

Psychological well-being among mothers of children with autism spectrum disorder: The role of family function

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ABSTRACT

The mother of children with autism is the most vulnerable person to have stress and depression. Therefore they need positive psychological well-being to optimize the caring of children. Family is the primary environment in supporting the mother's mental health. This study aimed to find out how family functions correlate with psychological well-being among the mother of a child with autism. A quantitative approach was applied, involving 142 mothers who had autistic children selected through purposive sampling techniques. The data was collected using Family Functioning and Psychological Well-being instruments. The data was then analyzed with regression analysis. The results show that family functioning and psychological well-being are correlated significantly. The more effective family function based on the perception of the mother, the higher the psychological well-being of the mother, and vice versa. Problem-solving, communication, affective response, and role are dimensions that influence psychological well-being, while behavior control and affection dimensions are not significant. The results of the study can provide input suggestions for the government, such as through family empowerment regarding the importance of supporting and optimizing the role of family members to stimulate the psychological well-being of mothers of children with an autism spectrum disorder.

Introduction

The parents of children with growth problems become the most vulnerable caregivers to suffer stress and may get a psychological problem. One type of growth problems on children is Autism Spectrum Disorder (ASD), further defined in this article as autism. Autism is a developmental problem with specific characters. Children with autism might have difficulty in developing social interaction capability and communication skills, such as shown by the lack of interest and limited social ability (Desiningrum, 2016). The manifestation of autism varies considerably depending on the level of growth, the chronological age of the child and followed by several behavior symptoms such as hyperactive, impulsive, aggressive, self-harming behavior, angry and delayed toilet training (Duarte, Bordin, Yazigi, & Mooney, 2005).

Autism has a prevalence which continues to increase. Before the 2000s period, there were two to five, or up to 15 to 20 children with autism per 1000 birth, or 1 to 2 children with autism per 1000 world populations. In 2000, the ASA (Autism Society of America) revealed that there were 60 children with autism per 10.000 birth, or around one

child per 250 world populations. In 2014, the CDC (Centers for Disease Control and Prevention, USA) reported that the rate of children with autism in the USA was 1.5%. That number had increased by 30% in two years (Kemenpppa, 2018). Other data showed that the estimated number of children with autism was 1 of 150 children (67 of 10.000) in the United States (Garrecht & Austin, 2011). Autism prevalence in Asia was 14.8 per 10.000 between 1980-2009 periods, while in China there was 10.3 per 10.000 children, of age 2-6 years old in 2000 ahead (Sun, Allison, Auyeung, Baron-Cohen, & Brayne, 2014).

In Indonesia, the prevalence of autism disorder is quite high (Desiningrum, 2016). The number of children age 5-14 with ASD was estimated for about 90.000 in 2010. In 2015, the number of children with autism was estimated at reaching 12.800 children while the number of children with autism spectrum was estimated at around 134.000 children.

Parents who raise children with autism face unique challenges. The parents of children with autism tend to have a poor quality of life, experience depression and have pessimistic view toward the future compared with the parents of children with other disabilities and parents of general children (Cappe, Wolff, Bobet, & Adrien, 2011; Johnson, Frenn, Feetham, & Simpson, 2011). These symptoms are more prevalent in mothers rather than fathers, which might be related to the role of mothers as the creators of family environments that handle the situation of a family (Altiere & von Kluge, 2009). Moreover, a mother as the primary caregiver of the child tends to a develop guilty feeling, tenseness, and worries toward her childcare skills (Koydemir & Tosun, 2009; Jose, Gupta, Gulati, & Sapra, 2017). During the first five years of children's growth, the development of communication and social skills and also basic life skills can be predicted through the interactions between mother and child (Cram, et al., 2001).

The stress level of parents during childcare affects childcare functions and the relation between parents and children (Mitchell, Whittingham, Steindl, & Kirby, 2018). One of the personal abilities involved in problem-solving and stress management is psychological well-being. Someone who has a high rate of stress, depression, and mentally ill is a part of people with poor psychological well-being (Desiningrum, 2018). Mothers of children with autism tend to have low psychological well-being (Cox, Eaton, Ekas, & Van Enkevort, 2015). Therefore the mother's coping strategy becomes ineffective. This ineffective coping strategy is apparent, such as in adaptation toward the child's limitations (Benson, 2010). The psychological well-being condition of mothers with children with autism, indicated by the quality of life and good mental health, affects the mothers' capability to adapt to the children's conditions thus optimizing the childcare (Hsiao, 2016). Therefore, having psychological well-being is important for mothers, because if mothers can appreciate themselves, they can provide better childcare and education for the children (Neff & Faso, 2015).

Research in intervention and education in the family assumed that the interactions among family members influeces the success of intervention programs (Grace & Gleasure, 2017). There is one psychological construct that needs further examination: family function. Family function is the activities and interactions among the entire family members to assist the fulfillment of family goals, provide instruments and source of emotional support and to encourage the flourishment of family well-being and developments among all family members (Mccreary, 2014). Epstein for forty years, had been developing a model of family function that involves six dimensions: affective

involvement, affective responsiveness, behavior control, communication, problem-solving, dan roles (Epstein, Ryan, Bishop, Miller, & Keitner, 2003; Whittingham, 2014).

In the perspective of system theory, a family is a sub-system of a more complex system (extended family, school, community). There are important assumptions related to the model. First, the involvement among family members. Second, if a part of the family is separated from the family system, then it cannot be understood completely. Third, on the contrary, family function cannot be understood through a part of family members only. Fourth, there are crucial factors that can predict the manifestation of a particular behavior in family members: family structure and family organization. Fifth, family member's behavior is also affected by the interaction pattern of the family system (Miller, Ryan, Keitner, Bishop, & Epstein, 2005).

In the ecological perspective of family system, some factors can affect the development of children with autism: adaptation, cohesion, social support, family dynamics and family function (Greenlee, Winter, & Diehl, 2018). Other than these factors, an excellent familial relationship can provide individuals with better stress management and with a better problem-solving attitude, giving parents with autistic children a better quality of life. (Derguy, Roux, Portex, & M'bailara, 2018). This positive attitude is essential since family function in a family with autistic children will experience some disturbance, such as: they cannot experience the daily life spontaneously but should be in a well-structured and organized manner; it is necessary for mothers to adapt their careers; less time for mothers to finish their chores; and the mothers' assumption that people have poor understanding toward autism (Meirsschaut, Roeyers, & Warreyn, 2010).

Researches in Indonesia showed that family function on children with autism supported the family adaptation process toward the child's autistic condition. Good family function would stimulate the involvement of parents, extended family, and relatives to minimize negative emotional conditions that can arise during the childcare process (Fahrudin, 2005; Retnowati, Widhiarso, & Rohmani, 2003). Those research results had not specifically engaged on individual well-being, particularly in the effect of family function toward the mother's psychological well-being. Hence, it needed a follow-up research to analyze the importance of parental participation and also the inclusion of extended family and relatives in supporting mother of children with autism so that it could stimulate mother's psychological well-being. This research explored the correlation between family function and the mother's psychological well-being of children with autism. Furthermore, it would analyze the impact of some dimensions of family function on the mother's psychological well-being of children with autism.

Method

This research employed a quantitative correlational approach. The data is collected using psychological instruments in a self-report form. After research subjects had been determined, the subject was given an informed consent form. The researcher then provided instrument form to be filled in by the subject who were waiting for their children at school or therapy facilities.

Research Participant

The subjects on this research were selected through purposive sampling method, with a total of 142 subjects. The subjects shared characteristics as mothers with an autistic child (of age 5-17) attending schools and/or therapy facilities in various cities in Central Java. The distribution of the geographical location of the subjects is as follow: Semarang (61), Kendal (31), Jepara (20) and Pekalongan (30).

Research Instrument

This research used Family Assessment Device (FAD), developed from McMaster Family Functioning Model (MMFF) (Epstein et al., 2003) to measure Family Function. Meanwhile, to measure psychological well-being, this research used the Psychological Well-being Instrument, which consists of 33 items (Ryff, in Keyes & Magyar-Moe, 2004). Both tools were translated into Bahasa Indonesia by two interpreters using translation-back translation, and adapted items were adjusted to the cultural context and conditions of family in Indonesia, and finally were reviewed by two experts.

FAD consists of six dimensions with 55 items distributed into several dimensions: affection engagement, behavior control, problem-solving, role, communication, and affection response. Examples for this instrument are: "My husband could listen to my complaints about the child"; "Grandfather/ grandmother is helping me during the child's therapy process". The discrimination index of the instrument ranged from .36-.95 with reliability of .95.

Psychological Well-being Instrument consists of several dimensions as follow: self-acceptance, positive relationship with others, independence, environment control, life objectives, and self-growth. Examples from this instrument: "I am proud of everything I have done in caring for my child"; "I allocate time for my hobbies in between my daily duties." The discrimination index of the instrument ranged from .31-.74 with the scale reliability of .91.

Data Analysis

Simple regression analysis technique was applied to analysis the data. The correlation between family function with psychological well-being condition and the impact of each family function dimension toward psychological well-being condition was analysed.

Results

As shown in Table 1, the simple regression analysis resulting F=5.614 with the significance of .008. This result show that there was a correlation between family function and psychological well-being. The result also revealed the correlation coefficient R=.708, means that the more effective family function, the higher psychological well-being of the respondents. Subsequently, the result of $R^2=.501$. Thus, the psychological well-being variable can explain the family function variable by 50.1% of the varians score.

Table 1
The Simple Regression Analysis of Family Functioning and Psychological Well-being

Statistic	Value	
R	.708	
R Square	.501	
Adjusted	.489	
R Square		
Std. Error of the Estimate	2.213	
F value	5.614	
Sig. F	.008	

The contribution of each dimension of family function toward psychological well-being is shown in Table 2. The significance value showed a significant correlation (p< .05). Based on Table 2, problem-solving, communication, and roles correlated positively with psychological well-being. Problem-solving was the most significant influence on psychological well-being. On the other hand, affective involvement and behavior control did not correlate with psychological well-being.

Tabel 2
Correlation between Dimensions of Family Function with Psychological Well-being

Dimensions of family function	Standardized Coefficient (β)	t value	Sig.t
Problem Solving	.399	3.445	.002*
Communication	.271	2.137	.006*
Role	.067	1.183	.041*
Affective Response	.071	1.402	.026*
Affective Involvement	.021	1.012	.162
Behavior Control	.028	1.037	.221

^{*}p<.05

Discussion

This research shows that there is a significant correlation between a family function with the psychological well-being of mothers of children with autism. The people with psychological well-being tend to cope with stress (Keyes, Shmotkin, & Ryff, 2002), in this case, mothers of children with autism (O'Brien, 2016; Schwartz et al., 2018), who experienced stress because of difficulties in communicating with their autistic children. There are three prominent indicators of children with autism: having difficulties in communicating, such as in starting or in maintaining focused communication; preoccupied hindrance or stiffness; and repeated activities (Desiningrum, 2016; Schwartz et al., 2018).

The result of this research finds that most psychological problems could be overcome through family management (Estrem, Thoyre, Knafl, Frisk Pados, & Van Riper, 2018). Family-based care on family systems theory (FST) becomes the primary solution in handling family members' problems (Pratt & Skelton, 2018). Through the optimization of family function, families could minimalize stress faced by parents or children (Gallo, Wertz, Kairis, & Blavier, 2018; Payne et al., 2017). The family function might encourage resilience and improve the individual quality of life so that it could prevent depression and

might support the individual psychological well-being (Lu, Yuan, Lin, Zhou, & Pan, 2017). This research is relevant to some previous researches, which showed that family function could help mothers of children with autism, and mothers might have better psychological well-being.

The following analysis of this research shows that the dimensions of family function, which provide a significant contribution to mothers' psychological well-being are problem-solving, communication, roles, and affective response. A family will never abandon the children with autism at home which certainly may affect family members' daily activities so that it needs an effort to build a positive relationship between all family members (Grace & Gleasure, 2017). Due to that condition, it is necessary to resolve any problems effectively. The problem-solving skills needed in the childcare process of an autistic child are therapy cost, caring, and education for the child (Chan, Lam, Law, & Cheung, 2018).

To optimizing the problem-solving skills, the family needs communication support and an appropriate relationship among family members. Larson (2008) further defined problem-solving skills as a family member's ability in overcoming any problems by applying family function effectively in order to build the psychological well-being of all family members. During caring children with autism, a balanced distribution of roles among family members and a warm, affective relationship is urgently needed so that the family may support mothers of children with autism (Altiere & von Kluge, 2009). The result of this research is also relevant to the theory assuming the contribution of role dimension and the significance of affective response toward the psychological well-being of mothers of children with autism.

The result of this research shows that behavior control and affective involvement dimensions do not significantly contribute to psychological well-being. When mothers, as the primary caregivers to autistic children, are feeling sad or upset during the childcare process, it would be better if other family members do not involve affectively, such as by feeling sad or upset as well. On the contrary, other family members, such as the husband, should give positive emotion to the mother (Derguy et al., 2018). Behavior controls do not correlate toward mothers' well-being since as the primary caregiver, the mothers are the most understanding people among others in caring for their children, so that they may regulate their own behaviors (Benson, 2010).

Psychological well-being is an essential aspect of childcare. It relies on the form of family systems (Chan & Lam, 2016). In the case of families with autistic children, family function is part of family systems and correlate significantly to the mother's psychological well-being. Nevertheless, there are other aspects that also affect the psychological well-being of mothers of children with autism, such as social relationships, personal competency, religiosity, personality, sex, social-economic status (Pinquart & Sörensen, in Desiningrum, 2010). Previous research found that the presence of groups for parents who have autistic children provides the parents with an opportunity to share knowledge related to autistic childcare (Bray, Carter, Sanders, Blake, & Keegan, 2017). Such social support might become a significant factor in developing mothers' psychological well-being (Bessette Gorlin, McAlpine, Garwick, & Wieling, 2016).

There are several limitations to this research. The first is unable to classify the type of autistic disorder based on the level of conditions that may affect the mothers' efforts in childcare process. Therefore, we suggest that future research might be able to look into a specific spectrum of autism. The second limitation on this research is that this research has not taken into account the correlation of several demographic factors toward the well-being of mothers with autistic children, such as the type of autism, age, sex, and economic income. Therefore, we suggest that future research might be able to take these variables into their statistical model, to better understand the correlation between demography aspects and the psychological well-being of mothers with autistic children.

Conclusion

This research concludes that family function contributes to the psychological well-being of mothers of children with autism. The dimensions of family function that contribute significantly toward the psychological well-being are problem-solving, communications, affective response, and roles. As an implication of this study, we suggest that the government might develop some programs for Indonesian families through family empowerment actions (for example BKKBN) whose aim is to provide assistance and optimization on family members' roles in order to stimulate psychological well-being of mothers of children with autism.

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