

THE LEVEL OF DEPRESSION AMONG PARENTS OF AUTISM CHILDREN: A QUANTITATIVE STUDY

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Abstract

Background: Caring for a child with autism in the family is a long-term challenge for the parents that impact physical and psychological health. Negative psychological problems that occur continuously will result in depression to the parents. Objective: The purpose of this study is to determine the level of depression in parents who have children with autism at four schools of special needs children (SLB Risantya, SLB Autis Prananda, SLB Jatis Hurip, and SLB D YPAC at Great Bandung Region. Methods: This study used a quantitative descriptive design with a cross-sectional approach. The sampling method used was total sampling, and 39 respondents were obtained. The instrument used was Beck Depression Inventory-II (BDI-II) standard instrument in the Indonesian version. Result: This study showed that 76,9% of parents who have children with autism had minimal depression/normal, 12,8% of mild depression, 7,7% of moderate depression, and 2,6% of severe depression. Conclusion: The Conclusions of this study indicate that many parents who have children with autism were at minimal/normal depression. However, there were still 2.6% of respondents in severe depression. Nurses needed to provide nursing care that focuses on families, such as counselling and sustainably doing depression screening to parents who have children with autism.

Keywords: Autism; depression; parents

I. INTRODUCTION

According to the World Health Organization (2011), the prevalence of people with disabilities has increased by 10% since 1970. Around 15% of the world's population lives with people with disabilities, especially in Autistic Spectrum Disorder or people with autism. According to WHO, the prevalence of people with autism has increased globally. The data from the Centers for Disease Control and Prevention (2018) shows that 1 in 59 children identified as having autism and increased by 15% of 2012.

In Indonesia, people with autism are one of the developmental issues of concern. The population of people with autism in Indonesia is estimated to be more than 112,000 people aged 5-19 years (Republika, 2013). According to the Education Department of West Java (Dinas Pendidikan Jawa Barat), in 2018, West Java province is the second-largest distribution area of children with autism, with a population of

1,524 children. According to Riskesdas (2018) data, the highest distribution of children with autism is in Kabupaten and Kota Bandung. Based on data from Dinas Pendidikan Jawa Barat in 2018, around 230 children with autism were spread in 45 SLBs in the city of Bandung.

People with autism are complex developmental disorders characterized by persistent difficulties in social interaction, difficulty in verbal and non-verbal communication, and limited and repetitive behaviour (American Psychiatric Association, 2018). Caring for and nurturing children with autism is a long term challenge for families, especially in parents as caregivers who are at risk to the health of both physical and psychological parents (Lin, 2015). One of the psychological health problems caused by caring for children with autism is depression (Bristol, 1987 in Benson, 2006). This statement is in line with Brown (2014), mentioning the symptoms of depression or

depression can be one of the effects parents show from caring for children with autism.

According to Abbeduto, Seltzer, Shattuck, and Murphy (2004), parents who have children with autism are more likely to show symptoms of depression than parents who have children with other disabilities. Symptoms that show the most signs of depression experienced by parents with disabilities children are guilt, low self-esteem, self-blaming, self-hatred, and feeling life is meaningless (Yulianti, Soewandi, & Sumami, 2011; Setiawan & Sukamto, 2007). In addition, parents will experience unexpected trauma, shock, despair, guilt, denial or disbelief, blame themselves, worry, shame, anger, and feel that this situation is painful to face when their child is diagnosed with autism (Das et al., 2017). Negative feelings that these parents continuously show can lead to depression, either mild, moderate, or severe depression (Setiawan & Sukamto, 2007).

Depression is an emotional state characterized by very sadness, feelings of guilt and worthlessness, withdrawing self from others, losing interest in sleep, and other unpleasant things (Muhith, 2015).

In a study conducted by Bitsika and Sharpley (2017), in Australia to 107 parents showed results of 60% of parents with children with autism experienced symptoms of depression, with categories of mild depression was 21%, moderate depression was 27.6%, and severe depression was 11.4%. Meanwhile, in Indonesia, the level of depression in parents who have children with autism in Depok in 21 respondents showed that all of them were at the level of mild depression (Qolina, Hamid, & Warandi, 2011).

Depressed parents have a low quality of life, given that quality of life is the result of evaluating one's physical, psychological, social, and environmental conditions (Imtihana, 2018). This is in line with Pisula and Porębowicz-Dořsmann (2017) research that parents who have children with autism have lower grades of quality of life and family function than families with other types of children with disabilities. Besides, if

parents, especially mothers, experience depression, the role and function as a caregiver will be disrupted, resulting in pathological relationships in children (Yosep & Sutini, 2014).

Research on the level of depression in older people with autism in Indonesia is still very limited. Even though according to Jatirahayu (2017), parents as caregivers are at a greater health risk than patients. They may not recognize or may ignore signs of illness, fatigue or depression that they experience. This will make parents able to be characterized as "hidden patients" who need treatment to overcome the effects of caring for and nurturing sick family members in a family (Family Caregiver Alliance, 2006). So the psychological impact of depression felt by parents in caring for, and nurturing children with autism needs to be known by nurses. The nurse's role in psychological impact is done by helping to examine or screen the psychological status of parents. Therefore, this study aims to identify the level of depression of parents who have children with autism in SLB Kota Bandung.

II. METHODS

A. Study Design

This study used a quantitative descriptive design with a cross-sectional approach.

B. Setting

This research was conducted at four schools of special needs children in Bandung Region, namely SLB Risantya, SLB Autism Prananda, SLB Jatis Hurip, and SLB YPAC D from May 13 to June 18, 2019.

C. Participants

The sample number in this study was 39 respondents who were parents (father/mother) who were the main caregivers and had a greater role in caring for and nurturing children with autism.

D. Instrument

The researcher used a standard instrument developed by Beck, Steer, and Brown in 1996 to measure the level of depression, namely the Beck Depression Inventory-II (BDI-II) questionnaire, which had been translated into Indonesian in Ginting, Nāringa, Velda, Srisayektic, and Becker

2013. This instrument consists of 21 statement items which are symptoms and attitudes of depression. Scoring of BDI-II instruments was categorized into four levels, which were 0-13 scores for minimal/normal depression values, 14-19 scores for mild depression, 20-28 scores for moderate depression, and 29-63 scores for severe depression (Beck et al., 1996).

The Indonesian version of the BDI-II instrument has been tested with the results of good validity and stated as a valid measuring instrument. In addition, the value of the Indonesian version of the alpha BDI-II Cronbach value in each group obtained results of 0.90 Cronbach alpha values in healthy participants and 0.91 in depressed patients so that the values indicated that this instrument had been stated reliably (Ginting, Naringa, Velda, Srisayektic, & Becker, 2013).

E. Data Analysis

The data analysis is presented in the form of frequency distribution and percentage. All statistical calculations are carried out using a number processing software program.

F. Ethical Consideration

This research has received ethical approval by Kementrian Riset, Teknologi and Pendidikan Tinggi University of Padjadjaran with number 633 / UN6.KEP / EC / 2019. The ethical principles used are Respect for Human Dignity, Respect for Privacy and Confidentiality, Respect for Justice and Inclusiveness, and Balancing Harms and Benefits.

III. RESULT

Table 1 shows the results of the analysis of characteristics of respondent analysis. It is known that the respondents in this study were 20 people (51.3%) in the age range of 36-45 (late adult), 34 people (87.2%) were female, as many as 25 people (64.1%) were Sunandese, 24 people (61.5%) had the last education level of college, 25 people (64.1%) did not work, and most of the respondents had family income more than the City Minimum Wage of Bandung City (> Rp. 3.339580) which were as many as 35 people (89.7%).

Meanwhile, based on characteristics of the respondent's children, most parents have

children in the age range of 12-16 years (early adolescents) as many as 14 people (35.9%) and 27 children (69.2%) have been diagnosed with autism since they were under three years.

Table 1 Frequency Distribution of Level of Depression among Parents of Autism Children (N=39)

Level of Depression	Frequency (f)	Percentage (%)
Minimal/normal	30	76.9%
Mild	5	12.8%
Moderate	3	7.7%
Severe	1	2.6%

Table 2 shows the results of research from 39 respondents, which tells that 30 people (76.9%) were at the level of minimal/normal depression five people (12.8%) were in the category of mild depression, three people (7.7 %) were in the moderate category, and one person (2.6%) was in the category of severe depression.

Table 3 shows the results of the five highest depression symptoms from the 21 items of the Beck Depression Inventory-II (BDI-II) questionnaire. It is shown that 56.4% feel tired, 53.8% of people experiencing changes in sleep patterns, 48.7% of people feel guilty, 46.2% of people criticize themselves, and 43.6% of people are easily angry

Table 2 Frequency Distribution of Respondents Characteristics (n=39)

Respondent Characteristics	Frequency (f)	Percentage (%)
Parents Age		
Early Adulthood (26-35 years old)	6	15,4%
Late Adulthood (36-45 years old)	20	51,3%
Early Elderly (46-55 years old)	12	30,8%
Late Elderly (56-66 years old)	1	2,6%
Gender		
Male	5	12,8%
Female	34	87,2%
Ethnic Group		
Sunda	25	64,1%
Java	7	17,9%
Mining	1	2,6%
Others	6	15,8%
Education		
Junior High School	1	2,6%
Senior High School	14	35,9%
College	24	61,5%
Job Status		

Respondent Characteristics	Frequency (f)	Percentage (%)
Not Working	25	64,1%
Working	14	35,9%
Family Income		
Less than the minimum wage (< Rp 3.339.580)	4	10,3%
More than the minimum wage (>Rp 3.339.580)	35	89,7%
Children Age		
Toddler (0-4 years old)	2	5,1%
School Age (5-11 years old)	13	33,3%
Early Adolescent (12-16 years old)	14	35,9%
Late Adolescent (17-25 years old)	10	25,6%
Age of Children Diagnosed Autism		
Less than three years old (< 3 years old)	27	69,2%
Since three years old (> 3 years old)	6	15,4%
More than three years old (> 3 years old)	6	15,4%

Table 3 Frequency Distribution and Percentage of The Most Answered Parents Depression Level's Questions

Questions	Frequency (f)	Percentage (%)
Tired of Fatigue	22	56,4%
Sleep Pattern Changes	21	53,8%
Guilt	19	48,7%
Self-criticism	18	46,2%
Angry easily	17	43,6%

IV. DISCUSSION

The results of this study indicate that parents with autistic children in Risantya SLB, Prananda Autistic SLB, Jatis Hurip SLB, and YPAC DFS are at the minimum/normal depression level (76.9%), mild depression category (12.8%), moderate depression category (7.7%), and severe

depression category (2.6%). This study indicates that many parents are at a level of minimal/normal depression in nurturing and caring for children with autism. However, there are not many other parents who experience mild to severe depressive disorders that is as much as 23.1% if it is accumulated from mild depression to severe depression.

The results of this study are similar to the research conducted by Lerthattasilp and Charernboon (2015) in Thailand to 51 parents who have children with autism showed results as much as 94.1% were not depressed/normal and as much as 5.9% were in the category of depression. However, it is different from previous studies. For example, the results of research conducted by Bitsika and Sharpley (2017) to 107 parents in Australia showed that as many as 60% of parents experience depression. In addition, in a study conducted by Qolina et al. (2011), to 21 parents in Depok using the Beck Depression Inventory (BDI), all respondents were in the category of mild depression. The researcher argues that the differences in results of this study are possibly influenced by various factors that can influence the state of parents who have children with autism.

Based on the results in Table 3 shows five symptoms of depression most felt by all respondents. The statement with the most number is a statement of tired or exhausted. The most number of parents who feel tired or tired are likely caused by the burden and higher demands in meeting all the needs of children with autism compared to other normal children. Children with autism have difficulty meeting all their own needs.

This study results are in line with the research of Seymour, Wood, Giallo, and Jellett (2013), showing that the existence of behavioural difficulties shown by children with autism makes mothers as caregivers experience fatigue and excessive fatigue compared to other children. Besides, the other largest number of statements is a change in sleep patterns, feeling guilty, self-criticism and irritability. Circular rhythm disorders that children with autism can contribute to parents' sleep patterns (Goodlin-Jones et al., 2008 in Pisula, 2011). This is in line with Hoffman et al. (2008, in Pisula, 2011), stating that the disturbance of circadian rhythms will impact fatigue and sleep patterns of parents that contribute to the stress incidence of parents. In addition, according to Wanei and Sudarmoto (2015, in Nisa, 2017), the birth of children with autism can cause couples to blame and fight each other, and parents think that because of the

sins they have committed, their children end up suffering from autism.

The number of parents at the level of minimal/normal depression is possibly caused by parents' meaning or positive thoughts towards the existence of children with autism. This state is in line with Tarabek (2011), that parents who think raising children with autism are a burden and difficult to control it are more described as having poor mental health than parents who think they feel capable of raising children with autism.

The level of independence or difficulty shown by children with autism is a possible cause of many parents' minimal/normal depression. This is in line with Tarabek (2011), which stated that the severity of the difficulties shown by children contributes to parents' mental health, where low levels of difficulty are associated with good mental health in older people. The researchers say this is likely to be the cause of the many parents who are at the level of minimal/normal depression.

Coping is how a person faces problems, solves problems and adapts to stressful situations (Stuart, 2013). Therefore, the number of parents at the level of minimal/normal depression may be caused by adaptive or effective coping to manage negative emotional responses such as depression felt by parents in caring for and nurturing children with autism. This result is in line with Lin (2015) study that shows the use of coping strategies can significantly be a factor that affects the incidence of depression in mothers who have children with autism. An example is that the use of problem-focused coping decreases the depression and burden level in parents caring for children with disabilities autism.

Social support received by parents who have children with autism is likely to cause many parents at the level of minimal/normal depression. As Boyd (2002, in Singh et al., 2017) said, the existence of social support can affect the state of positive mental health and parental adjustment of children diagnosed with autism and other disabilities. This is in line with Benson (2006) study,

which revealed that social support could significantly reduce depression in parents as caregivers who have children with autism.

Based on the results of this study, not many respondents experienced depression (mild to severe). Respondents with the severe depression category had the lowest percentage. However, this still needs to be considered. Depressed parents have a low quality of life (Imtihana, 2018). At the same time, parents' good quality of life will influence parents' attitude of parenting towards the child (Larson, 2010 in Catur, 2017).

In addition, mothers who are depressed will show a maladaptive parenting style, show resistance, and be coercive (Lovejoy et al., 2000 in Brown, 2014). Maladaptive care demonstrated by parents, such as allowing children or being abusive, will inhibit the development and growth of the child. These things indicate that parents who are depressed have a negative impact on themselves, their families, and their children, which must be a concern of health workers.

The role of nurses that can be done is to provide nursing care that focuses on family or family-centred care (FCC). Family-centred nursing care (FCC) is a care that focuses on all individuals in the family, not only on the sick individuals (Kozier, Erb, Berman, & Snyder, 2010). For example, family-centred nursing care (FCC) that can be done to parents who have children with autism is to always care about the emotional state of each family member, ensure the best level of flexibility and accessibility in providing health care services, especially for families with children who need special and chronic therapy, ensure that parents can use effective coping strategies, and ensure that there is the support given by each family member to other family members (Festini, 2014).

The limitation of this study is that the number of samples is still less than the population, while more samples are needed to describe the level of depression in parents who have children with autism. Besides, some parents were not willing to be respondents in this study, and the results were different from the initial estimates

because the location of the study was not under the place of the preliminary study.

V. CONCLUSION

The study results on the level of depression of parents who have children with autism in 4 SLB Kota Bandung, namely SLB Risantya, SLB Prananda Autism, SLB Jatis Hurip, and SLB YPAC D, showed that many parents were at a minimum/normal level of depression. However, 2.6% of parents are at the level of severe depression, which must be considered. Meanwhile, the signs and symptoms of depression that most parents feel are feeling tired or exhausted, experiencing changes in sleep patterns, feelings of guilt, self-criticism, and irritability.

The school is expected to cooperate with nurses, especially mental nurses, to provide counselling facilities and psychological services for parents and children to discuss and find out the (physical and psychological) conditions of parents. Furthermore, the nurse can carry out a continuous screening of depression and conduct further examinations for parents who are depressed to be referred to experts. In addition, it is expected that other researchers will conduct research with a more significant number of samples and examine related factors that influence depression in parents who have children with autism and can achieve this research qualitatively.

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