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Parental perspectives on maltreatment of children with autism spectrum disorder and their associated factors: A cross-sectional survey in Indonesia

Lilis Lestari [1,2]*, Ramadhaniyati Ramadhaniyati [1,2], Ruka Saito [3], Akiko Tsuda [3]

1. Division of Health Sciences, Graduate School of Medical Sciences, Kanazawa University, Ishikawa, Japan
2. Maternity and Child Health Nursing Department, School of Nursing, ITEKES Muhammadiyah Kalbar, Pontianak, Indonesia
3. Faculty of Health Sciences, Institute of Medical, Pharmaceutical and Health Sciences, Kanazawa University, Ishikawa, Japan

* Correspondence: Lilis Lestari. Division of Health Sciences, Graduate School of Medical Sciences, Kanazawa University, Ishikawa, Japan. Tel: +6282195879354; Email: lilis@stikmuhptk.ac.id

Abstract

Background: Parental maltreatment of children with autism spectrum disorder (ASD) remains a serious global issue and continues to be reported in developing countries. Parental perspectives on maltreatment can directly influence how parents take care of their children with ASD. Research specifically examining this issue in developing countries is limited. This study aimed to explore parental perspectives on maltreatment of children with ASD and their associated factors in Indonesia.

Methods: A cross-sectional study was conducted among 345 parents who were caring for children with ASD. Participants were selected by consecutive sampling in schools and facilities for children with special needs in two major cities in West Kalimantan Province, Indonesia, from January to March 2023. A self-administered questionnaire was developed for the Indonesian context. Data analysis involved descriptive, comparative, and multivariate regression analyses.

Results: This study included 251 participants, with a response rate of 72.8%. The majority were mothers (84.9%), with a mean age of 38.1 ± 7.1. The majority were aged > 35 years (60.6%). Only 32.7% of the participants had the appropriate perspective that children with ASD should not be maltreated. Factors associated with appropriate perspectives were being a parent whose first child did not have ASD (OR=2.240, CI=1.227–4.090, p=0.009), having knowledge of typical development (OR=1.254, CI=1.048–1.499, p=0.013) and of ASD (OR=1.743, CI=1.316–2.309, p=<0.001), and a high need for pre-diagnosis support (OR=1.225, CI=1.042–1.439, p=0.014). Conversely, participants aged > 35 years were more likely to have inappropriate perspectives (OR=0.532, CI=0.290–0.976, p=0.042).

Conclusion: Parental perspectives on maltreatment and their associated factors may contribute to the increased risk of maltreatment in children with ASD. Pre-diagnosis support, opportunities for socialization, and training aimed at increasing knowledge of non-violent parenting are needed to address inappropriate parental perspectives that tolerate the maltreatment of children with ASD in developing countries, especially Indonesia.

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Highlights

What is current knowledge?

Parental perspectives on maltreatment which can directly influence the parenting patterns in developing countries remain unexplored.

What is new here?

Most parents considered maltreatment as necessary to make it easier to interact with children with ASD.

Introduction

According to the 1989 Convention on the Rights of the Child, every child has the right to receive comprehensive protection from all forms of maltreatment (1). However, maltreatment remains a serious global issue and continues to be reported in various countries (2). Children with autism spectrum disorder (ASD) are at a high risk of parental maltreatment (3), particularly physical and psychological forms (4). Maltreatment can cause negative effects on children with ASD including increased attention deficits, and attachment problems, potentially leading to hyperactivity, aggression, and anger (5). In severe cases, maltreatment can even result in death (3). However, some parents in developing countries still use physical (Hitting) and psychological maltreatment (Shouting or threatening to harm or kill) when interacting with children with ASD (4). A similar situation has been reported in Indonesia, where acts of maltreatment (e.g., pinching) are used as part of parenting strategies for these children (6).

Parents have been reported to experience more difficult challenges in raising children with ASD compared to raising children with other developmental disorders (7), due to limitation in social interaction, communication, behavioral patterns, and unusual activities in children with ASD (8), are what may underlie parents having inappropriate perspectives that tolerate the maltreatment of children with ASD. Parental perspectives can affect the parenting patterns for children with ASD (9). Inappropriate perspectives that tolerate maltreatment can lead to violent parental responses to the behaviors of children with ASD, potentially contributing to the increased risk of maltreatment in this population. Exploring parental perspectives on maltreatment and their associated factors can provide deeper insights into maltreatment of children with ASD.

Limited studies have specifically examined parental maltreatment of children with ASD in developing countries, including Indonesia. Most research has focused on developmental disorders associated with a high risk of maltreatment (10), the types of maltreatment commonly experienced by children with ASD (4,10-12), and contributing factors such as parenting stress (11) and cultural influences (13) that increase the risk of parental maltreatment of children with ASD. This study aimed to explore parental perspectives on maltreatment of children with ASD and their associated factors in Indonesia.

Methods

Study design and setting

A cross-sectional study was conducted from January to March 2023 in two major cities, namely Pontianak and Singkawang in West Kalimantan Province, Indonesia, evaluating 345 parents caring for children with ASD. These cities were selected because they are representative of different regions in Indonesia. We sent research permission letters to all 70 schools for children with special needs and child development facilities in the two cities. Of these, 53 schools and facilities granted approval for us to collect data at their institutions. Participants were selected by consecutive sampling by these institutions. We held meetings with principals of schools for children with special needs and heads of child development facilities to discuss this study. Principals and heads then gathered parents of children with ASD for scheduled information sessions, and we explained the purpose and confidentiality of the study verbally and in writing. Parents who agreed to participate in the study signed a consent form. Parents caring for children with ASD aged ≥2 years were included in this study. They were recruited through schools and facilities for children with special needs, and they provided informed consent after receiving information about the study's purpose, benefits, and risks. Parents whose children had chronic illnesses or multiple disabilities, as documented in medical records at each study site, were excluded. For parents who were unable to attend on the scheduled days, follow-up opportunities were provided within the same data collection period. Data were collected using a self-administered printed questionnaire in Indonesian.

Measurement tools

The questionnaire was developed by a multidisciplinary team of experts in the development of children with ASD. It collected information on participant demographics and characteristics of children with ASD across 12 categories: perspectives on parental maltreatment of children with ASD, using 3 questions based on original research (14), scored using the Guttman Scale (1 for a correct answer and 0 for an incorrect answer); knowledge of typical development and ASD, using 7 questions, each based on child developmental milestones (15), maternal and child monitoring books used in Indonesia (16), published surveys (17,18), and the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition, Text Revision criteria for children with ASD (8), evaluated using the Guttman Scale (1 for a correct answer and 0 for an incorrect answer); awareness of the attachment behaviors of children with ASD, using 5 questions based on original research (14,19,20), scored using a 2-point Likert scale (1 for disagree; 2 for agree); and support needs in caring for children with ASD, using 10 questions based on original research (21-27), assessed using a 2-point Likert scale (1 for no need; 2 for need). Two parents of children with ASD and three experts on ASD in Indonesia tested the content validity of the questionnaire. Parents rated the clarity of the questionnaire on a scale of 1 (Very unclear) to 5 (Very clear). The average clarity score was 4.9, with a standard cut-off point of 3.0, indicating that the questions can be understood clearly. The relevance of the questionnaire yielded an average score of 0.98 (S-CVI/Ave=0.90) (28), demonstrating that the questions are substantially relevant to the research topic. Conversely, the clarity assessment by experts showed an average score of 0.98 (S-CVI/Ave=0.90) (28), which indicated that the questions can be clearly understood.

Statistical analysis

Descriptive statistics including percentages and frequencies were used to describe the data. We categorized perspectives on maltreatment into two categories (Appropriate and inappropriate) adjusted to the Indonesian context. A total score of ≥2 was considered to indicate an appropriate perspective on maltreatment of children with ASD. For univariate analysis of categorical data, we used the chi-square test. Multivariate logistic regression analysis with a stepwise method was utilized to determine the factors influencing parental perspectives on maltreatment. We conducted a multicollinearity test and found that all variables had a variance inflation factor (VIF) score below 5, which indicates that there are no serious multicollinearity concerns. Model fit was determined using the Hosmer-Lemeshow test. P-values less than 0.05 were considered statistically significant. All data analyses were performed using IBM SPSS Statistics 29.

Results

This study included 251 participants, with a response rate of 72.8%. The majority were mothers (84.9%), with a mean age of 38.1 ± 7.1. The majority were aged >35 years (60.6%). Most children with ASD were boys (72.5%) and were aged ≥6 years (73.7%). Only 32.7% of participants had the appropriate perspectives that children with ASD should not be maltreated. However, when responding to statements that children with ASD only understand commands if their parents shout at them, threaten them, or pinch them, 53.8%, 66.1%, and 62.6% of participants, respectively, had appropriate perspectives.

The majority of the participants aged >35 years (60.6%) and more participants with children with ASD aged ≥6 years (78.7%) held inappropriate perspectives (Table 1). Approximately 46.2%, 49.0%, and 52.6% of the participants correctly identified crucial signs for recognizing early ASD symptoms such as limited eye contact, communication, and social interaction, respectively. These proportions were smaller than those for the other four items. Regarding knowledge about ASD, 73.3% and 74.5% correctly answered that children with ASD have hypersensitivity and that ASD can be cured with medication, respectively. The remaining five items had higher correct response rates (Table 2). More than 50% of the participants reported difficulties in interpreting the wishes expressed by their children with ASD (Table 3).

Over 80% of the participants indicated needing pre-diagnosis support through education on typical development and ASD. Approximately 88.8% reported needing post-diagnosis support through programs that guide appropriate responses to children with ASD and emotional support from healthcare professionals to encourage their child's development (Table 4).

Table 5 shows the results of the logistic regression analysis. The participants whose first child did not have ASD (Odds ratio [OR]=2.240, confidence interval [CI]=1.227–4.090, p-value [p]=0.009), who had knowledge of typical development (OR=1.254, CI=1.048–1.499, p=0.013) and ASD (OR=1.743, CI=1.316–2.309, p=<0.001), and who stated needing pre-diagnosis support (OR=1.225, CI=1.042–1.439, p=0.014) showed greater odds of having appropriate perspectives. Conversely, the participants aged >35 years were more likely to have inappropriate perspectives (OR=0.532, CI=0.290–0.976, p=0.042).

Table 1. Association between the participants' demographics and perspectives on maltreatment of children with ASD

Characteristics	Total	Perspectives on maltreatment		P-Value
		Appropriate	Inappropriate	
	N (Percentage)			
Relationship with child				
Father	38 (15.1)	9 (23.7)	29 (76.3)	0.200
Mother	213 (84.9)	73 (34.3)	140 (65.7)	
Age, year				
≤ 35	99 (39.4)	42 (51.2)	57 (33.7)	0.008
> 35	152 (60.6)	40 (48.8)	112 (66.3)	
Marital status				
Married	227 (90.4)	77 (93.9)	150 (88.8)	0.194
Divorced	24 (9.6)	5 (6.1)	19 (11.2)	
Educational level				
High	108 (43.0)	39 (36.1)	69 (63.9)	0.312
Low	143 (57.0)	43 (30.1)	100 (69.9)	
Occupational status				
Unemployed/Housewife	146 (58.2)	51 (62.2)	95 (56.2)	0.368
Employed	105 (41.8)	31 (37.8)	74 (43.8)	
Annual household income				
Upper	75 (29.9)	24 (32.0)	51 (68.0)	0.883
Lower	176 (70.1)	58 (33.0)	118 (67.0)	
Child's sex				
Male	182 (72.5)	60 (73.2)	122 (72.2)	0.870
Female	69 (27.5)	22 (26.8)	47 (27.8)	
Firstborn has ASD				
Yes	140 (55.8)	39 (27.9)	101 (72.1)	0.068
No	111 (44.2)	43 (38.7)	68 (61.3)	
Child's current age, year				
≤ 5	66 (26.3)	30 (36.6)	36 (21.3)	0.010
≥ 6	185 (73.7)	52 (63.4)	133 (78.7)	

ASD, Autism Spectrum Disorder; p-value was determined using the chi-square test.

Table 2. Association between the participants' knowledge on typical development and ASD and perspectives on maltreatment of children with ASD

Variables	Total	Perspectives on maltreatment		P-Value
		Appropriate	Inappropriate	
	N (Percentage)			
Knowledge on typical development				
A 1-3-month-old child does not yet have the skills to look other people in the eye.[a]	116 (46.2)	45 (54.9)	71 (42.0)	0.055
A 1-3-month-old child shows the ability to smile at others, which will develop with age.	200 (79.7)	65 (79.3)	135 (79.9)	0.910
A 6-9-month-old child looks happy (Laughs) when invited to play peek-a-boo.	211 (84.1)	75 (91.5)	136 (80.5)	0.026
A 9-12-month-old child responds by turning his/her head or walking toward the sound when he/she hears his/her name called.	187 (74.5)	69 (84.1)	118 (69.8)	0.015
A 12-18-month-old child is unable to ask for something by pointing at the object he/she wants without crying.[a]	123 (49.0)	48 (58.5)	75 (44.4)	0.035
A 2-3-year-old child cannot climb stairs independently.[a]	142 (56.6)	55 (67.1)	87 (51.5)	0.019
A 2-3-year-old child is not yet interested in playing with his/her peers.[a]	132 (52.6)	50 (61.0)	82 (48.5)	0.064
Knowledge on ASD				
ASD is a developmental disorder.	218 (86.9)	74 (90.2)	144 (85.2)	0.268
Children with ASD are more common in high-income families.[a]	214 (85.3)	82 (100.0)	132 (78.1)	< 0.001
Children with ASD are more common in families with a higher educational background. [a]	217 (86.5)	81 (98.8)	136 (80.5)	< 0.001
Immunization is one of the causes of ASD in children.[a]	206 (82.1)	76 (92.7)	130 (76.9)	0.002
ASD can be cured with medication.[a]	187 (74.5)	74 (90.2)	113 (66.9)	< 0.001
Children with ASD have speech limitations, even though they are already at the age they should be able to speak fluently.	217 (86.5)	71 (86.6)	146 (86.4)	0.966
Children with ASD show oversensitivity to taste, sound, light, smell, or touch.	184 (73.3)	60 (73.2)	124 (73.4)	0.973

ASD, Autism Spectrum Disorder; Total (n [%]) is the total number of correct answers; [a] negative statement; p-value was determined using the chi-square test.

Table 3. Association between the participants' awareness of the attachment behaviors of children with ASD and perspectives on maltreatment of children with ASD

Awareness of the attachment behaviors of children with ASD	Total	Perspectives on maltreatment		P-Value
		Appropriate	Inappropriate	
	N (Percentage)			
My child still recognizes me, even though we do not see each other after a few hours.	182 (72.5)	62 (75.6)	120 (71.0)	0.444
My child is more comfortable around me than around strangers.	207 (82.5)	67 (81.7)	140 (82.8)	0.825
Speaking gently is enough to make my child understand the order I give him/her.	172 (68.5)	65 (79.3)	107 (63.3)	0.011
It is difficult to interpret what my child wants.	127 (50.6)	29 (35.4)	98 (58.0)	< 0.001
Understanding something according to what my child wants to convey can only be realized if I am more sensitive to interpreting the unique patterns, he/she shows.	198 (78.9)	60 (73.2)	138 (81.7)	0.122

ASD, Autism Spectrum Disorder; Total (n [%]) is the total number of agreeing answers; p-value was determined using the chi-square test.

Table 4. Association between the participants' support needs in caring for children with ASD and perspectives on maltreatment of children with ASD

Variables	Total	Perspectives on maltreatment		P-Value
		Appropriate	Inappropriate	
	N (Percentage)			
Support needs before ASD diagnosis				
Education about general child development	207 (82.5)	74 (90.2)	133 (64.3)	0.024
Education about ASD	208 (82.9)	75 (91.5)	133 (78.7)	0.012
Guidance from a healthcare professional who can help me develop sensitivity to reading signals that my baby may be showing	182 (72.5)	65 (79.3)	117 (69.2)	0.095
Information on where to go for a developmental consultation	191 (76.1)	71 (86.6)	120 (71.0)	0.007
Consistent sensorimotor therapy for my child even before he/she turns 2 years old	191 (76.1)	71 (86.6)	120 (71.0)	0.007
Consistent behavioral therapy for my child even before he/she turns 2 years old	184 (73.3)	67 (81.7)	117 (69.2)	0.036
Support needs after ASD diagnosis				
A program whose material is delivered in the group section of parents of children with ASD	216 (86.1)	77 (93.9)	139 (82.2)	0.012
A program that can teach me to give the proper response to my child	223 (88.8)	79 (96.3)	144 (85.2)	0.009
Emotional support from healthcare professionals such as soothing words that support the progress of my child's condition	223 (88.8)	77 (93.9)	146 (86.4)	0.076
A handbook that contains information about children with ASD that can be useful while I am at home	216 (86.1)	78 (95.1)	138 (81.7)	0.004

ASD, Autism Spectrum Disorder; Total (n [%]) is the total number of agreeing answers; p-value was determined using the chi-square test.

Table 5. Logistic regression analysis of the factors associated with parental perspectives on maltreatment of children with ASD

Parental perspectives on maltreatment of children with ASD		
Influencing factors	**P-Value**	**AOR (95.0% CI)**
Age, year		
≤ 35	1.00	-
> 35	0.042	0.532 (0.290-0.976)
First born has ASD		
Yes	1.00	-
No	0.009	2.240 (1.227-4.090)
Knowledge on typical development	0.013	1.254 (1.048-1.499)
Knowledge on ASD	< 0.001	1.743 (1.316-2.309)
Support needs before ASD diagnosis	0.014	1.225 (1.042-1.439)

ASD, Autism Spectrum Disorder; CI, Confidence Interval; AOR, Adjusted Odds Ratio; CI and AOR were determined using the stepwise method; Hosmer-Lemeshow test: 0.870; Cox & Snell R2: 0.178; Nagelkerke R^2: 0.248.

Discussion

In this study, most participants considered physical and psychological maltreatment necessary to make it easier for parents to interact with children with ASD. This finding is supported by previous reports that in Indonesian culture, parental maltreatment is often interpreted as normal and is considered important to instill obedience in children including those with ASD (13). Similar findings were reported in a study conducted in Bangladesh, also a developing country, where parental maltreatment was considered necessary to help control the behavior of children with ASD (4). These findings reflect similar parental perspectives on maltreatment often seen in ASD childcare practices in developing countries.

Our findings showed that the participants aged >35 years and those whose first child had ASD were more likely to have inappropriate perspectives that tolerate maltreatment. Older parents are likely caring for older children with ASD compared to younger parents. Similar to parents of older typically developing children, parents caring for older children with ASD share similar hopes for their children's future, including access to education and job opportunities (29). However, when hopes for their children's future do not align with their dreams, these parents may experience hopelessness (21). Such conditions could lead to inappropriate perspectives that tolerate maltreatment.

Parenting children with ASD is often reported to trigger stress (30). This stress may be more intense for parents whose first child is diagnosed with ASD, as they typically face challenges including increased role differentiation during the transition to parenthood compared to parents with prior parenting experience (31). These challenges may hinder parents from developing appropriate perspectives in responding to their child's behaviors. The active involvement of healthcare professionals in providing ongoing parental support, especially during transitional periods, is essential. This support can help prevent parenting stress that could lead to inappropriate perspectives on maltreatment of children with ASD.

This study found that knowledge about typical development and ASD and the need for pre-diagnosis support also influenced the perspectives on maltreatment of children with ASD. The participants who had poor knowledge about typical development and ASD and those who stated not needing pre-diagnosis support were more likely to have inappropriate perspectives. However, this may be linked to limitations within Indonesia's ASD treatment system, including inadequate human resources, uneven distribution of facilities, and high therapy costs (32). These limitations often make it difficult for parents to determine the best support and may lead them to switch between treatment centers without clear referral systems, resulting in suboptimal care for children with ASD and further hindering parents' understanding of the condition. Comprehensive improvements to the ASD treatment system in Indonesia are needed, including enhancing parental knowledge about child development and pre-diagnosis support, beginning with efforts to increase the competence of healthcare professionals, ensure equitable distribution of facilities, and make support services for children with ASD more affordable. This study used a cross-sectional design, which provided only an overview and allowed the interpretation of the relationship between the variables without establishing causality. Another limitation is that this study examined only parental perspectives regarding maltreatment of children with ASD, without investigating whether the parents actually engage in abusive behaviors when interacting with their children. Therefore, it remains unclear whether parents with appropriate or inappropriate perspectives are more likely to maltreat children with ASD. Further research into how parental perspectives may influence acts of maltreatment toward children with ASD is needed to provide a comprehensive understanding of parenting to prevent maltreatment, especially in developing countries. Additionally, the study data were obtained from parents living in West Kalimantan Province, which is not a metropolitan province in Indonesia. Thus, the data collected may not fully represent all regions in Indonesia. In conclusion, this study found that most parents have an inappropriate perspective that tolerates maltreatment of children with ASD. Parental perspectives that tolerate maltreatment can lead to harsh parental responses to the behavior of children with ASD, which potentially contributes to the increased risk of maltreatment in this population in developing countries such as Indonesia.

Conclusion

Most parents caring for children with ASD in Indonesia have inappropriate perspectives that tolerate maltreatment. Parental age of >35 years, first child with ASD, poor knowledge about typical child development and ASD, and lack of need for pre-diagnosis support can influence parental perspectives on maltreatment of children with ASD. Ongoing support, opportunities for socialization, and training aimed at improving knowledge of compassionate parenting and pre-diagnosis support, beginning with increasing the competence of healthcare professionals, ensuring equitable distribution of facilities, and reducing the cost of support services for children with ASD, are needed to address inappropriate parental perspectives on maltreatment of these children. Parental perspectives may influence acts of maltreatment toward children with ASD is needed to provide a comprehensive understanding of parenting to prevent maltreatment, especially in developing countries.

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Ethical statement

This study has been reviewed and approved by the Research Ethics Committee in Indonesia (Number: 80/II.I.AU/KET.ETIK/III/2022) and also obtained administrative approval from the Ministry of Health, Ministry of Education, and the Department of Research and Development of West Kalimantan Province. All participants involved in this study have given informed consent. In addition, anonymity, the right to withdraw from the research, and data confidentiality were also ensured.

Conflicts of interest

The authors state that no conflicts of interest are present.

Author contributions

LL, design the project, data collection and formal analysis. RR, design the project, and formal analysis. RS, design the project, and formal analysis. AT, design the project, and formal analysis. All authors; Writing-review, editing, and final approval of published version.

Data availability statement

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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