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Research Article

Parental first concern according to age and type in children with Autism Spectrum Disorder

Dian Dwi Sary¹, Irwanto², Ahmad Suryawan³, Mira Irmawati⁴, Budi Utomo⁵

1) Department of Child Health, Faculty of Medicine, Universitas Airlangga

2) Department of Child Health, Faculty of Medicine, Universitas Airlangga

3) Department of Child Health, Faculty of Medicine, Universitas Airlangga

4) Department of Child Health, Faculty of Medicine, Universitas Airlangga

5) Faculty of Public Health, Universitas Airlangga

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***Correspondence:**

dian_dwisary@yahoo.com

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ABSTRACT

Parents' developmental problems are a further diagnostic step for children with Autism Spectrum Disorder (ASD). Research is needed to find a picture of the child's behavior complained of by parents. Investigations about parents' first concerns with ASD and comparisons of the same with children diagnosed with other developmental disorders are rare. We want to examine the type and age of parents' concerns in children with ASD and other developmental disorders. A cross-sectional study was conducted in Child Developmental Centre in Surabaya, Indonesia, from August 1 to December 30, 2019. T-test and chi-square tests were used to analyze differences in subject variables and types of concern. Most parents of both children diagnosed with ASD and non-ASD indicated first concern were in communication, social skill, and behavior problem. The average age of ASD children (54,77 months) is older than non-ASD children (51,44 months), but the average age of parents' first concern was younger for children with an ASD diagnosis (30,14 months) compare with non-ASD children (31,39 months). There is no specific difference type between parental concerns of children with ASD and non-ASD. The average age of first concern was significantly younger for children with an ASD diagnosis than other developmental disorders.



INTRODUCTION

Autism spectrum disorder (ASD) is a neurodevelopment disorder characterized by deficits in social communication and social interaction and limited or repetitive behaviors or interests (American Psychiatric Association, 2013). Globally, the number of autistic patients is expected to increase. The Center for Disease Control and Prevention (CDC) in 2014 said the prevalence rate had increased to 1 per 59 children (CDC, 2018). One reason is the increase in public awareness and knowledge of parents about the symptoms of autism (Boyd *et al.*, 2010).

The high number of children with ASD calls for a proper early diagnosis for early intervention to be done immediately, producing optimal outcomes in children with ASD (Kelley, Naigles, and Fein, 2010). A study by Barbaro and Dissanayake stated that clinicians were expected to be able to diagnose children with autism at an early age, even at the age of 2 years (Barbaro and Dissanayake, 2012) but several studies have shown that patients with ASD were diagnosed in the later age. Research in the United States reports the average age of diagnosed ASD children around four years (Zwaigenbaum *et al.*, 2009). Another study in Lebanon says the average age to diagnose ASD is four years and seven months (Akoury-Dirani, Alameddin, and Salamun, 2013).

In contrast to the late diagnosis of ASD in children, parents' concerns about the possibility of developmental delays often appear earlier. Parents can recognize the disorder in children. This can be useful for the early identification of ASD, as mentioned in a study by Becerra-Culqui. The study by Becerra-Culqui claims that the average age of children with ASD when parents first complained about the disorder was 31.5 months (Becerra-Culqui *et al.*, 2018). Another study by Richard said that the average age for complaints from parents

to ASD children was 14 months. The study also stated that it is crucial for clinicians to pay attention to parental complaints as part of the diagnostic process (Richards, Mossey, and Robins, 2016).

In addition to the age when parents first raise their concern, studies on the types of concern itself also need to be conducted. Communication disorders become the most common initial complaint reported among parents of children with ASD (Becerra-Culqui *et al.*, 2018; Kozslowki *et al.*, 2011; Zablotsky *et al.*, 2017). Researchers also report other behaviors that also raised parents' concerns, such as limited/recurring behavior disorder and socialization disorder (Richards, Mossey, and Robins, 2016; Kozslowki *et al.*, 2011).

Parents' concern is the first indicator that a child has a developmental problem. It can be the first step in identifying children who need further screening or assessment. Research conducted to assess the first complaint in parents of children with ASD and compared with other developmental disorders has not been done much. Therefore, this study aims to evaluate and compare the initial complaints reported by parents of children with ASD and not ASD. The study also assessed whether there was an age difference between the onset of the first complaint between ASD and non-ASD children.

METHOD

Study design

A cross-sectional study was conducted in Child Developmental Centre in Surabaya, Indonesia, from August 1 to December 30, 2019.

Participants

One hundred and nineteen children who visited the Child Growth and Development Center in Surabaya from August 1 to December 31, 2019, were screened to participate in this study. Two



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hundred and one children were included, and they fulfill the following criteria: aged between 2 and 6 years with complaints of developmental disorders, parents or guardians agreed to participate in the study and sign informed consent. Children with blindness, deafness, Down syndrome, intellectual disabilities, and cerebral palsy were excluded from the study.

Data collection

The study sample was divided into two groups: The first group was for children who met the diagnostic criteria for ASD, and the second group was for children who have atypical development but did not meet the diagnostic criteria for ASD. The diagnosis of ASD was made by a Growth and Development pediatrician based on the criteria from the Diagnostic and Statistical Manual of Mental Disorder, Fifth Edition (DSM-5) (American Psychiatric Association, 2013). Parents of these children would then fill a socio-demographic data and a questionnaire on the age at which the complaints first appear and the types of complaints.

Ethics

This research was approved by Ethics Committee Universitas Airlangga Institutional Review Board (170/EC/KEPK/FKUS/2019).

Material

Parents' responses on concern were categorized into five items, as adapted from research by Hess (Hess and Landa, 2011). Responses are categorized into the following items: Communication (including speech, verbal communication, and non-verbal communication), motor (including fine motor and gross motor), socialization, behavior/temperament (including stereotyped/repetitive behaviors, and interests; challenging behavior, for example, aggression; temperamental characteristics such as stubbornness), and sensory (including sensory defensiveness or sensory seeking). All respondents' answers

were recorded. If parents complain about more than one problem, every complaint would be recorded according to these categories. The percentage of complaints is calculated both for ASD and non-ASD.

American Academy of Pediatrics (AAP) (2020) stated that the diagnosis of ASD must be established according to DSM-5 criteria (Hyman *et al.*, 2020). In the DSM-5, core symptoms were divided into two domains social communication and social interaction and restrictive, repetitive patterns of behaviors). To meet diagnostic criteria for ASD by using the DSM-5, all 3 symptoms of social, affective difference need to be present in addition to 2 of 4 symptoms related to restrictive and repetitive behaviors. The DSM-5 notes that a diagnosis may be made at older ages, when the social or school environment demands may result in functional impairment (American Psychiatric Association, 2013).

Data analysis

T-test and chi-square test were used to analyses differences in subject variable characteristics and types of complaints of research subjects using IBM SPSS Statistics for Windows, version 21 (IBM Corp., Armonk, N.Y., USA

RESULT

The demographic data for the two groups are present in Table 1. There were no significant differences between the ASD and non-ASD groups in age, sex, order of children and number of siblings, and age and education level of parents.

There were no significant differences between the ASD and non-ASD groups for the parents' first concern about their child's development. The average age when parents first raise their concern was 30.14 months (range = 12-60 months) for children with ASD. This is earlier compared to the non-ASD group, which has an average of 31.39 months (range 10-72 months).



Table 1. Demographic for subjects and each diagnostic group

Variable	ASD n = 66	Not ASD n = 135	
Child			
Gender, n (%)			
- Male	51 (77,27)	100 (74,07)	0,75
- Female	15 (22,73)	35 (25,93)	
^a Age (month)			
mean (sb)	54,77 (14,16)	51,41 (14,18)	0,13
median (min-max)	57 (25-72)	52 (24-72)	
^a Age of concern (month)			
mean (sb)	30,14 (12,34)	31,39 (13,25)	0,49
median (min-max)	24 (12-60)	27 (10-72)	
Birth order, n (%)			
- First	32 (48,48)	66 (48,88)	0,65
- Second	19 (28,79)	45 (33,33)	
- Third or more	15 (22,73)	24 (17,79)	
Number of siblings, n (%)			
- None	27 (40,91)	56 (41,48)	0,57
- One	22 (33,33)	53 (39,26)	
- Two	14 (21,21)	20 (14,81)	
- Three or more	3 (4,55)	6 (4,45)	
Mother			
Age (year)			
Mean (sb)	35,02 (5,17)	33,54 (5,80)	0,81
Median (min-max)	35 (24-47)	33 (20-48)	
Education, n (%)			
- Low	34 (51,51)	84 (62,22)	0,19
- High	32 (48,49)	52 (37,38)	
Father			
^a Age (year)			
mean (sb)	37,91 (5,22)	36,04 (6,41)	0,02
Median (min-max)	38 (26-48)	35 (22-52)	
Education			
- Low	33 (50)	69 (51,11)	1,00
- High	33 (50)	66 (48,89)	

Chi-square test, ^aMann-Whitney test (data distribution is not normal)

Table 2. Percentage of concern by ASD and non-ASD parent groups.

Category	ASD n (%)	Non-ASD n (%)	X ²
Communication	65 (98,40%)	102 (75,55%)	0,00
Social skill	45 (68,18%)	89 (65,92)	0,87
Behavior/temperament	29 (43,93%)	15 (11,11%)	0,00
Sensory	10 (15,15%)	3 (2,22)	0,00
Motoric skill	6 (9,09%)	7 (5,18%)	0,45



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Among the parents of children diagnosed with ASD, the first concerns reported were communication (98.40%), social skills (68.18%), and behavior/temperament disorders (43.93%). Concerns reported by parents of non-ASD children for the first time were communication (75.55%), social skills (65.92%), and behavior/temperament disorders (11.11%) (Table. 2). Parents of children with ASD were significantly more likely to report communication problems ($p < 0.001$), behavior or temperament disorder ($p = 0.001$), and sensory problems ($p = 0.001$) compared to parents of non-ASD children.

DISCUSSION

The expression of parental concerns may be a clinician's first indicator that a child is experiencing developmental difficulties. Therefore, parental input can be essential in identifying children who need further screening or assessment for early diagnosis and intervention, as mentioned in a study by Richard (2016) (Richards, Mossey, and Robins, 2016). AAP also says parental concerns as an essential component of ASD screening (Hyman *et al.*, 2020). However, despite the importance of parental concerns in early diagnosis and intervention of ASD, studies that compare parents' first concern between non-ASD children and ASD children are still limited.

The average age of concern for parents of ASD children found in this study is 30.14 months, which is relatively older than the findings in other studies done by Kozlowski (12.94 months), Richard (13.77 months), Becerra-Culqui (32 months), and Zuckerman (30 months) (Kozlowski *et al.*, 2011; Richards, Mossey, and Robins, 2016; Becerra-Culqui *et al.*, 2018; Zuckerman, Lindly, and Sinche, 2015). This difference occurs because previous studies use at-risk populations and are conducted on tertiary referral sites. This caused symptoms to be more prominent, thus more recognizable for parents (Becerra-Culqui *et al.*, 2018; Kozlowski *et*

al., 2011). A study in China shows a similar average age, which is 3.1 years. This study also stated that the presence of negative stigma and lack of knowledge about ASD also caused parents to raise their concerns at a later age (Qian, Reichle, and Bogenschutz, 2012). The same condition is also present in this study, where parents have low awareness of ASD symptoms and assume that the symptoms will decrease and disappear as the child develop. This caused parents to report concerns about their children's behavior around the age of 3 years old.

This study also reports that parents of non-ASD children first reported their concern at an average age of 31.39 months, longer than parents of children with ASD. This aligns with the results of studies conducted by Zuckerman and Kozlowski which also found that parents of non-ASD children reported concerns about their child's development several months later than parents of ASD children (Zuckerman, Lindly, and Sinche, 2015; Kozlowski *et al.*, 2011). However, this finding contradicts the AAP statement that early signs are difficult for parents to detect if ASD symptoms are mild and the child's cognitive abilities are average or above average (Hyman *et al.*, 2020).

It has been suggested that mothers with old age and a history of infertility tend to dismiss their children's late developmental signs, resulting in an older age of concern (Chawarska *et al.*, 2007). This does not appear to be the case. Results of this study showed that age, mother's education, number of siblings, and birth order were not contributing factors in the age of concern in children with ASD. Studies by Chawarska (2007) and Herlihy (2015) further suggested that birth order and the number of siblings can be significant if the previous children have ASD (Chawarska *et al.*, 2007; Herlihy *et al.*, 2015). However, this study cannot come to a similar conclusion because these supporting data were not collected.



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The results of this study showed that the first concern for most parents in both groups is communication problems, followed by social skills, behavior/temperament problems, sensory and motor skills. These results indicate that the initial complaints reported by parents of children with ASD care not necessarily relate to symptoms of autism. This finding consists of the results of previous studies on similar subjects (Richards, Mossey, and Robins, 2016; Kozslowki *et al.*, 2011; Hess and Landa, 2011; Coonrod and Stone, 2004).

In this study, we found that communication problems are the most common complaint seen in both groups. Although communication problem is one of the core aspects of the DSM-5 criteria to diagnose autism, it is not exclusive to autism disorder only and can indicate other global development delays (Richards, Mossey, and Robins, 2016; Kozslowki *et al.*, 2011). Parents in the children with ASD group almost all complained about communication problems, compared to 75.5% of parents of non-ASD children. This result shows that communication problems often occur in children who receive various diagnoses of developmental disorders.

Another most common parental concern we found in this study concerns the ability to make social interactions. There is no significant difference in complaints of social interaction between parents of children with ASD and parents of non-ASD children. This study also finds that parental concern about socialization skills arises when the child is around three years of age. A possible explanation for the lack of significant difference between these groups is that these symptoms are not always realized by parents, especially those who have no experience of caring for older siblings or have compensatory mechanisms for children (Coonrod and Stone, 2004; Twymana *et al.*, 2009; Karp *et al.*, 2017). Socialization skills are also usually acquired in older children

when they start to interact with their peers, which might explain why the parental concern of socialization skill might arise later, despite findings by Twyman in 2009 about how socialization impairment can be detected in children as young as 18 months old (Beccerra-Culqui *et al.*, 2018; Hess and Landa, 2011; Twymana *et al.*, 2009).

The next parental concern that arises in this study is behavior/temperament issues reported by parents when the child is around 3 years old or as the problems arise. Parents tend to dismiss the behavioral problems to realize the concern when the normal developmental phase has passed. It is very hard for parents to recognize ASD-specific behavior in the early years since it usually appears when they are around 2 years old. A study by Sacrey in 2015 found that behavioral issues tend to arise when the child is around 2-3 years old (Herlily *et al.*, 2015; Canu *et al.*, 2020; Sacrey *et al.*, 2015). This condition can be exacerbated by issues caused by other behavioral disorders like ADHD (Zablotsky, Bramlett, and Blumberg, 2017).

One of the least-reported parental concerns in this study is only focusing on certain objects or unusual responses to touch, taste, smell, and/or sound, which is a new criterion to diagnose ASD based on DSM-5 (American Psychiatric Association, 2013). This symptom will often appear in children with ASD, which is following with the result of this study that finding this symptom can differentiate between children with ASD and non-ASD children.

There has been no correlation between parental concern on motor function and ASD. Previous studies have stated that motor disturbance in children with ASD may happen early, even as early as 18 months (Sacrey *et al.*, 2015; Lee and Bo, 2015). There is a possibility that in this study, parents did not raise a concern about the motor function of their children until these children have passed the normal developmental phase.



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CONCLUSION

This study found no specific difference type between parental concerns of children with ASD and non-ASD. The main concern of parents of both groups is communication problems, socialization skills, and behavioral issues. Parents of children with ASD would first report concerns at an early age compared to parents of children with no ASD diagnosis.

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