to be specifically related to autism.

Another communicative deficit that manifests in autistic children is “**echolalia**”. Echolalia means the delayed imitation (echoing) of words they have heard either from people around or from TV cartoons and programs after a period of time has passed (Tager-Flusberg & Calkins, 1990). Thus, it is highly important that parents refer to professionals for immediate diagnosis when the child is not babbling and gesturing by 12 months of age, not producing single words by 24 months, or if there is any sign of spontaneous language loss or social interaction at any age.

Table 1: Normal developmental milestones of speech and language in children.

Age	Communicative skills
6 months	Turn to sounds and voices, laugh, vocalize (coo)
9 months	Babble; make single syllables, utter “mama”, ‘dada’, ‘baba’
12 months	Follow single commands, initiate new sounds, utter single words, may wave ‘bye-bye’
15 months	Utter one-to-three words
18 months	Make simple pointing and utter three to six words.
2 years	Make advanced pointing, combine words, and name things.
2.5 years	Point to body parts, know some actions and speak partially understandable words.
3 years	Know two adjectives, name one color, and speak nearly fully understandable words.
4 years	Define five words and name four colors, and speak fully understandable words and sentences.

Adapted from Green & Palfrey (2000). Bright Futures: Guidelines for Health Supervisions of Infants, Children, and Adolescents.

3.2 Social Impairments (attention and interest)

The second vital area in which autistic children encounter problems is social interaction. Studies show that typically developing children demonstrate social interaction skills like gazing at people, turning toward voices, smiling, etc., from the early days of life. Rochat and Striano (1999) recognize that typical infants display remarkable attention to social stimuli, such as sounds, movements, human faces, etc., as early as the first 6 weeks after birth. At the age of 5 months, most typical infants show sensitivity to even small deviations in adults' eye gaze during social interactions (Symons, et al., 1998). In contrast, children with autism are usually unable to initiate and/or maintain eye contact during an interaction. In addition, research assures that by 12 months of age, most children with autism show atypical social attention and weak responsiveness to events and people around them (Yoder et al. 2009; Ozonoff et al., 2010). Bodgashina (2005) states that one of the early features of autism is a lack of body-to-environment responsiveness. For example, families of autistic children mostly complain that their child seems to be unresponsive to callings, to the extent that they expect him/her to be deaf (Baranek, 1999).

Moreover, joint attention acts were also reported via retrospective studies as being impaired in autistic children less than 12 months of age. The American Psychiatric Association (2004) considered joint attention as one of the early-emerging social impairments presented in autistic children as early as 1 year of age. Joint attention has been described as the ability to refer to the same stimuli shared by another person through following their gaze, pointing, showing, etc. (Bodgashina, 2005). Key et al. (2015) point out that the absence of joint attention discriminates infants with ASD from typically developing ones as early as their first birthday. This inability to engage in joint attention limits their cognitive and communicative development as well as their social interactions as they miss the use of normal nonverbal social cues (Charman, 2003). All of these skills are usually displayed by most infants by 12 months of age, as reported by Carpenter et al. (1998). Deutsch and Urbano (2011) also indicate that a 10-month-old child usually follows adults' gaze when they look at an event or object. This developmental skill is known as "gaze monitoring" (ibid, p. 5). Children with autism, however, are supposed to lose the ability to divide their attention between the targeted object and the person who communicates about it due to an

inability to shift attention by perceiving attention-cueing signals, or an innate inability to recognize people.

In a retrospective study, Rozga et al. (2011) point out that children who have been later diagnosed with autism were unlikely able to engage in social interaction or recognize and respond to social stimuli during infancy. Moreover, Swettenham et al. (1998) report that autistic children have fewer and shorter overall looks at people than objects.

Explaining the reality of social disturbances in autistic children, Bogdashina (2005) claims that the early emergence of sensory problems (impairments in information perception and interpretation) in the child's life causes a kind of social and environmental overload on him/her forcing them to resort to self-isolation and "self-imposed sensory deprivation" where they start losing connection with people around them (ibid, p. 89). This emotional and social withdrawal and isolation from people usually start before the age of three (Feinstein, 2010).

3.3 Behavioral dysfunctions (behaviors and imagination)

In comparison with communication and social impairments, behavioral disruptions may be less commonly recognized in the early stages of development in autism. Still, several studies have reported that abnormal behaviors and a lack of imaginative skills in children with autism occur between 12 and 36 months. For example, repetitive/stereotyped behavior (including repetitive plays and movements) represents the early behavioral manifestation of autism in children (Loh et al., 2007; Christensen et al., 2010). Deutsch and Urbano (2011) state that autistic children exhibit resistance to change, and they have a special interest in routines and sameness to the extent that any interruption might cause them emotional disturbance and aggression.

Other unusual behaviors that may indicate early signs of autism are atypical movements, such as hand-flapping, twisting, and rocking; preference for being alone, avoiding looking at others, no mutual smiling, spinning in circles, unpredictable screaming, lack of awareness of danger; lack of imaginative play skills; atypical sensory behaviors, such as hyper or hyposensitivity to sounds, taste, touch, and visual stimuli. Such dysfunctional behaviors happen nearly during the second to third year of age (Volkmar & Kiln, 2005).

4. Is Early Diagnosis of Autism Possible?

Although autism is a persistent and chronic disorder, as clinicians claim (Howlin, Mawhood & Rutter, 2000), early diagnosis and intervention are possible “if the child is picked up early” as Bogdashina (2005, p. 199) puts it. Cbakraharti et al. (2005) claim that developmental impairments usually appear early in infancy and maybe even present from birth, and autism is no exception. For instance, Matson et al. (2008) stated that about 50% of parents notice autism symptoms in their children by age 2, while around 93% of parents reported autism signs recognition in their children by age 3. In addition, Baird et al. (2001) strongly believed that autism can be diagnosed at 2.7 years of age. Early recognition of initial symptoms and early diagnosis of autism can highly improve opportunities for early treatment (Dawson, 2013). Savucu (2020) believes that in approximately 50% of the children who received the right training after early diagnosis, symptoms of autism decreased apparently and considerable improvement is observed. Thus, knowing the initial unusual developmental features of autism during early childhood has a great impact on intervention efficiency and timing.

Recently, the American Academy of Pediatrics (2021) has recommended that all 1.5–2.5-year-old children should get screened for autism spectrum disorders. Further, both the general public and healthcare institutions should also increase their awareness of the detection of autism, meaning that they all need advances in early diagnostic procedures and tools to achieve early diagnosis and protection. During the early seventies, autism was diagnosed at age 4 due to limited diagnostic tools. Recently, however, research confirms that autism can be identified and diagnosed in the 2nd year of the child’s life (Moore & Goodson, 2003) or even younger (12-15 months) (Klin et al., 2004).

In a seminal study, Rogers and Di Lalla (1990) examined the earliest manifestations of autism as reported by mothers of 39 children diagnosed with autism. Among the basic symptoms parents reported during the first year of their child’s life is abnormal temperamental characteristics as children were described as passive and very difficult to deal with. Other reported signs included erratic physiological acts, inability to be soothed, and/or being too quiet, undemanding, and very satisfied to play alone in their bed. Furthermore, Videotape Analysis Studies prove to be very beneficial in determining features of typical versus atypical child developmental patterns. Several studies of home video analysis show that infants with autism are easily differentiated from their typical as well as developmentally delayed ones in the very first year of life (Volkmar

& Klin, 2005). For instance, Maestro et al. (2002) analyzed videotapes of six-month infants who were later diagnosed as autistic to compare their results with the other typical control group. They found that typically developing infants engage naturally in visual attention and show affective responsiveness to various stimuli. In contrast, autistic infants videotaped showed less visual attention to people, less vocalization, limited mutual smiling as well as poor response to their names. These results indicate that the characteristics of autism appear from the early months of life when infants show limited sensitivity to outside stimuli compared to typically developing ones. Thus, early detection and diagnosis of autism are possible, workable, and useful.

5. Methodology

5.1 Participants:

Sixty parents of autistic children from different urban areas of Iraq participated in this study. Eight participants were males (fathers) and fifty-two were females (mothers) with 75% having a boy with autism and 24% having a girl. All parents report having just one child with autism except one who stated to have another baby boy diagnosed with autism at 6 years of age. All participants, except four, are of university educational level.

5.2 Data Collection

A self-designed questionnaire was written in Arabic for the parents of autistic children and translated into English, as shown in Appendix A. It was constructed by the researchers and delivered electronically to the parents who showed consent to participate in this study. The Questionnaire is composed of 19 questions designed to assess the parents' awareness and recognition of early signs of autism as well as the diagnostic timing and procedures. Data were collected in 25 days. The researchers faced considerable impediments concerning the plain interaction with families of autistic children who mostly showed caution and embarrassment due to social and psychological factors, such as the unwillingness to admit to having an autistic child, even with the warranties of anonymity given to them by the researchers such as providing no names, no emails or any other private details in the questionnaire form. Such deterrents hampered many other parents from participating and made it hard for the researchers to have more participants.

5.3 Data Analysis and Discussion

Thematic analysis can, according to Braun and Clarke (2006, as cited in Gray, 2014, p. 609), be ‘inductive’ when themes are elicited from data without being affected by the researchers’ theoretical presuppositions, or otherwise, it is ‘theoretical’ as what we are following in this study. In addition, Bryman (2016, p. 584) alluded to the idea that thematic analysis can be influenced by the literature and influencing it.

After reading the parents’ responses multiple times for coding and thematizing, we could arrive at four major themes labelled, analyzed, and discussed next.

5.3.1 Theme 1: The Onset of the Recognition of Atypical Developmental Signs.

Mostly 85% of the participating parents, meaning 51 out of 60, reported late recognition of autism signs in their autistic children. The average age of their autistic children at diagnosis time was 4 years. Even worse, 11 children were diagnosed after the age of 9. Twenty-three mothers were unsure about the abnormal development indicators and thought their kids were just late in speech production. Later, at pre-school age, those mothers became more concerned that something was going wrong with their children. Twenty-eight parents, on the other hand, were plainly unaware that their children were different from the normally developing ones until some family members and/or relatives drew their attention to think seriously about their children’s abnormality. Only seven mothers and two fathers could detect early indicators of atypical development signs in their children as early as the second year of age and therefore resorted to referring them to pediatricians for clinical diagnosis and treatment. The common thread linking the parents’ responses with the late recognition of their children’s autism signs is their lack of knowledge of the basic developmental milestones in normal children. By acquiring such knowledge, parents can compare their children with the typically developing ones for early detection and diagnosis of abnormality (see 3.1 and Table 1 above for more details about these basic developmental milestones).

Commenting on the onset of autism signs in children, Ozonoff et al. (2010) point out that “the majority of [autistic] children display developmental abnormalities within the first 2 years of life”. Some children with autism, however, may display normal development in the first year and then exhibit a loss of communication and basic social skills between 12-18 months of age (ibid). Still, research literature reveals that children who are later diagnosed as autistic usually have

been manifesting symptoms of autism during infancy; these symptoms then increase a few years after the onset (Dahlgren and Gillberg 1989; Vostanis et al., 1998; Sheinkopf et al. 2000). Several retrospective studies, for example, Ohta et al. (1987), along with the home videos analysis of the children diagnosed later as autistic (Baranek, 1999) reveal that autism signs are observable and possible to be diagnosed by attentive parents during the first 2 years of the child's life. Dawson et al. (2010) report that infants who were identified as autistic between 18 and 24 months of age and directly received an appropriate developmental and behavioral treatment showed a remarkable improvement in autism severity in the next years. Similarly, early identification and treatment of younger children with autism between 18–48 months of age resulted in significant communicative, developmental, and behavioral improvements compared to the late recognition of autistic children, as demonstrated by Vivanti et al. (2016).

Further, a study by Baghdadi et al. (2003) points out that 30% of the parents were able to recognize that their children had atypical developmental signs prior to 1 year of age, and 80% of them could detect their children as having clear impairments by the second year of the child's age. These parental reports where early instances of autistic behaviors being detected as early as 6 months of age proved to be significant and successful in making early diagnosis and intervention possible for minimizing autism severity. Most of these detected observations include: limited eye contact which is considered vital to engage in joint-attention learning; inability to either recognize or use noises (human and/or nonhuman) communicatively; and a lack of interpersonal communicative engagement (Wimpory et al., 2000). By the second year of age, these initial symptoms become more noticeable as they progress to: inability to greet, weak visual attention, and restriction to repetitive behaviors. As a result, the earlier diagnosis, intervention, and treatment occur, the less autism severity and better gains are earned.

5.3.2 Theme 2: Limited Awareness of Autism among Parents

Although most of the parents in the study (41 out of 60) were at the university level of education, they had poor knowledge about early predictors of autism in their children. Only nine of them were able to early recognize atypical behaviors in their children. They had this prior knowledge of autism over the Internet and the media, with mothers being more knowledgeable about their children's condition than fathers. Having a poor perception of autism as a prevailing childhood disorder, nearly 80% of the parents in the study had a notice from family or relative members that their child was not behaving like normal children, while the rest of the parents were able to

identify some of the behavior deviations themselves. One of the mothers reported that “although I have been teaching school-age children for many years, I have not had any clues about autism or other developmental disorders.” Three other mothers related that they tried to ignore the condition and did not even ask for a diagnosis until their children reached school age, thinking that it was a normal delay. Other women told that they thought it could be a temporary stage rather than a developmental problem. Different factors may contribute to such poor knowledge of autism by parents, as they showed in their answers to the questionnaire. Chief among them are: limited interest by parents in clinical issues; poor, if any, educational programs about autism; and a serious lacking of overall public awareness of autism symptoms in our culture (Iraq). Likewise, examining the public awareness of autism, Alsehemi and his colleagues (2015) also pointed out that there is a poor awareness of autism among parents and educational staff in Saudi Arabia for almost the same reasons just mentioned. They, too, called for initiating educational campaigns to target public awareness and enhance knowledge about autism.

Recently, there has been a major increase in the prevalence of autism spectrum disorders in Iraq, as mentioned by the media and clinical staff, though unofficially stated, with no official statistics. During the last ten years, non-official rehabilitation centers have increased, too, and large numbers of children attended them in the hope of receiving the right and appropriate treatment programs. Afterwards, Iraqi people are supposed to be more aware of the prevailing condition of autism in the communities.

5.3.3 Theme 3: Misunderstanding of Autism as Speech/Language Delay.

Data collected in the questionnaire showed a fundamental misunderstanding about autism and speech/language delay by parents. Thirty-nine mothers reported speech delay as the initial symptom in the atypical development of their children. However, due to the lack of knowledge of autism, they misunderstood it as a simple developmental delay that should be spontaneously corrected later. “Our children used to speak late,” one mother reported, “so I took it for granted that my child followed his siblings’ trend!” The other five mothers compared their children’s language development with their peers of the same age and started having concerns about them, especially with the presence of other social communication impairments (see 3.2). Some other cases of autistic children reported by their parents (n=5) showed that their children were losing their ability to keep what they had already learned of the language production of words when their age was between 12-16 months. Those parents thought that it could possibly be a

developmental problem while it is another remarkable indicator of autism in early childhood, which they ignore as speech loss/regression (see 3.1).

Abnormal or delayed speech development is reported as the most common initial symptom of autism alongside social and behavioral dysfunctions. However, children diagnosed as only speech-delayed are usually socially related and don't have unusual behaviors akin to autistic children (Sheinkopf et al., 2000). Nevertheless, the lack of knowledge about other defective developmental functions may confuse parents, being the first observers, in having real concerns about the condition. Autism is different from a speech/language delay in that it has a variety of symptoms like poor eye contact, lack of joint attention acts, limited responsiveness, and unusual behavioral aspects, among others, that co-occur with language delay. Those symptoms appear to predate the speech delay problem that the participating parents identified as a merely developmental delay at the time of recognition. Importantly, retrospective parent interviews and home videos (as reported for example by Baron-Cohen et al., 1992 and Stone et al., 1999) revealed that several social milestones were also delayed or impaired during the first two years alongside speech delay (also see 4. & Theme1). These atypical behaviors include a lack of social referencing, poor eye contact, inability to orient to names and callings, and lack of shared imitation and attention.

5.3.4 Theme4: Fearing “labelling”:

One of the major barriers families in Eastern cultures face is stigmatic feelings toward mental and developmental disorders. Most parents refused to accept the idea of having a child labelled as abnormal. One parent, for example, clearly declared that they would rather keep their child at home, silent, and socially isolated than refer to a clinical practitioner and hear the word abnormal. This fear causes them to keep any problems within the family in the hope that things will become better without external support. This is exactly what 20 parents of autistic children reported in the questionnaire. One mother admitted that it took them 5 years to have the courage to just say that there is something “wrong” with their son due to the fear of “labelling” their child as “disabled” or “mentally retarded.” Another mother said that she was “resisting” the idea of “something atypical” about her child by trying not to be engaged in social gatherings so that others would not notice her daughter's behaviors. For most parents, having a clinical diagnosis for their children with the result of being “impaired” was a hard shock to cope with.

Consequently, those cultural constraints, such as fear and social stigma may discourage some parents from speaking up about their child's special needs in healthcare.

6. Results, Recommendations, and Conclusions:

The present study examines Iraqi parents' awareness of the early signs of autism and the effect of such awareness on early diagnosis and treatment. The study showed that nearly 80% of the parents had poor knowledge about the first "red flags" of autism prior to 3 years of age. The lack of awareness among parents and institutions resulted in both the prevalence of autism in Iraq and the complications of treatment efficiency. In addition, only 20% of the children received a diagnosis before the age of 4, also considered late, while others were diagnosed as autistic after the age of 5, worse further. By this late diagnosis, many signs of the disorders could have been missing by then, and the child could have lost an important chance for having an early intervention and treatment; this delay of diagnosis occurs due to the lack of knowledge and awareness of autistic early signs by both parents and inexperienced physicians. This highlights the considerable need for parents, especially being the first and direct surveillance, to be aware of the early symptoms and act upon increasing their knowledge about basic developmental milestones to quickly refer for evaluation and clinical assessment as early as possible. Early symptoms include disturbances and/or delays in communication (verbal and non-verbal), abnormal behaviors, loss of certain normal children's skills, and limited or absence of social interaction. Therefore, parents should seek assistance as soon as they notice such signs in their children.

Moreover, although autism prevalence varies within and between regions, there is a drastic rise in autism among children from 1 per 2000 during the 1970s to 1 per 54 in recent data as noted by Edelson (2021), with an average estimate of 1 per 160 children across the world, as stated by the World Health Organization (WHO, 2021). Given the unprecedented rise in autism and the devastating effects it can have on children, their families, teachers, and society in general, it is imperative that educating parents about child developmental disorders in general, and autism, in particular, should be the focus of the media, health institutions, and education programs attention to educate people and help families take the right measures. Parents' awareness of autism spectrum disorders should also be enhanced through planning different educational programs to be offered publicly in childcare centers and preschools to ensure early recognition of any deviated developmental behaviors. In conclusion, early identification and diagnosis will

definitely help in providing proper intervention during a period of brain plasticity (early childhood) which in turn prevents secondary developmental, behavioral, and social disorders.

References

Alsehemi, A. M, Abousaadah, M.; Sairafi, R. A. & Jan, M. M. (2015). Public awareness of autism spectrum disorder. *Neurosciences*; Vol. 20 (3): 213-215

American Academy of Pediatrics (2021). Autism spectrum disorders. Available at: <https://www.aap.org/en/patient-care/autism/>.

American Psychiatric Association (2014). *Diagnostic and statistical manual of mental disorders: DSM-5*. 5th ed.

Baghdadi, A., Pascal, C., Grisi, S., & Aussilloux, C. (2003). Risk factors for self-injurious behaviours among 222 young children with autistic disorders. *Journal of Intellectual Disabilities Research*, 47(Pt. 8), 622–627.

Baird, G., Charman, T., Cox, A., Baron-Cohen, S., Swettenham, J., Wheelwright, S., et al. (2001). Screening and surveillance for autism and pervasive developmental disorders. *Archives of Disease in Childhood*, 84, 468–475.

Baranek, G. T. (1999). Autism during infancy: A retrospective video analysis of sensory, motor and social behaviors at 9–12 months of age. *Journal of Autism and Developmental Disorders*, 29,213–224.

Baron-Cohen, S., Scott, F. J., Allison, C., Williams, J., Bolton, P., & Matthews, F. (2009). Prevalence of autism-spectrum conditions: UK school-based population study. *Br J Psychiatry*; 194: 500-509.

Baron-Cohen, S., Allen, J., & Gillberg, C. (1992). Can autism be detected at 18 months? The needle, the haystack, and the CHAT. *Br J Psychiatry* 161:839–843,

Bates, E., O'Connell, B., & Shore, C. (1987). Language and communication in infancy. In J. Osofsky (Ed.), *Handbook of infant development* (pp. 149–203). New York: Wiley.

Belmonte, M. K., Allen, G., Beckel, M. A., Boulanger L. M., Carper R. A., & Webb, S. J. (2004). Autism and abnormal development of brain connectivity. *Journal of Neuroscience*, 24(42), 9228-9231.

Bespalova, I. N. & Buxbaum, J. D. (2003). Disease susceptibility genes for autism. *Annals of Medicine*, 35 (4),274–281

Bogdashina, O. (2001) *Theory of Mind and the triad of perspectives on autism and Asperger Syndrome: A View from the Bridge*. London: Jessica Kingsley.

Bogdashina, O. (2005). *Communication issues in Autism and Asperger syndrome: Do we speak the same language?* Jessica Kingsley Publishers, London.

Bryman, A. (2016). *Social research methods*. 5th. ed. Oxford: Oxford University Press.

Carpenter, M., Nagell, K., & Tomasello, M. (1998). Social cognition, joint attention, and communicative competence from 9 to 15 months of age. *Monographs of the Society for Research in Child Development*, 63(4, Serial No. 255), 1–143

Cbakraharti, S.; Haubus, C.; Dugmore, S. Orgil, G. Devine, F. (2005). Model of early detection and diagnosis of autism spectrum disorder in young children. *Infants Young Children*. Vol. 18, No. 3, pp. 200-211

Centre for Disease Control (CDC) (2014). Prevalence of autism spectrum disorders, Autism and Developmental Disabilities Monitoring Network, 11 sites, United States. *MMWR Surveillance Summary*, 63 (2), 1–21.

Centers for Disease Control and Prevention (CDC). (2006). Prevalence of autism spectrum disorders – Autism and Developmental Disabilities Monitoring Network, United States. *MMWR Surveill Summ*, 58, pp. 1-20

Charman, T. (2003). Why is joint attention a pivotal skill in autism? *Philosophical Transactions of the Royal Society B: Biological Sciences*, 358(1430), 315–324.

Charman, T., & Baird, G. (2002). Practitioner review: Diagnosis of autism spectrum disorder in 2- and 3-year-old children. *Journal of Child Psychology and Psychiatry*, 43(3), 289-305.

Christensen, L., Hutman, T., Rozga, A., Young, G. S., Ozonoff, S., & Rogers, S. J., et al. (2010). Play and developmental outcomes in infant siblings of children with autism. *Journal of Autism and Developmental Disorders*: 40., 946–957.

Clark, E. V. (1977). *From gesture to word: On the natural history of deixis in language acquisition*. Oxford University Press.

Coo, H., Ouellette-Kuntz, H., Lloyd, J. E., Kasmara, L., Holden, J. J., & Lewis, M. E. (2008). Trends in autism prevalence: Diagnostic substitution revisited. *Journal of Autism and Developmental Disorders*, 38, 1036–1046

Dahlgren, S. O., & Gillberg, C. (1989). Symptoms in the first two years of life. *European Archives of Psychiatry and Neurological Science*, 238, 169–174.

Dawson, G. (2013). Early intensive behavioral intervention appears beneficial for young children with autism spectrum disorders. *Journal of Pediatrics*;162(50).

Dawson G, Rogers S, Munson J. (2010). Randomized, controlled trial of an intervention for toddlers with autism: The early start Denver model. *Pediatrics.*; 125(1):17-33.

De Giacomo, A.D & Fombonne, E. (1998). Parental recognition of developmental abnormalities in autism. *Eur Child Adolesc Psychiatry*. 7:131–136.

Deutsch, S. I., & Urbano, M. R. (2011). Autism spectrum disorders: The role of genetics in diagnosis and treatment. In Tech, Rijeka, Croatia, 83-102.

Edelson, S. M. (2021). Debating the role of genetics in Autism [editorial]. *ARRI*; 34: 3.

Emmons, P. G. & Anderson, L. M. (2006). *Understanding sensory dysfunction, learning, development and sensory dysfunction in autism spectrum disorders, ADHD, Learning Disabilities and Bipolar Disorder*. Jessica Kingsley Publishers London and Philadelphia.

Feinstein, A. (2010). *A history of autism conversations with the pioneers*. Wiley-Blackwell.

Fenson, L., Dale, P. S., Reznick, J. S., Bates, E., Thal, D., & Pethick, S. (1994). Variability in early communicative development. *Monographs of the Society for Research in Child Development*, 59(5), 1–173.

Ghanizadeh A. (2008). A preliminary study on screening prevalence of pervasive developmental disorders in school children in Iran. *Journal of Autism Developmental Disorders*; 38:759-763

Goin, R. P., & Myers, B. J. (2004). Characteristics of infantile autism: Moving toward earlier detection. *Focus on Autism and Other Developmental Disabilities*, 19(1), 5-12.

Gray, D. E. (2014). *Doing research in the real world*. 3rd. ed. London: Sage.

Green M, Palfrey JS, eds. (2000). *Bright futures: Guidelines for health supervision of infants, children, and adolescents*. 2nd ed., revised. Arlington, Va.: National Center for Education in Maternal and Child Health.

Howlin, P. (2003). Outcome in high functioning adults with autism with and without early language delays: Implications for the differentiation between autism and Asperger syndrome. *Journal of Autism and Developmental Disorders*, 33, 3–13

Howlin, P., Mawhood, L., & Rutter, M. (2000). Autism and developmental receptive language disorder—A follow-up comparison in early adult life. II. Social, behavioral, and psychiatric outcomes. *Journal of Psychology and Psychiatry*, 41, 561–578.

International Classification of Diseases (1992). Geneva, World Health Organization,

Isaksen, J., Diseth, T. H., Schjølberg, S., & Skjeldal, O. H. (2013). Autism spectrum disorders— are they really epidemic? *European Journal of Pediatric Neurology*, 17(4), 327–333.

Key, A. P., Ibanez, L. V., Henderson, H. A., Warren, Z., Messinger, D. S., & Stone, W. L. (2015). Positive affect processing and joint attention in infants at high risk for autism: An exploratory study. *Journal of Autism and Developmental Disorders*, 45(12), 4051-4062.

Klin, A., Chawarska, K., Paul, R., Rubin, E., Morgan, T., Wiesner, L., & Volkmar, F. R. (2004). Autism in a 15-month-old child. *American Journal of Psychiatry*, 161, 1981–1988.

Knapp, M., Romeo, R., & Beecham, J. (2007). *The economic consequences of autism in the UK*. London: Foundation for People with Learning Disabilities.

Locke, A. (1978). *Action, gesture, and symbol: The emergence of language*. New York: Academic Press.

Loh, A., Soman, T., Brian, J., Bryson, S. E., Roberts, W., Szatmari, P., et al. (2007). Stereotyped motor behaviors associated with autism in high-risk infants: A pilot videotape analysis of a sibling sample. *Journal of Autism and Developmental Disorders*, 37., 25–36.

Lord, C., Risi, S., DiLavore, P. S., Shulman, C., Thurm, A., & Pickles, A. (2006). Autism from 2 to 9 years of age. *Archives of General Psychiatry*, 63(6), 694-701.

Maestro, S., Muratori, F., Cavallaro, M. C., Pei, F., Stern, D., & Golse, B., et al. (2002). Attentional skills during the first 6 months of age in autism spectrum disorder. *Journal of the American Academy of Child and Adolescent Psychiatry*, 41(10), 1239–124

Matson, J. L., Wilkins J., & Gonzalez, M. (2008). Early identification and diagnosis in autism spectrum disorders in young children and infants: How early is too early. *Research in Autism Spectrum Disorders*, 2, 75–84.

Moore, V., & Goodson, S. (2003). How well does an early diagnosis of autism stand the test of time? A follow-up study of children assessed for autism at age 2 and development of an early diagnostic service. *Autism: International Journal of Research and Practice*, 7(1), 47–63.

Mundy, P., & Neal, A. R. (2001). Neural plasticity, joint attention and a transactional social-orienting model of autism. In: Glidden, L. M., editor. *International Review of Research in Mental Retard: Autism*. Vol.23, San Diego, CA.

Murray, S. & Silverman, C. (2012). Negotiating autism in an epidemic of discourse. *Disability Studies Quarterly*, Vol. 33 No. 2, 312-340.

National Institute of Child Health and Human Development (2001). *Autism questions and answers for health care professionals*.

Ohta, M., Nagai, Y., Hara, H., & Sasaki, M. (1987). Parental perception of behavioral symptoms in Japanese autistic children. *Journal of Autism and Developmental Disorders*, 17, 549–563

Ozonoff, S., Iosif, A. M., Baguio, F., Cook, I. C., Hill, M. M., & Hutman, T. (2010). A prospective study of the emergence of early behavioral signs of autism. *Journal of the American Academy of Child & Adolescent Psychiatry*. Vol. 49; p. 256-266.

Rochat, P., & Striano, T. (1999). Social–cognitive development in the first year. In P. Rochat (Ed.), *Early social cognition: Understanding others in the first months of life* (pp. 3–34). Mahwah, NJ: Erlbaum.

Rogers, S. J., Di Lalla, D. (1990). Age of symptom onset in young children with pervasive developmental disorders. *Journal of the American Academy of Child & Adolescent Psychiatry*. 29:863–972

Rozga A, Hutman T, Young GS, Rogers SJ, Ozonoff S, & Dapretto M, et al (2011). Behavioral profiles of affected and unaffected siblings of children with autism: Contribution of measures of mother–infant interaction and nonverbal communication. *Journal of Autism and Developmental Disorders*. 41:287–301.

Rutter, M. (1978). Diagnosis and definition of childhood autism. *Journal of Autism and Childhood Schizophrenia*. 8: 139–61.

Savucu, Y. (2020). The importance of early diagnosis, education and physical activity in children with autism. *IJSETS*, Vol 6, Issue 3, 105 –109

Sheinkopf, S., Lester, B., Lagasse, L., Bauer, C., Shankaran, S., & Bada, H., et al. (2000). A case study of autism in early infancy. Paper presented at the American Academy of Child and Adolescent Psychiatry 47th Annual Meeting, New York, NY, October 27, 2000.

Short, C.B., & Schopler, E. (1988). Factors relating to the age of onset in autism. *Journal of Autism and Developmental Disorders*, 18, 207–216

Stone, W. L., Lee, E. B., Ashford, L. (1999). Can autism be diagnosed accurately in children under 2 years? *Journal of Child Psychology and Psychiatry* 40:219–226.

Swettenham, J., Baron-Cohen, S., Charman, T., Cox, A., Baird, G., & Drew, A. (1998). The frequency and distribution of spontaneous attention shifts between social and nonsocial stimuli in autistic, typically developing, and nonautistic developmentally delayed infants. *Journal of Child Psychology and Psychiatry*.; 39(5):747–753.

Symons, L. A., Hains, S. M. J., & Muir, D. W. (1998). Look at me: Five-month-old infants' sensitivity to very small deviations in eye-gaze during social interactions. *Infant Behavior & Development*, 21, 531–536.

Szatmari, P., Archer, L., Fisman, S., Streiner, D. L., & Wilson, F. (1995). Asperger's syndrome and autism: Differences in behavior, cognition and adaptive functioning. *Journal of the American Academy of Child and Adolescent Psychiatry*, 34, 1662–1671

Tager-Flusberg, H., & Calkins, S. (1990). Does imitation facilitate the acquisition of grammar? Evidence from the study of autistic, Down's syndrome and normal children. *Journal of Child Language*, 17, 591–606.

The California Department of Health and Human Services (1999). Prevalence of Autism. Available at: www.cdph.ca.gov/Programs/CCDCPHP/DEODC/EHIB/EES/Pages/autism.aspx.

Verhoeven, J. S., De Cock, P., Lagae, L., & Sunaert, S. (2010). Neuroimaging of autism. *Neuroradiology*, 52(1), 3-14.

Vivanti, G., & Dissanayake, C., (2016). Outcome for children receiving the early start Denver model before and after 48 months. *Journal of Autism and Developmental Disorders*, 46 (7):2441–2449.

Volkmar, F. R. & Klin, A. A. (2005). Issues in the classification of autism and related conditions. In F. R. Volkmar, R. Paul, S. J. Rogers, & K. A. Pelphrey (eds.), *Handbook of autism and pervasive developmental disorders*, vol. 1. Diagnosis, development, and brain mechanisms. Hoboken, NJ: John Wiley & Sons

Vostanis, P., Smith, B., Corbett, J., Sungum Paliwal, R., Edwards, A., Gingell, K., Golding, R., Moore, A., & Williams, J. (1998). Parental concerns of early development in children with autism and related disorders. *Autism*, 2,229–242.

Wimpory, D. C., Hobson, R. P., Williams, J. M., & Nash. S. (2000). Are infants with autism socially engaged? A study of recent retrospective parental reports. *Journal of Autism and Developmental Disorders*, 30, 525-536

World Health Organization (WHO) (2021). ASD fact sheet newsroom. Available at: <https://www.who.int/news-room/fact-sheets/detail/autism-spectrum-disorders>

Yoder, P., Stone, W. L., Walden, T., & Malesa, E. (2009). Predicting social impairment and ASD diagnosis in younger siblings of children with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 39(10):1381–1391.

Zwaigenbaum, L. (2010). Advances in the early detection of autism. *Current Opinion in Neurology*, 23, 97–102.

Appendix A: A Questionnaire for Parents

1. Has your child been diagnosed as autistic? If ‘yes’, who has diagnosed him?
2. How old is your child?
3. Does your child have a brother or a sister who is autistic too?
4. Does your child have normal development during childhood?
5. Have you noticed any abnormal signs in your child’s development and/or communication skills? If ‘yes’, at what age?
6. What was the first sign through which you noticed that there was something wrong with your child, and when?
7. What did you do when you noticed that your child was showing abnormal development in comparison to other same-age children?
8. When did s/he start uttering his/her first words? Was it late?
9. Did you notice that your child’s speech production was impaired? If ‘yes’, how and when?
10. Were you comparing his/her and other same-age children’s intellectual and communicative skills?
11. Did anyone inform you that your baby did not seem as normal as other children? If ‘yes’, what did you do?
12. Has your child shown normal responses to callings and/or communicative interactions made by others?
13. Have you noticed that your child doesn’t make normal eye-contacts while speaking or communicating (whether verbally or non-verbally)? If ‘yes’, when?
14. Have you noticed that your child doesn’t point at things using his/her finger? If ‘yes’, how does s/he point at things?
15. Have you noticed that your child prefers to play alone? If ‘yes’, when?

16. Upon noticing that your child has not shown normal development, have you referred him/her for medical examination (have you sought medical assistance/ advice), if 'yes', what was the doctor's specialty?
17. What was the diagnosis given by the doctor to your child's case and what was the treatment plan?
18. Have you ever heard of "autism" as a child developmental disorder prior to diagnosing your child as autistic? If 'yes', how and when?
19. Have you known of any autistic child before? If 'yes', how and how?