

Parents' Acceptance of Children with Autism Spectrum Disorder (ASD) in Pontianak City

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Abstract

This study aims to describe parents' acceptance of children with autism spectrum disorder (ASD) in Pontianak City. The research method used is descriptive with a cross-sectional approach. The research instruments used were the Parental Acceptance-Rejection Questionnaire (PARQ) and the Demographic Data Questionnaire. The respondents who participated in this study were 40 parents, consisting of 16 fathers and 24 mothers. A total of 18 (45 percent) parents accepted, and 22 (55 percent) refused. Most of the respondents were in the category of early middle age (65 percent), married (92 percent), high school graduates (50 percent), housewives/not working (35 percent), and high and very high income (35 percent). The characteristics of parents who accept their child's condition are early middle age adults, married, high school graduates, housewives/not working, and have moderate-income levels, while the characteristics of parents who refuse are the same as those who accept but have high-income levels. The process of accepting parents who have children with ASD is not easy. Fathers and mothers have different acceptance of children with ASD. Therefore, it is important to know parents' acceptance of children with ASD starting from the child's initial diagnosis so that it can help parents make decisions regarding the treatment of children with ASD.

Abstrak

Penelitian ini bertujuan untuk mengetahui gambaran penerimaan orang tua terhadap anak dengan *autism spectrum disorder* (ASD) di Kota Pontianak. Metode penelitian yang digunakan adalah deskriptif dengan pendekatan *cross-sectional*. Instrumen penelitian yang digunakan adalah *Parental Acceptance-Rejection Questionnaire* (PARQ) dan Kuesioner Data Demografi. Jumlah responden yang berpartisipasi dalam penelitian ini adalah 40 orang tua, terdiri atas 16 orang ayah dan 24 orang ibu. Sebanyak 18 (45 persen) orang tua menerima dan 22 (55 persen) lainnya menolak. Sebagian besar responden berada pada kategori usia paruh baya awal (65 persen), menikah (92 persen), tamat SMA (50 persen), ibu rumah tangga/tidak bekerja (35 persen), serta tingkat penghasilan tinggi dan sangat tinggi (35 persen). Karakteristik orang tua yang menerima adalah berusia dewasa pertengahan, menikah, tamat SMA, ibu rumah tangga/tidak bekerja, dan tingkat penghasilan sedang, sedangkan karakteristik orang tua yang menolak adalah berusia dewasa pertengahan, menikah, tamat SMA, ibu rumah tangga/tidak bekerja, dan tingkat penghasilan tinggi. Proses penerimaan orang tua yang mempunyai anak dengan ASD memang tidak mudah. Ayah dan ibu memiliki pe-

nerimaan yang berbeda terhadap anak dengan ASD. Oleh karena itu, penting untuk mengetahui penerimaan orang tua terhadap anak dengan ASD mulai dari awal diagnosis anak, sehingga dapat membantu pengambilan keputusan orang tua terhadap penanganan anak dengan ASD.



INTRODUCTION

The definition of autism spectrum disorder (ASD), according to the American Psychiatric Association (2013), is a neurodevelopmental disorder characterized by barriers to social communication and social interaction, patterns of behavior and limited interests, and repetitive activities. ASD is caused by a combination of genetic and nonspecific environmental variables, including advanced parental age, low birth weight, and fetal exposure to valproate hemorrhage in early pregnancy. Children with ASD will experience disturbances consisting of behavioral disorders, communication disorders, and social interaction disorders. Common symptoms in children with ASD include a tendency to be silent and aloof, unable to respond when called by others, engaging in repetitive activities, being able to speak but not clearly and having a tendency to overdo it, avoiding being approached, not caring about their surroundings, disliking crowds, and being unable to socialize with others (Sugara et al., 2018).

World Health Organization (2013) stated that the prevalence of people with ASD is 1 in 160 people, so there are estimated to be more than 7.6 million people with ASD worldwide. The estimated prevalence of children with ASD in 2016, according to Maenner et al. (2020), is 18.5 per 1,000 (1 in 54) children aged eight years. This result is estimated to be 10% higher than the 16.8 estimated prevalence reported in 2014 and around 175% (2.8 times) higher than the first estimate reported in 2000 and 2002. In addition, based on the sex of people with ASD, it was found that boys are 4.3 times more than girls (Christensen et al., 2018).

Physical and mental disorders in children will tend to cause stress and anxiety in parents.

This reason can cause parents to adopt the wrong attitudes and methods in dealing with children with ASD. The attitude that parents generally show to children with ASD is an attitude that is too indulgent or even ignores their children. The attitude of parents who are indulgent and too compassionate will affect the child's adjustment to their social environment. In contrast, the attitude of parents who tend to ignore children can make the child's great potential not appear optimal (Susanto, 2014). Parents who have children with ASD need adaptations to be able to accept the disturbances that occur in children. However, if parents accept their child's situation, they will tend to expect the best according to their child's capacity and abilities (Tameon & Tlonaen, 2019).

Parental acceptance is any parenting behavior that shows warmth and affection (Valentia et al., 2017). This attitude is defined as a simple expression of liking or disliking anything associated with their child. The general attitude of parents can be both positive and negative. Acceptance by parents means that parents are aware of the weaknesses and strengths of their children, so they must have a place in the heart of the family, and children deserve love from their parents (Tameon & Tlonaen, 2019).

Parents who can accept the situation of their autistic child will significantly affect the child's development process. Parents' acceptance of children includes various aspects, not only being able to accept the child's condition but also through the attitude of parents trying to make self-development efforts through various stages of self-acceptance, can accept themselves and adapt to uncomfortable circumstances, have a mature personality, and able to perform the func-

tions of life properly (Faradina, 2016). The parenting style provided by parents who can accept the condition of their autistic child usually manifests in the form of educating children with warmth, affection, a sense of care, comfort, attention, and always providing support to their children (Kosasih, 2017).

Characteristics are one of the factors that can influence parents' acceptance of ASD in their children, such as age, marital status, educational level, and socio-economic. Age will affect the level of individual maturity. Maturity level of good parents will generally be able to accept their child's diagnosis more calmly (Santoso et al., 2018). Harmony in the household has a relationship with high acceptance due to mutual reinforcement between good partners.

Another factor influencing parental acceptance is the level of education. Parents with a good educational background tend to seek information about their child's development and condition from various sources, such as books and the internet. This factor will affect parental acceptance of the child's situation (Sudarmintawan & Suarya, 2018). Adequate parental socio-economic status factors can also increase parental acceptance of children. Parents will try to meet the child's needs with various facilities that support the child's needs, such as therapy needs and others (Rupu, 2015).

Gusrianti et al. (2018) previously conducted research on parental acceptance in Temanggung and Semarang. The research was conducted on parents who have children with intellectual disabilities. The results showed that of the 20 parents who were research respondents, as many as eleven parents (55%) could accept their child's condition, while the other nine (45%) did not accept it. Those who accept their child's condition fully acknowledge all the limitations that children have and are satisfied with the talents that God has bestowed on their children (Gusrianti et al., 2018).

According to the previous explanation, it is important for every group to learn the accep-

tance of parents toward children with ASD. It is intended that every child with this disorder can have the opportunity to experience better growth and development so that later they will receive equal rights and obligations in society. Research on parental acceptance of children with ASD has never been done before in West Kalimantan, so based on the above background, this study was conducted to determine parental acceptance of children with ASD in Pontianak City. The aims of this study were: (1) to find out the description of parents' acceptance of children with ASD; (2) to know the characteristics of parents who have children with ASD; and (3) to assess the dimensions of parental acceptance of children with ASD.

METHODS

This research is a descriptive study with a cross-sectional design. Data collection was carried out using a quantitative method to describe parents' acceptance of children with autism at the Special School for Autism in West Kalimantan. The sample was selected using the non-probability sampling technique of the consecutive sampling type, a sample selection technique in which each research subject has the same opportunity and opportunity to be selected or not selected as the research sample. The total sample involved in this study was 40 parents consisting of 16 fathers and 24 mothers. The sample criteria for this study were: (1) fathers and/or mothers who have children with autism spectrum disorder (ASD); (b) fathers and/or mothers who live in the same house with a child with ASD; (c) willing to become research respondents and fill out informed consent.

Data was collected by filling out the research questionnaires through Google Forms. Primary data collection was carried out using the guided interview method, which began with briefings on research explanations, informed consent, and the Indonesian version of the Parental Acceptance-Rejection Questionnaire (PARQ), which has obtained a license from Rohner Research Publications (Rohner, 2021). PARQ consists of

four scales: warmth/affection, hostility/aggression, indifference/neglect, and undifferentiated rejection. The warmth/affection scale consists of eight items, hostility/aggression and indifference/neglect each consists of six items, and undifferentiated rejection consists of four items. PARQ has 24 items adapted from instruments carried out by previous studies with a Cronbach alpha value of 0.834 and a corrected item-total correlation of 0.193–0.628 (Rohner & Ali, 2020). Secondary data collection was conducted by contacting the school to obtain data on the number of children with ASD in the Special School for Autism in West Kalimantan. Respondents were accompanied by the research team when filling out the questionnaire to help respondents who experienced problems filling out the questionnaire.

The result of the data normality test using the Shapiro-Wilk test is 0.017. Because the results obtained are less than 0.05, it can be concluded that the data used in this study are not normally distributed; therefore, the median value of 37 is used (minimum value is 26; maximum value is 55).

The PARQ version used in this study is the short PARQ version with a license. The scale utilized in this PARQ ranges from one to four according to the four available answer choices: (1) one equals almost never happened; (2) two equals rare; (3) three equals sometimes true; and (4) four equals almost always true. PARQ scores range from 1 to 96, with a score less than 37 categorized as acceptance and more than or equal to 37 categorized as rejection.

RESULTS

Data collection in this study was done by distributing questionnaires online in the form of Google Forms. Of the 25 children, 50 parents received and returned the questionnaire, and four parents of two children were excluded because they were not the child's biological parents. This causes the remaining number of parents to only come from 23 children. The parents of 17 children consist of a father and mother, while the parents of six other children only fill in from one side. This is because the parents of three children are single parents, and the other three children do not agree to be respondents in this study. Therefore, the total number of parents meet the criteria is 40 parents. This study used total sampling so that the total number of parents who participated in this study was included. Of the 40 parents, 18 (45%) accepted, and 22 (55%) refused.

Distribution of Respondent Characteristics

1. Based on age, most research respondents were in the early middle age category (36 to 45 years old).
2. Based on marital status, most research respondents were married.
3. Based on the education level, most research respondents were in the high school graduate category.
4. Based on the occupation, most respondents in the survey were private-sector employed fathers and housewives or unemployed mothers.
5. Based on total income, most respondents were high-income fathers and moderate-income mothers.

Table 1.
Distribution of Respondent Characteristics

No.	Characteristic	n (%)	Parental Acceptance	
			Father n (%)	Mother n (%)
1	Age			
	Early middle age	4 (100%)	0	4 (100%)
	Late middle age	26 (100%)	10 (38.4%)	16 (61.6%)
	Late adulthood	10 (100%)	6 (60%)	4 (40%)
2	Marital Status			
	Married	37 (100%)	16 (43.24%)	21 (56.76%)
	Single parent	3 (100%)	0	3 (100%)
	Divorce	0	0	0
3	Education			
	Never received formal education	0	0	0
	Elementary school dropped out	1 (100%)	0	1 (100%)
	Elementary school graduate	5 (100%)	1 (20%)	4 (80%)
	Middle school graduate	7 (100%)	3 (42.8%)	4 (57.2%)
	High school graduate	20 (100%)	8 (40%)	12 (60%)
	Diploma	1 (100%)	1 (100%)	0
Bachelor	6 (100%)	3 (50%)	3 (50%)	
4	Occupation			
	Laborer	3 (100%)	2 (66.7%)	1 (33.3%)
	Civil service	4 (100%)	0	4 (100%)
	Private employee	11 (100%)	9 (81.8%)	2 (18.2%)
	Entrepreneur	5 (100%)	2 (40%)	3 (60%)
	Housewives/unemployed	14 (100%)	0	14 (100%)
	Indonesian national army	3 (100%)	3 (100%)	0
5	Income Level			
	Very high income	8 (100%)	4 (50%)	4 (50%)
	High income	15 (100%)	6 (40%)	9 (60%)
	Moderate income	13 (100%)	5 (38.5%)	8 (61.5%)
	Low income	4 (100%)	1 (25%)	3 (75%)

Distribution of Parental Acceptance

1. Based on age, most accepting and rejecting parents are early middle aged (36 to 45 years old).
2. Based on marital status, most accepting and rejecting parents fall within the same category: married status.
3. Based on the education level, most parents who accept and reject are those with a high school graduate.
4. Based on their occupation, most accepting and rejecting parents are housewives or unemployed.
5. Based on income level, moderate-income parents are most likely to accept, while high-income parents are most likely to reject.

Table 2.
Distribution of Parental Acceptance

No.	Characteristic	n (%)	Parental Acceptance			
			Father		Mother	
			Accepting (< 37)	Rejecting (≥ 37)	Accepting (< 37)	Rejecting (≥ 37)
1	Age					
	Early middle age	4 (100%)	0	0	1 (25%)	3 (75%)
	Late middle age	26 (100%)	4 (40%)	6 (60%)	9 (56.3%)	7 (43.8%)
	Late adulthood	10 (100%)	3 (50%)	3 (50%)	1 (25%)	2 (75%)
2	Marital Status					
	Married	37 (100%)	7 (43.8%)	9 (56.2%)	9 (42.9%)	12 (57.1%)
	Single parent	3 (100%)	0	0	2 (66.7%)	1 (33.3%)
	Divorce	0	0	0	0	0
3	Education					
	Never received formal education	0	0	0	0	0
	Elementary school dropped out	1 (100%)	0	0	1 (100%)	0
	Elementary school graduate	5 (100%)	0	1 (100%)	2 (50%)	2 (50%)
	Middle school graduate	7 (100%)	1 (33.3%)	2 (66.7%)	2 (50%)	2 (50%)
	High school graduate	20 (100%)	4 (50%)	4 (50%)	5 (41.7%)	7 (58.3%)
	Diploma	1 (100%)	0	1 (100%)	0	0
	Bachelor	6 (100%)	2 (66.7%)	1 (33.3%)	1 (33.3%)	2 (66.7%)
4	Occupation					
	Laborer	3 (100%)	2 (100%)	0	1 (100%)	0
	Civil service	4 (100%)	0	0	1 (25%)	2 (75%)
	Private employee	11 (100%)	4 (44.4%)	5 (55.6%)	1 (50%)	1 (50%)
	Entrepreneur	5 (100%)	0	2 (100%)	1 (33.3%)	2 (66.7%)
	Housewives/unemployed	14 (100%)	0	0	7 (50%)	7 (50%)
	Indonesian national army	3 (100%)	1 (33.3%)	2 (66.7%)	0	0

No.	Characteristic	n (%)	Parental Acceptance			
			Father		Father	
			Accepting (< 37)	Accepting (< 37)	Accepting (< 37)	Accepting (< 37)
5	Income Level					
	Very high income	8 (100%)	3 (75%)	1 (25%)	2 (50%)	2 (50%)
	High income	15 (100%)	1(16.67%)	5 (83.3%)	4 (44.4%)	5 (55.6%)
	Moderate income	13 (100%)	4 (80%)	1 (20%)	6 (75%)	2 (25%)
	Low income	4 (100%)	0	1 (100%)	2 (66.7%)	1 (33.3%)

Table 3.

Distribution of Parental Acceptance Based on Dimensions

PARQ Dimensions	Father (n = 16)	Mother (n = 24)
Warmth/Affection	11 (8–17)	10.50 (8–19)
Hostility/Aggression	11 (7–14)	12 (6–17)
Indifference/Neglect	9.50 (6–14)	10 (6–16)
Undifferentiated Rejection	6 (4–7)	5 (4–9)
Total PARQ Score	38.50 (30–50)	37 (26–55)

DISCUSSION

The results showed that of the 40 parents who participated as research respondents, there were 18 parents (45%) accepted, and 22 (55%) refused. These results differ from research conducted by Gusrianti et al. (2018) which revealed that out of 20 parents, 11 parents (55%) accepted and nine parents (45%) refused. This difference in result can occur due to differences in the characteristics of parents in the previous research area and this study (Gusrianti et al., 2018).

Age is closely related to the existence of emotional intelligence in an individual. As people age, individuals are more likely to understand their own emotions and those of others because they learn from past experiences in life. Therefore, a person's age will affect the level of maturity of that person. Between the ages of 36 and 45, a person reaches physical and psychological maturity. Many problems regarding life have been passed through, including problems encountered during the developmental period towards maturity, so that they can place themselves with the realities of life that are being faced and try to find solutions to these problems (Chen et al., 2016). The older a person is, the greater the level of acceptance that person has (Fitrianingrum et al., 2021).

Harmony formed in the household will enable husband and wife to mutually strengthen each other to form good acceptance (Rupu, 2015). Social support from husbands is a factor that significantly influences the level of well-being of mothers who have children with ASD. The social support partners can provide, such as motivation, attention, and advice, can assist individuals in adopting optimistic attitudes by promoting positive thinking. This level of welfare will also describe the parental acceptance of the child's condition (Pradana & Kustanti, 2017).

According to Ginting & Lubis (2010), education is a stage in the world of formal education that will influence the mother's behavior in dealing with every problem and thing that happens in her life. The research by Sudarmintawan &

Suarya (2018) revealed that mothers who were high school graduates showed good acceptance because of the desire and initiative of each mother to seek and dig up information related to their child's condition. However, at the high school education level, it is also the category with the highest number of rejections made by parents because, in this category, parents also have insufficient knowledge and curiosity about the treatment of children with autism (Pujiastuti, 2014).

The highest acceptance is found among housewives because parents who do not work have more opportunities to be with their children. Parents who do not work have more time to accompany their children during therapy, retrain them at home, manage their diet, and care for their children's other needs (Sudarmintawan & Surya, 2018). In addition, Vilaseca et al. (2019) revealed that the influence of the length of interaction between mother and child on language development would be mediated by the quality of the interaction, both in terms of affection, responsiveness, non-intrusive behavior and linguistic stimulation. However, on the other hand, it is common for housewives or those who do not work to feel tired in handling their children who have requests that are difficult for others to understand, so mothers must have extra patience in dealing with children's behavior. This causes in the same category, the number of rejections from parents is also high (Susanti, 2015).

Research conducted by Fitrianingrum et al. (2021) revealed that income below 1.5 million could be more accepting of their children's conditions than parents with more than 1.5 million monthly income. These results indicate that less income does not rule out the possibility of causing parents to have greater acceptance. In essence, family income does not contribute statistically to parental acceptance. Additionally, earlier research by Riany et al. (2016) revealed that there are parents of autistic children in Indonesia who hold what are known as fatalistic

beliefs. Parents who participated in the study believed that their child's diagnosis with ASD at this point was a predestination from God. As their attention is on their children, God's gifts that they should be grateful for, parents with middle to lower-income families may have a higher sense of acceptance.

CONCLUSION

This study revealed that more than half of the respondents who were parents of children with ASD rejected the child's condition. The characteristics of parents who reject the child's condition are early middle aged, married, high school graduates, housewives/unemployed, and have a high income. Parents who accept have the same characteristics as those who reject but have a moderate income. The dimensions of parental acceptance of children with ASD are hostility/aggression. Acceptance of parents will lead to optimal effort in providing treatment for children with special needs. Therefore, the role of parents is significant in the successful development of children with ASD to obtain the best quality of life.

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