



Research Article

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Psychological Well-being of Mothers with Autistic Children

Asmadi Alsa¹

Rila Sovitriana¹

Agustina Ekasari¹

Endri Endri^{2*}

¹Universitas Persada Indonesia YAI, Jakarta 10430, Indonesia

²Universitas Mercu Buana, Jakarta 11650, Indonesia

*Corresponding Author

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Abstract

Severe stress and depression are common phenomena among mothers of children diagnosed with autism. As a consequence, adequate support becomes necessary in ensuring balanced mental health. Furthermore, religiosity and resilience are key factors influencing psychological well-being development, particularly for mothers, related to self-acceptance, personal development, life goals, understanding of the environment, independence, and positive relationships. Therefore, the objective of this research was to examine the theoretical model of religiosity's effect on psychological well-being with resilience as a mediator for mothers with autistic children in Jakarta, Bogor, Depok, Tangerang, and Bekasi. The purposive sampling technique was applied to 184 respondents with a psychological scale. Also, structural equation modeling (SEM) was employed to assess relevant data, using analysis of moment structure (AMOS v.24). The results were reported to successfully and empirically matched the study objectives. These observations showed mothers in this circumstance were expected to intensely develop resilience by religiosity commitment, and therefore, instigating a very significant psychological well-being.

Keywords: Psychological well-being, autistic children, religiosity, resilience

1. Introduction

Autism, otherwise referred to as autism spectrum disorder (ASD), is described as a complex progressive condition among children, instigating communication, social interactions, and behavioral disabilities. The general symptoms include impediments in cognitive, language, character, and societal relations. Hooley et al. (2017) identified the ailment as a neurobiological developmental disorder involving a wide variety of challenging conducts, both chronic and lifelong. Moreover, the sickness appears complicated, and without any precise source. The majority of the cases are probably due to genetic susceptibility, triggered by certain environmental factors, including infection (rubella, cytomegalovirus), pregnancy, chemicals (food preservatives, coloring, flavorings, and other cooking additives), as well as pollutants, e.g. lead, or mercury from fish contaminated with mercury as a

vaccine preservative. Apart from social interactions, communication, and behavioral effects, about 75-80% of autistic patients experience accompanying symptoms of mental retardation, while 10-35% generate seizures. However, considering autism as a polymorphic genetic disorder and influenced by several factors, the sickness varies from mild to severe stages. Therefore, comprehensive management with accurate knowledge or expertise becomes greatly required.

The worldwide prevalence of autism, based on 2011 UNESCO data, appears approximately 35 million persons, were on average, 6 out of 1,000 are known, victims. In addition, 11 out of 1,000 and 8 out of 1,000 children were reported in America and Indonesia, respectively. As a consequence, the statistics of cases continue to increase annually. Director of Mental Health Development of the Ministry of Health, Diah Setio, estimated 112,000 out of 66,000,805 children in Indonesia suffer from autism, and are between the age range of 5-19 years, based on 2010 central statistics data. However, 6,314 out of 789,291 cases aged 0-14 years in Bekasi city were reported in 2018. These figures continue to expand drastically, and no official data on the number of children diagnosed with autism is available, according to the Minister of Health. Generally, diverse persons with the condition reside in urban settlements, including Jakarta, Bogor, Depok, Tangerang, and Bekasi (Jabodetabek), due to massive urbanization growth between 1970-1980, as big cities evolve, e.g. Jakarta (Evers, 2016).

Metropolitan experiences significantly impact lives, including families of children with autism, and the minimum period spent with loved ones tends to limit the quality of relationships and childcare, particularly for mothers. As an urban society, working mothers are common, but in the case of children with autism, various adjustments become very essential, including sacrificing incredible careers or continue with the respective endeavors due to expensive medical charges. These circumstances probably form an obstacle to a successful autistic management program, and the challenges appear more visible, as the family is unable to play an important role being the closest and primary factor in the child's development.

2. Literature Review

Ruseski et al. (2011) stated the effectiveness of various initiatives in handling children and adolescents with developmental constraints greatly depends on the family's absolute participation and support. Essentially, the program's success is barely centered on the responsibility of related educational institutions (Silitonga et al., 2020; Mujahidin et al., 2021). Parents are the foremost educators, and in managing the victims' conditions, the role of parents, father, and mother, is also majorly considered. This involvement is a significant aspect in treatment success, apart from professional and therapeutic functions (Ceka & Murati, 2016). Parents are believed to demonstrate the greatest influence on the children's development, with an estimation of approximately 92%, while therapists and teachers occurred between 3-4%. Therefore, it is common to discover autistic children with great potentials in achieving optimal development during adolescence and adulthood, including attending undergraduate education and working in certain fields according to special interests and talents (Gurbuz et al., 2019).

These patients tend to act excessively or inadequately but appear very distinct. These undue behaviors are potentially self-injurious, e.g. hitting, biting, and scratching one's self; aggressive, e.g. kicking, hitting, biting, and pinching others as well as tantrums e.g. screaming, crying, and jumping. Inadequate conduct is characterized by speech disorders, inappropriate social actions, certain sensual deficits. Therefore, victims are occasionally considered deaf, playing in an improper manner and unacceptable emotions, including laughing or crying without any reason, as well as daydreaming. This behavior causes the parents to be consistently observant, despite appearing frustrating, as children's needs appear relatively difficult to comprehend. According to Liao and Deng (2021), parents, specifically, mothers adopted body language or gestures during communication by observing physical signs, to build social relationships, e.g. as the child expresses sadness tears become obvious. However, effective communication is not an instant experience but requires consistency, seriousness, and openness to knowledge about the subject matter (Mansur et al., 2021). Therefore, it is not

uncommon for parents to observe certain psychological changes while caring for autistic children. Williams and Wright (2007) reported a series of unique and varying emotional events among the families. In addition, every parent demonstrates distinct responses and emotions as a child is diagnosed with autism. Particular reactions include expressing guilt or worry about wrong actions during pregnancy or in motherhood, a sense of lost dreams and aspirations for the child, as well as fear of the future, and therefore tend to demand specific changes or adjustments. Another reaction revealed certain parents were actively seeking information, including joining support communities to learn and share various experiences. However, particular families avoid or ignore information about topics related to autism, due to the inability to accept the child's condition or comprehend the prevailing situation.

Parents with autistic children suffer higher stress levels, compared to an opposite scenario, and are also more pessimistic or skeptical about the future. Despite several developmental disorders causing continuous grief, autism appears very distinct and is considered the single most complex case (Bashir et al., 2014), possibly due to limitations in social interactions. In general, mothers of autistic children record more depression, anxiety, and stress, attributed to financial constraints, inadequate facilities, incompetent staff, social and unnecessary family pressures, compared to fathers. Furthermore, the impact of autism potentially influences the parents' psychological well-being, and therefore, inconveniences suffered tend to prevent the search for an effective solution, in terms of childcare.

Dykens et al. (2014) show that the psychological well-being of mothers with autistic children reported higher psychological well-being and the ability to reduce stress by accepting the child's condition, without being pressured or overburdened. The mothers also demonstrated a closer relationship with family and the environment, felt independent and positive to develop an emotional connection with the autistic children. Also, caregivers with extensive psychological well-being generally include parenting as the most important aspect of life's goals, establish control over limitations, observe parenting demands in a broader perspective and initiate the optimum possible experiences. These parents tend to manage inner thoughts and emotions in dealing with various arising problems. Conversely, minimal psychological well-being instigates declining emotions with a burdensome view on parenting an autistic child.

Resilience appears as a significant factor influencing psychological well-being. This attribute refers to an individual's ability for personal development to ensure an improved standard of living and also triggers the capacity to accomplish responsibilities and solve problems effectively (Gardner, 2020). Furthermore, mothers with high resilience no longer focus on disappointment, sadness, and shame, but on searching for alternative solutions. Meanwhile, poor resilience causes overwhelming situations, resulting in inadequate management of patients' conditions.

2.1 Autism Spectrum Disorder

Autism originated from the Greek word "autos" meaning self and is used in psychiatry to indicate withdrawal symptoms (Chown, 2010). This disorder is described as the inability to interact with others, in terms of language, delayed mastery, echolalia, sentence reversals, repetitive and stereotypical play activities, strong memory routes, as well as an obsessive desire to maintain order. The condition is also perceived as a very complex pervasive developmental disorder (PDDs). Symptoms and characteristics vary in separate cognitive levels. These distinct patterns complicate the differential diagnostic process in certain instances. Particular definitions characterize autism as interference in interaction and communication.

In the book entitled "The Encyclopedia of Autism Spectrum Disorder", several concepts were portrayed on autism as a severe developmental disorder affecting an individual's capacity to communicate, interact socially, and respond appropriately to an environmental stimulus (Faras et al., 2010). In addition, the ailment is further described as a "spectrum of disorders", where the symptoms and characteristics appear in a very wide variety, ranging from mild to severe state. Therefore, it is a "developmental disorder" indicating the appearance of symptoms during the first three years of

childhood and continues for the entire lifetime. Despite the severe and complex nature, the exact cause of this disorder remains unknown. Victims exhibit difficulty in maintaining eye contact and socializing with others, show-specific attachment to an object, poor communication, tantrums, aphasia, and display aggressive or hyperactive actions, in addition to self-harm, and loss of emotional response. Kavaliotis (2017), reported the resilience of parents with autistic children is influenced by internal factors, including personal competence, tolerance for negative impacts, positive personal acceptance, self-control, religiosity, and individual efficacy. Also, resilience is impacted by external indicators, e.g. support from spouses, family, relatives, and friends.

Religious performances, otherwise called religiosity, are referred to as a major contributing factor to resilience. This aspect plays an important role in human existence, by developing a mental structure totally and consistently directed towards the creator of the absolute, satisfying, and supreme value, termed God. Consequently, individuals embrace religion to fulfill spiritual needs and obtain peace in a closer relationship and service to the Almighty. Villani et al. (2010) described religiosity as the level of spiritually professed knowledge, as well as an overall sacred comprehension. In this context, religiosity depicts an individual with divine attachment as a means of religious foundation in solving problems. Parents with special needs children, particularly autism, and with high religiosity, respond positively to these conditions as an inevitable part of life perceived as God's will. Furthermore, persons with high religiosity easily accept both conditions (mother and child), and therefore, exude unique strength to source for the best solution. This circumstance matched the research by Manning et al. (2019), where resilience in terms of autism, was dependent on several internal factors, including demonstrating solid faith in God.

2.2 Psychological Well-Being

Psychological well-being refers to a condition where individuals function effectively, are more emotionally stable, maximize full potentials, display sufficient maturity, and demonstrate positive mental health. However, wellness does not only refer to happiness or freedom from negative emotions, but also the extent of self-acceptance, existence of environmental control, self-autonomy, positive relationships with others, clarity of purpose, and a sense of personal development. Based on Ryff and Keyes (1995), the foundation of psychological well-being is dependent on a mentally sound person, with the ability to function positively. Individual dimensions with positive psychological functions are termed, wellness including a positive self-assessment of present and past life experiences (self-acceptance), the desire to offer quality connections with others (positive relations), independence (autonomy), capacity to effectively control life and surrounding situations (environmental mastery), and personal belief of focused living (life's purpose).

Ryff and Keyes (1995) described various factors influencing an individual's psychological well-being. However, the considerations in the present study include resilience, religiosity, self-efficacy, and social support for couples. Religiosity. Leondari and Gialamas (2009), confirmed the existence of a relationship between religiosity and psychological well-being. The results showed higher levels of psychological well-being and less trauma in individuals with great religiosity. Resilience. Herbert et al. (2013) defined resilience as an inherent ability to effectively adapt to severe tragedies, traumas, difficulties, and stress. Karimirad et al. (2018) revealed a significant relationship between resilience and personal life quality. Self-efficacy. Self-belief instigates active behavior towards finding potential solutions and the strength to confront various pressures. This circumstance also contributes to personal life quality.

3. Methods

3.1 Sample

This research employed a quantitative approach and involves 184 respondents with the following characteristics: 1). Mothers of children with autistic disorders or ASD 2). Having a partner/husband,

3). Residing in the Jakarta, Bogor, Depok, Tangerang and Bekasi regions. Also, a purposive sampling technique was adopted, with the consideration of limited data on the number of children with autism in the selected locations.

3.2 Instrument

Questionnaires were used to collect the data, involving five psychological scale instruments, including religiosity, self-efficacy, partner social support, to measure exogenous/independent variables, and resilience scale to determine mediator variables, as well as psychological well-being to evaluate endogenous/dependent parameters (Y). However, the fifth model was developed, using a Likert scale with six alternative inputs, termed SS (very appropriate), S (appropriate), AS (less appropriate), ATS (less inappropriate), TS (inappropriate), and STS (very inappropriate).

3.3 Procedure

Furthermore, structural equation modeling (SEM) was applied as the data analysis technique and is processed using the AMOS program to test the measurement model suitability with existing field data, as well as the proposed hypothesis. The use of SEM achieved two primary objectives, including the determination of the model fitness, based on available data, and examine previously constructed hypotheses.

4. Results

Analyzing the first or major hypothesis was to confirm religiosity's effect on psychological well-being, using resilience as a mediator. The result revealed a complete match with the empirical data.

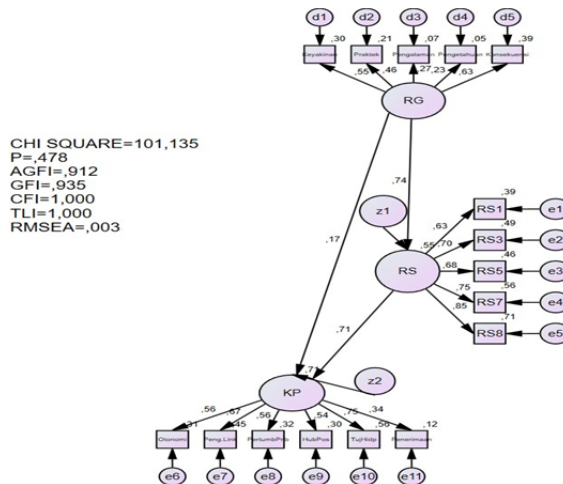


Figure 1: Model Analysis Test Results

Based on the analysis results, the standardized regression weight of RS resilience to KP psychological well-being was estimated as 0.726 with $p = 0.003$, indicating a positive and significant effect. This showed a direct effect of a mother's resilience with an autistic child on personal happiness, both in terms of self-acceptance, quality social relationships, life's goals, self-worth, as well as effective environment control. Based on the analysis, the standardized regression weight of RG religiosity to

KP psychological well-being was estimated as 0.124 with $p = 0.596$, indicating no significant impact. Based on the analysis, the standardized regression weight of RG religiosity to RS resilience was evaluated as 0.872 with $p = 0.000$, indicating a positive and significant influence. Sobel test results showed a value of 2.123 with $p = 0.017$. This estimation indicated the resilience significantly mediated religiosity's effect on psychological well-being.

5. Discussion

Resilient individuals can overcome stress and difficulties, to achieve an optimal and functional life, both against specific barriers at certain developmental stages and entire existence (Smith & Osborn, 2015). From a lifelong perspective, resilience originated from an extensive process involving protective and varying risk factors between individual progressive phases (Luthar et al., 2015). The majority of respondents in this research recorded a high resilience, although psychological well-being was barely moderate. Moreover, the subject characteristics, mostly middle-aged housewives, with reasonable education at a bachelor's degree level, showed the possibility to learn from life experiences, and build effective problem-solving competencies. Armed with extensive insight into various obstacles, these mothers were able to demonstrate adequate resistance to achieve sincere happiness. Despite not only dealing with bitter experiences, but particular respondents were also able to effectively utilize functional skills, to build adaptability and flexibility. Most participants have children with autism aged 6-10 years, and several undergoing therapy, both at home, clinics, and special schools. This condition embraces the opportunity to develop an adaptation pattern in challenging situations, resulting in higher resilience. Conversely, the current pandemic does not necessarily increase psychological well-being, due to unpredictable conditions, as these families certainly suffer more complex problems, compared to normal homes.

Research by Koenig (2012) results revealed individuals with strong religious beliefs reported extensive life satisfaction, sufficient personal happiness, and lower negative impacts of traumatic events, compared to the normal state. Meanwhile, Myers (2000), portrayed religion as an important influence on humans, as practical adherence probably ensures an improved life. Furthermore, a study of Seligman and Csikszentmihalyi (2000) described the values in religious teachings as significant, to overcome various psychological problems by building positive emotions, and therefore influencing psychological well-being. Moreover, previous papers also denoted religiosity as an essential factor in the improvement of psychological well-being. However, the results of this research were not in line with the above report, due to most respondents exhibiting a high religiosity level, but moderate psychological well-being. This observation matched the reports from Elosúa (2015), where no significant effect of religiosity on psychological well-being was recorded but was more influenced by the gratitude variable. Furthermore, Elosúa (2015) described the gratitude felt and expressed by an individual was believed to be more reconciled with unpleasant conditions. Meanwhile, in this research, religiosity affects psychological well-being through resilience variables.

Religiosity refers to an absolute relationship between humans and Gods, resulting in total dependence on the ability to meet daily provisions, both physically and spiritually. The presence of autistic children with the need for high parental commitment and complex handling with high religiosity appears as a condition, where the religious individual is expected to accept God's overall decisions. This circumstance inspired resilience in the face of difficulties. Kavaliotis (2017), research on religion and resilience of parents of children with autism spectrum disorders confirmed a relationship between religious values and parental resilience. Also, resilience is a key concept in dealing with autistic conditions, where mentally stable parents in a position to meet these special needs, are not expected to drown in loneliness and isolation, known to adversely affect families and disrupt composure.

Previous research by Myers (2000), confirmed the importance of religion in human life, as proper adherence possibly leads to an improved life. The resilience of parents with autistic children is a key concept in facing associated challenges, where mentally stable parents in a position to meet the special needs of autistic children, are not expected to drown in loneliness and isolation. Parents,

specifically mothers with high religiosity, employ various sources to strengthen resilience. However, the effect of this religiosity aspect appears stronger with the support of resilience, including the ability to recover after experiencing challenging situations. The subjects, mostly housewives in the mature/middle ages, demonstrated sufficient education equivalent to a bachelor's degree level and have been in the process of developing religiosity with a close relationship to God, where life's events appeared more easily and gracefully accepted. Therefore, supporting the stabilization of resilience, in terms of expressing enthusiasm and not submitting to difficult situations, tends to develop greater psychological well-being. These parents showed sufficient self-acceptance, were able to establish positive relationships with the environment, possessed strong self-control, and are growth-oriented in terms of achieving personal goals.

6. Conclusion

Based on the results and discussions, the structural model of religiosity's effects on psychological well-being, using resilience as a mediator matched the empirical data. Also, a direct, positive, and significant impact of resilience on the psychological well-being of mothers with autistic children in Jakarta, Bogor, Depok, Tangerang, and Bekasi was observed. However, no effect of religiosity was reported. Furthermore, resilience was known to significantly mediate religiosity's effect on psychological well-being. The study used a limited number of samples for areas with densely populated areas and did not represent cases of children with autism nationally for a large area of Indonesia and a large population. Religiosity and resilience of mothers of autistic children are not further elaborated because the applied quantitative research methods limit the use of factors through a psychological scale. Apart from that, many other factors contribute to the psychological well-being of the mother of the autistic child. For further research, it is suggested to involve more factors, especially those related to household happiness and harmony, as well as mutual support by involving many samples with a combination of qualitative and quantitative methods.

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