

# Psychological Well-being of Autistic Caregiver: A Pilot Study

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**Abstract:** This is a pilot study on the psychological well-being of autistic child caregivers. The current study investigates the level of psychological well-being among caregivers of autism using a descriptive research design. Data on psychological well-being were obtained through a scale of psychological well-being given to 21 autistic child caregivers. Ryff's psychological well-being scale has been adapted to Indonesian and given to participants. The scale measures psychological well-being through six dimensions: autonomy, environmental mastery, personal growth, positive relation with others, purpose in life, and self-acceptance. The results showed that 51.7% of caregivers have psychological well-being in the middle level. Meanwhile, 42.9% of caregivers' psychological well-being is at the highest level. Furthermore, data analysis for each dimension varied, from lower to higher level. The finding leads to other investigations for future research to know more variables contributing to autistic caregiver's psychological well-being and the fit model of psychological well-being.

## 1 INTRODUCTION

Autism, a neurodevelopmental disorder, has been being investigated for years ago because the number of children that have been diagnosed with autism increases globally. According to the World Health Organization, approximately one in 160 children is an autistic child. Some studies reported higher, but the prevalence of autistic cases in the low and middle countries is unclear (WHO, 2021).

Furthermore, autistic cases in Asia are unknown. Still, a publication of systematic research in Asia found that the prevalence of autistic numbers in other countries such as Iran is 0.06%, and as many as 2.64% in Korea (Qiu et al., 2019). Even though cases of autism are unclear, Kemenpppa (Ministry of Females' Empowerment and Child Protection of the Republic of Indonesia) predicts the number of autistic cases in Indonesia is 2.4 billion (kemenpppa, 2018).

In addition, a report from ASEAN autism mapping (2019) reported that autistic cases vary among some countries in Southeast Asia. The data can be seen in table 1.

Commonly, an autistic child will be nurtured by caregivers, parents, or close relatives. Nurturing them need abundant energy, both physical and psychological, as autistic children need attention and

Table 1: Autistic cases in southeast Asia (data of 2019).

Countries	Autism cases	Years
Brunei	1858	2018
Cambodia	1313	2019
Laos	3663	2019
Malaysia	8546	2018
Myanmar	No specific data	2008-2009
Indonesia	3663	2019

special caring in many aspects such as education, self-help, and therapy throughout their life. However, autistic child caregivers have been very often found to have mental problems and low psychological well-being (Andrez, et al, 2020; Hickey et al., 2019; Shorey, et al, 2019). Some phenomena such as caregiver burden, emotional support, family functioning, feeling of shame and embarrassment, self-blame, and others relate to caregivers' mental health (Papadopoulos, Lodder, Constantinou, & Randhawa, 2019)

Even though autism issues have been investigated massively by many researchers in past decades, most of the research topic focuses on autistic children. Meanwhile, research on the caregiver, as a person treating them, is minor. Psychological well-being is a

term for explaining how well a person shows their function. Psychological well-being is essential to be investigated as the autistic caregiver must nurture autistic children for years ahead. They cannot do the responsibility well if they are not unwell or have low psychological well-being. A person with lower psychological well-being tends to ignore their own life (Muqodas et al., 2020). Furthermore, research showed a positive association between meaning in life and psychological well-being, mainly in some dimensions, including self-acceptance, purpose in life, global psychological well-being, environmental mastery, and personal growth (García-A landete, Martínez, Nohales, & Lozano, 2018). Caregivers who have a high score on those dimensions will be able to nurture autistic children.

Psychological well-being is also used for describing wellness or mental health achieved by improving positive psychological functions. According to Ryff (1996), there are six dimensions of psychological well-being: autonomy, environmental mastery, purpose in life, self-acceptance, personal growth, and positive relation with others. To achieve good psychological well-being, someone should have a high score on those six dimensions.

*Current research* is a pilot study aiming to describe the psychological well-being of autistic caregivers. Future research will investigate the fit model of psychological well-being on autistic child caregivers. In addition, through this study, we also predict the reliability of the psychological well-being scale. The scale has been translated from English into Indonesian following the language and cultural adaptation procedure.

## 2 METHOD

### 2.1 Research Design

Descriptive research is a part of the quantitative design, which aims to describe phenomena using numbers that explain participants' characteristics. The purpose of this study is limited to describing the characteristics as seen. According to Metler (2014), this design will provide descriptions of the current status of the individual, setting, conditions, or event.

### 2.2 Measures

Psychological well-being was measured by using the scale of psychological well-being from Ryff (1996). It measured six dimensions of psychological well-being: autonomy, environmental mastery, purpose in

life, personal growth, positive relation with others, and self-acceptance. The scale was adapted by Rachmayani & Ramdhani (2014) following translation and adaptation cultural rules, and it was tested on 140 students. The total adapted items are 86 items. It is fitted with items composed by Carol Ryff. After testing the scale to 140 students, the total items turned to 48 with a scale reliability of 0.92.

However, the 86 items that Rachmayani and Ramdhani (2014) adapted were tested again on 21 autistic child caregivers, as the characteristics between students and autistic child caregivers differ. Item numbers after given to autistic child caregivers reduced to 32 items with six dimensions still complete. Reliability test was measured by using Cronbach's alpha. Furthermore, the reliability of each dimension and the number of items of each dimension are described below in table 3. Reliability of dimension range from 0.734 to 0.915.

### 2.3 Participants

As many as 21 autistic child caregivers filled psychological well-being scale consisting of male and female. They completed the scales in Laboratory Psychology of Universitas Islam Riau. More information about participants is presented in table 2.

Table 2: Characteristic of Participants.

Variables	Frequency
Gender	
Male	5
Female	16
Occupation	
Housewives	9
Entrepreneur	9
Employee	
Others	2
	1
The number of children	2
One	
Two	10
three	6
Four	2
five	1
Marital status	
Married	18
Divorce	2

## 2.4 Procedures

This study began with determining suitable caregivers with respondent criteria, such as having autistic children and staying in Pekanbaru. After reading and signing the consent form, participants were given a scale of psychological well-being consisted of 86 items that have been adopted. After the data analysis process, it was found that 32 items had good reliability with Cronbach alpha from 0.734-0.915). The next process was analyzing 32 items from 21 respondents to describe the psychological well-being of autistic child caregivers.

## 2.5 Data Analysis Technique

Data will be analyzed through descriptive statistic using SPSS software

Table 3: Item number after being tested to 21 autistic caregiver and its reliabilitiesn.

Dimensions	Number of Items	Reliability
Autonomy	5	0.734
Environmental mastery	5	0.915
Personal growth	5	0.806
Positive relation with others	5	0.808
Purposivein life	6	0.802
Self-acceptance	6	0.855

## 3 RESULT

### 3.1 Demography

The number of participants in this study is twenty-one, and the number of children they have vary, ranging from two to five children. Most of them are married, but one of them divorce. The participants' detail can be seen in table 1.

There are four types of occupation among participants, including housewife, entrepreneur, employee, and nurse.

Descriptive data for those participants based on occupation is in table 3. Most participants work as entrepreneurs and housewives. The mean of psychological well-being among entrepreneurs is higher than housewives. Based on the median score, as many as 19.8 % of both housewives and

entrepreneurs have low psychological well-being, and 23.8 % of both groups have a high score of psychological well-being (Table 4).

Table 4: Psychological well-being based on occupation.

Occupation	High (%)	Low (%)
Housewives	23.8	19.8
entrepreneur	23.8	19.8

As many as 19 participants are married, and 2 of them divorced. In addition, all caregivers register their children to therapy centers to receive therapies. One of the participants who is divorced has lower psychological well-being, while the other has high psychological well-being.

Table 5: Marital status of Caregivers.

Marital status	Number
Married	19
divorce	2

Overall, by comparing the mean of psychological well-being between males and females, psychological well-being of males is higher than females. However, independent sample test analysis shows that there was no significant difference in the score for male psychological well-being (M=112.8; SD=25.084) and female psychological well-being (M=115.5; SD=17.259) condition  $t(19)=-.275, p=0.786$ .

Table 6: Mean of Psychological well-being for male and female.

Gender	Total	Mean	Std. Deviation
Male	5	112.8	25.084
Female	16	115.50	17.259

Generally, there are mean differences in each dimension of psychological well-being between male and female, but the analysis using the independent sample test showed that there was no significant difference. The description is available in table 7 below. In the dimension of purpose in life, the difference between females (M=22.69; SD=4.347) and males (M=21.00; SD=4.183) does not differ significantly though the mean of females is higher than males. Autonomy in females is higher than in males. Conversely, it does not differ significantly based on the independent sample test. Sequentially,

independent sample test for male and female are (M=14.8; SD=5.23), (M17.63; SD3.94), conditions  $t(19)=-1.295$ ,  $sig=2.11$ .

In environmental mastery, the mean of the females is also higher than males. Similarly, the two-dimension above do not differ significantly. The mean and standard deviation are  $M=18.13$  and  $SD=3.91$ , consecutively.

The mean of the personal growth dimension differs between males and females, in which the mean of females is higher compared to males, but the independent sample test does not differ significantly,  $t(19)=-.855$ ,  $p=.403$ . Compared to other dimensions, the mean of self-acceptance for males is higher than females even though it does not differ significantly,  $t(19)=.730$ ,  $p=0.474$ . Likewise, for the dimension of positive relationships with others, the mean for females is higher than males. However, it does not differ significantly,  $t(19)=-0.218$ ,  $p=0.830$ .

Table 7: Mean of psychological well-being dimension for male and female.

Dimensions	Mean	Std. dev
Autonomy		
Male	14.80	5.263
Female	17.63	3.984
Environmental		
Mastery		
Male	17.60	6.348
Female	18.13	3.914
Personal Growth		
Male	17.20	5.070
Female	18.06	4.008
Purpose		
In life		
Male	21	4.183
Female	22.69	4.347
Positive		
Relation		
Male	19.80	3.834
Female	20.25	4.091
Self-acceptance		
Male	22.40	5.857
Female	22.44	5.072

### 3.2 Psychological Well-being

The description of psychological well-being of caregivers was divided in two categories including high and low, in which it depends on the median of

psychological well-being. Data of median can be seen in table 10. Meanwhile, data frequency of psychological well-being can be seen in table 8.

By using the median score, categories of psychological well-being is made. Scores below 116 are categorized as a low group, and scores above 116 are the high group. Table 9 shows the number of participants who are in low and high psychological well-being.

Table 8: Frequencies of psychological well-being.

Data	Score
Mean	116.90
Median	116
Mode	91
Standard Marital deviation	18.488

Furthermore, analysis for each dimension of psychological well-being is divided into two categories: high and low. The median score of all dimensions of psychological well-being can be seen in table 10, and a description of dimensions of psychological well-being can be seen in table 11.

Table 9: Respondents' distribution according to their psychological well-being.

Psychological well-being	Frequency N=21	Percentage
High	11	52.4
Low	10	47.6

Table 10: The Median scores for all dimensions.

Dimensions	Median
Autonomy	16
Environmental	19
Personal growth	18
Purpose in life	21
Positive relation with others	21
Self-acceptance	20

Generally, most dimensions of psychological well-being of caregivers are in high categorize as describe in table 11.

Table 11: description of participants' dimensions of psychological well-being.

Dimensions	Low	High
Autonomy	42.9	57.1
Environmental	47.6	52.4
Personal growth	47.6	52.4
Purpose in life	38.1	61.9
Positive relation with others	47.6	52.4
Self-Acceptance	61.9	38.1

## 4 DISCUSSIONS

Psychological well-being is related to terms of positive psychology issues for and mental health. Therefore, discussion about psychology is often similar with mental health and, positive psychology. According to data analysis, the levels of psychological well-being among participants differs slightly in which the frequency of participants in

high psychological well-being is 11 people (52.4%), and participants in low level are ten people (47.6 %). In addition, many respondents have high level in five dimensions of psychological well-being, but most of them have a low level of self-acceptance dimension, 61.9 % of participants.

Generally, both male and female, caregivers face many challenges while caring for autistic children. These challenges can harm their health, psychological well-being, societal reactions, and financial balance. At the micro-level, interpersonal conflict happens between husband and wife in line with caring the autistic children. One of the causes of conflict is the lack of information about autism in early diagnosis of a child, which then makes parents feel anxious, and they begin to be aggressive toward others (Tathgur & Kang, 2021). Parents as caregivers also feel angry, self-blame, hopelessness on their children's diagnosis, higher levels of worry, depression, anxiety, and stress (Herrema et al., 2017; Shorey et al., 2019). The factors directly impact parents' relationship satisfaction in which they are not satisfied with their relationship. High relationship satisfaction is associated with low parenting stress (Sim, Cordier, Vaz, Parsons, & Falkmer, 2017). They experience parenting stress, a situation full of tension, impacting some of the dimensions of psychological well-being, such as positive relationships with others.

Mental health difficulties of autistic child caregivers also occur due to other reasons: child's intellectual disabilities, daily living skills impairment, elevated emotional and behavioral difficulties, high educational level of caregiver, and household income (Salomone et al., 2018). Specifically, mental health difficulties focus on incapability to perform a regular function, such as concentrating on daily activities and undergoing psychological distress.

In addition, by comparing the mean of psychological well-being for male and female, the mean of psychological well-being of females is higher than males. However, it does not differ significantly when it was analyzed using independent sample test.

In addition, analysis for each dimension of psychological well-being found that females have mean score higher than males, and only in the score of the self-acceptance dimension that males have higher mean than females. However, independent sample test showed it does not differ significantly.

Furthermore, a study showed that there was a difference between the psychological well-being of males and females. Matud, López-Curbelo, and Fortes (2019) it do found that males and females differ in four dimensions of psychological well-being, such as self-acceptance, positive relation with others, autonomy, and personal growth. Besides, the score for males in the dimension of self-acceptance is higher than females in which it is similar to the research.

Furthermore, a study investigating the difference between mental health between males and female caregivers found that female caregivers are more significantly unhealthy in mental and physical conditions than males, even though they do not differ in general health or life satisfaction (Edwards, Anderson, Thompson, & Deokar, 2017). Generally, their study supports the result of this study that there is a difference between male and female 's caregivers' psychological well-being [a1]. One reason why the psychological well-being of males is higher than females is that males' quality of life of men is higher than females, and they also have fewer neuropsychiatric symptoms (Lethin et al., 2017).

Another study shows that females experience a higher level of parenting stress and depression symptoms than males in nurturing children with autism. This relates to lower family functioning. It was reported that lower family functioning increases parenting stress and relates to lower quality of life. (Pisula & Porebowic-Dorsmann, 2017). The lower psychological well-being of mothers significantly

relates to their perception toward ASD child's symptoms and behavior problems (Hickey, et al, 2019). The more parents think negatively about ASD symptoms and behavior problems, the lower their psychological well-being of an ASD child. Hsu and Barrett (2020) stated that females report more depressive symptoms and lower autonomy, environmental mastery, and self-acceptance than males.

Mother's perceived stress, parental sense of competence, child behavior disorders, and individual coping are significantly related to psychological well-being (Hatta, Derôme, De Mol, & Gabriel, 2019). Mothers who feel stressed in caring for ASD children tend to be angry with the situation and this reflects that they have not accepted their condition. Besides, children who indicate severe symptoms of autism also add mothers' stress. Furthermore, the stress level of mother rises when they do not have positive coping to solve all problems. Therefore, those three factors impact mothers' psychological well-being.

In addition, life satisfaction indicates low psychological well-being because people who do not satisfy with their life mean that they cannot accept their negative experiences. Furthermore, a study of 184 parents of autistic children found that life satisfaction was caused by three factors such as health problems, career rewards, and financial difficulties. (Landon, Shepherd, & Goedeke, 2018).

It seems that the role of the caregiver in caring for ASD children impacts the caregiver's psychological well-being. A study measuring the roles of grandparents in nurturing ASD children showed that grandparents and their psychological well-being associate significantly. The greater the role played by grandparents, the higher their psychological well-being (Desiningrum, 2018). When caregivers are involved in nurturing ASD children wholeheartedly, it reflects their self-acceptance as they enjoy the process of caring for ASD children.

As caregivers, such as for Alzheimer patients, females tend to have psychological problems than males because of work overload. They also have poor health perception (Hernández-Padilla et al., 2021). These factors contribute to the low psychological well-being of females. A comparative study between caregivers of schizophrenia and non-caregiver, involving 100 participants in Pakistan, showed that caregivers of people with schizophrenia have more significant depression and poor psychological well-being than non-caregivers (Ehsan, Johar, Saleem, Khan, & Ghauri, 2018)

A comparative study between two countries in

Europe, Italy, and Sweden, reported that informal caregivers of dementia patients experience symptoms associated with low psychological well-being such as anxiety and depression. Furthermore, it happens because

Caregivers did not get enough information of behavior of dementia patients, for example how to treat them when patients show inappropriate behavior. The prolonged situation leads caregivers to depression (Wulff, Fänge, Lethin, & Chiatti, 2020). In line with ASD children, caregivers who show low acceptance of ASD children will indicate depression symptoms. Furthermore, caregivers who refer show self-blame on children's condition and despair on the situation had worsening mental health (Da Paz, Siegel, Coccia, & Epel, 2018).

Psychological well-being correlates with a burden on caregivers, especially for caregivers of patients who have mental health problems. For example, a study from Gupta, Solanki, Koolwal & Gehlot (2014) showed that caregivers with high psychological well-being have low burden in nurturing patients of schizophrenia (Gupta, Solanki, Koolwal, & Gehlot, 2014). The burden is a defined level of multifaceted strain perceived by caregivers who are caring for a family for an extended period. Specifically, burden has three attributes, including self-perception of an individual, multifaceted strain, and over time (Liu et al., 2020). Self-perception of caregiver is how caregiver reflects their personal experience during caregiving process. It could be a positive or negative feeling. When an autistic caregiver feels dissatisfied with their life, feels the children hamper their activity, or feels embarrassed, it is categorized as a negative feeling.

The multifaceted strain comes from the accumulation of many events, such as health, social, and emotional problems. Caregiving patients for an extended period may impact health problems such as weight loss, fatigue, sleep disturbance. A systematic review about caregivers who care for cancer patients found that caregiver well-being is disturbed. About 40 % of informal caregivers had comorbidities, and 22% of caregivers' health worsened because of caregiving (Adashek & Subbiah, 2020).

A study that measured the psychological well-being over time of caregivers of dementia patients showed that less caregiver burden was a predictive factor for improving caregiver psychological well-being. (Lethin et al., 2017). Their study supports the association between psychological well-being and burden.

The caregiver also faces an emotional problem, for example, feeling lonely. Impact on social life

changes their schedule and limits their social activity (Liu et al., 2020). Caregivers of autism also deal with this condition as they are caregiving ASD children for an extended period.

Another factor that impacts psychological well-being is marital status. One sample in this study who is divorced has lower psychological well-being. It is noted for further research to give attention to the marital status of participants. (Hsu and Barrett, 2020) Through their research involving 1711 samples (males = 778 and females = 993), Hu and Coulter (2016) found that marital status is linked [a1] [a2] with psychological well-being. It can be concluded that married people have good psychological well-being compared to divorced people and singles (Hu & Coulter, 2016)

According to Ryff and Singer (1996), as part of positive psychology, the term psychological well-being is related to the presence of wellness indicated by a high score in six dimensions. Generally, people with high psychological well-being or wellness will control their behavior or free from social pressure. They do something because they want it, not because people want them to do it. Second, they are also good in using every chance and, effective in managing daily activity. Third, as an individual, they develop continuously, accept every experience, and aware that their behavior improves from time to time. Fourth, they have a positive relationship with others in which they show empathy reciprocally, engage in an intimate relationship, and show affection toward people. Fifth, their life is meaningful because they have a purpose in life. Lastly, they have a positive attitude toward themselves, so they accept themselves, both their weaknesses and strengths (Ryff & Singer, 1996).

In particular, caregivers of autistic children who have high psychological well-being scores are also in control of their behavior.; They do not feel disturbed because their child is autistic, they are not angry about it, and does not reflect their feelings through their behavior. Therefore, caregivers focus more on managing daily activities because their minds are not busy with useless things and do many positive activities to get and learn new experiences.

As stated previously, most participants have a high level in five dimensions of psychological well-being, except in the self-acceptance dimension, in which most participants are at a low level (61.9

%). A lower score in self-acceptance reflects a negative attitude toward self, which is shown through blaming behavior and, regretting unwanted things that come into their life.

### Limitations

This is a pilot study intended to obtain a description of psychological well-being in autistic child caregivers. Therefore, the number of samples is limited. The number of respondents in further research is expected to be larger than this in this study. In addition, demographic data of autistic child caregivers need to be added, such as level of education of autistic child caregivers. A significant sample is also needed to measure the validity and reliability scale. It is noted that considering age participants as part of demographic data is essential as there is a significant association between age and psychological well-being, where psychological well-being increases slightly with age (Hu & Coulter, 2016). Other demography data such as the education of caregivers and household income also correlate with psychological distress (Salomone et al., 2018) and, also crucial to investigate in future research.

## 5 CONCLUSIONS

Data from the pilot study showed that the occupations of participants vary, divided into four categories. The average score of psychological well-being among occupations was divided into two categories, low and high. However, it does not differ significantly. In addition, the average score of psychological well-being of female caregivers is higher than males, although it is not significantly different. The average score of five dimensions of females' psychological well-being is higher than males. However, males are higher than females in the dimension of self-acceptance.

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