



Grandparents' roles and psychological well-being in the elderly: a correlational study in families with an autistic child

Dinie Ratri Desiningrum

Faculty of Psychology, Diponegoro University, Tembalang, Semarang, Indonesia

KEYWORDS

The role of grandparent;
Psychological well-being;
Elderly;
Grandchild;
Autism spectrum disorder

Abstract

Objective: The purpose of this study was to explore the family roles and psychological well-being of grandparents who are caregivers of grandchildren with autism spectrum disorders.

Method: The study used quantitative methods with a correlational design. A self-administered questionnaire was used as an instrument to measure the variables of psychological wellbeing and the grandparenting role. This research involved 108 grandparents from Semarang, Jepara and Kendal, obtained through a quota-purposive sampling technique. Quantitative data analysis was based on simple regression analysis.

Results: The study results showed $r_{xy} = 0.397$; $P = .000$ ($P < .05$), which indicates a positive and significant correlation between the role played by grandparents and their psychological well-being.

Conclusions: The test results indicate a significant correlation between the roles of grandparents and their psychological well-being. The greater the role played by grandparents, the higher psychological well-being they experienced, and vice versa. Grandparents play an important role in families where there is a child with autism; they take care of the child when the parents are not at home, help with the cost of therapy, and take care of them when sick.

© 2018 Elsevier España, S.L.U. Todos los derechos reservados.

Introduction

Autism spectrum disorder (ASD) is a neurodevelopmental disorder characterized by the failure of social interaction, communication difficulties and repetitive and restrictive behavior, with onset before the age of three. Included in the diagnostic criteria for ASD are autistic disorder, pervasive developmental disorder not otherwise specified (PDD-NOS), and Asperger's disorder¹. The Childhood Autism Rating Scale is commonly used to evaluate the behavior, adapta-

tion to change, listening responses, verbal communication, and interaction with others of children aged two and above. The children's behavior is then scored and ranked based on a comparative scale for normal children at the same age².

In recent years, the prevalence of autism has increased. It is predicted that the number of children with autism is 1 in 150 (1 in 10,000) in the United States³. The prevalence of ASD in Asia has been around 14.8 per 10,000, from 1980 until the present, and in China, it has been 10.3 per 10,000 children aged 2-6 years, from 2000 until the present⁴. The

E-mail: dn.psiundip@gmail.com

incidence of autism in Japan is 27.2 per 10,000⁵. In Indonesia, from klinikautis.com, no national data about the number of children with autism has been collected; however, it was estimated that in 2013 there were more than 112,000 children with autism at the age of 5–19 years old⁶. Other data suggest that the city of Palangkaraya has the highest concentration of children with autism in Indonesia. Nearly 200 children in a population of about 250,000 are affected, making the prevalence of autism 1 in 250 inhabitants or the equivalent of 40 per 10,000 people⁷.

Parenting a child with autism is not an easy matter. The characteristics of autism, which usually include hyperactivity or hypoactive behavior, could become a burden for caregivers⁸. Hyperactive behavior manifests in very active movements that could make the caregivers feel overwhelmed, while hypoactivity is manifested by slow and unwilling movements that often make caregivers feel annoyed. Furthermore, some children with autism have developmental disabilities that hamper their independence. Although they are 5–9 years old, they have to be treated like babies. Communication barriers in children with autism become a major obstacle in caring for them. Children with ASD do neither recognize nor understand important nonverbal behavior from the environment, and they ignore nonverbal cues and social cues such as facial expressions that help social interaction⁹. These communication barriers can make it difficult for caregivers to transfer educational or life values to the child. They result in autistic children becoming more developmentally impaired and, in some cases; they create misunderstandings that make the caregivers feel irritated and treat children with autism badly. Physical and psychological aggression towards children with autism is mediated by the effects of rearing stress¹⁰.

Autism is spread throughout Indonesia, from cities to villages and from the rich to the poor. Indonesian society culturally embraces collectivism, and extended families commonly live together. In Europe, grandparents who have a role in rearing their grandchildren enjoy better health and well-being than those who are not caregivers of their grandchildren¹¹. In Indonesian culture, grandparents are often active members of the family and have a role in child rearing. The kinship of children with parents and grandchildren with grandparents are very close, such that grandparents cannot be separated from the growth and development of children. Young parents therefore tend to feel safe entrusting their children grandparents rather than to babysitters. However, when there is a child with autism in the family, subjugated tensions may cause problems between the child's parents and grandparents.

Since 2000, the number of grandparents living with grandchildren has increased by about 30% per decade. In 2000, about 2.3 million grandparents aged 60 or older lived with grandchildren under the age of 18. By 2010, this number had increased to 3.1 million¹². Approximately 915,000 or about 30% of these grandparents had primary responsibility for at least one grandchild, including meeting basic needs such as food, clothing, and shelter. The data that is available demonstrates that in Indonesia it is quite common for children to be reared by their grandparents. Grandparenthood occupies an important part of the life cycle and has an important impact on the family. This impact can be characterized in terms of gender roles, grandparenting styles, and direct

and indirect patterns of influence from grandparents to grandchildren¹³.

One in 166 older people will become a grandparent of a child with autism. The role of a grandparent may become complex if the parents of autistic children experience depression due to social isolation and financial burden, or the household head is a single or divorced parent. The grandparents will then be exposed to two loads; adapting to the conflicts that arise and at the same time providing emotional and instrumental support¹⁴. Not all grandparents are involved in the care of grandchildren with autistic disorders¹⁵. However, among those who are involved, social stress, financial problems, and the impact on health of the whole family including the grandparents, were observed¹⁶.

Grandparents who have a role in taking care of their grandchildren can experience stress, anxiety, and depression. If they do not have social support from family members or other social environments¹⁷; conversely, a positive perception of the grandparent-grandchild relationship sees it as significant and important, where the emotional closeness of grandparents to their grandchildren can improve the quality of life and health of grandparents¹⁸. Healthy and happy grandparents are the focus of much research on successful aging today. Grandparents can attain happiness and success if they feel good psychologically¹⁹, which is achieved through psychological well-being. The concept of grandparents' psychological welfare was pioneered by Bernice Neugarten in 1961, when she defined it as a psychological condition achieved by a person at an advanced age²⁰ and related it to the theory of life satisfaction.

According to Ryff²¹, an individual in a condition of psychological well-being is one who has positive psychological functioning. Ryff²¹, asserted that, psychologically, people who have positive attitudes toward themselves and others are those who recognize and accept various aspects of themselves, both good and bad; feel positive with their past life (self-acceptance); have positive relations with others; are capable of performing and directing their behavior independently; have autonomy; have purpose in life; can continue to develop their own potentials based on their ability (personal growth); and are able and allowed to take an active role in meeting their needs from their environment (environmental mastery)²².

Inconsistent parenting between parents and grandparents results in imbalance in children's psychological development. Grandparents usually show more affection and freedom to their grandchildren, exceeding what they gave to their own children. A study conducted in Tonga Hawaii²³ about grandparenting proposed that grandchildren are a center of cultural preservation, adapting the custom of local culture. It found that grandparenting entails protective factors that consist of a sense of unconditional love, reciprocity between grandparents and grandchildren, loyalty to their grandchildren, applied discipline, and prayer from grandparents throughout the children and grandchildren's journey of life. There has been no research on the role of grandparents in rearing children with autism in Indonesia and its impact on the well-being of the grandparents.

The purpose of this study was to discover if there is any correlation between the roles of grandparents and their psychological well-being in families having children with autism. The hypothesis of this study is that the roles of

grandparents are associated with their psychological well-being in families having children with autism.

Methods

Research design

The study used a correlational design with two variables²⁴. The data were collected by a self-administered questionnaire using a psychological scale. The variables used in the research were grandparent's role as predicting variable and psychological well-being as the criterion variable. The inclusion criteria of research subjects were: *a)* grandparents; *b)* who were living with grandchildren with autism, and *c)* who were not suffering from chronic or acute illnesses.

Research subject

The sampling technique used was quota-purposive sampling²⁵ within the inclusion criteria of the subjects. The subjects of the study were 108 grandparents who have grandchildren with autism at the: *a)* Sekolah Luar Biasa Negeri (Government Special Education School) in Semarang (49 grandparents); *b)* Yayasan Terapi Autis (Autism Therapy Foundation) in Kendal (22 grandparents); *c)* Yayasan Bintang (Star Foundation) in Semarang (15 grandparents); *d)* Sekolah Autisme (Autism School) in Jepara (17 grandparents), and *e)* Sekolah Autis Putra Mandiri (Autism School "Putra Mandiri") in Semarang (5 grandparents).

We have informed consent from all participants. Table 1 gives the demographic characteristics of the participants.

Data analysis

The data collected and analyzed to determine the correlation between grandparents' role and their psychological well-being using Pearson correlation coefficient. To observe the contribution of the grandparents' role to their psychological well-being, an analysis using simple linear regression was conducted using SPSS 21.0 software.

The measurement tool

This research used two measurement tools. The first of these was a measure of psychological well-being which consisted of 33 questions with 21 positive items and 12 negative items. Psychological well-being was defined as the individu-

al self-evaluation that they can function optimally through the roles in their life. The items for this were derived from psychological well-being indicators²⁶. The second instrument measured the grandparents' roles by asking if the participants acted as culture transfer agents, moral and ethical providers, financial providers, emotional support providers, supporters of well-being, and providers of childcare²⁷⁻²⁹. This consisted of 30 items.

Results

Measurement tool pretests

Table 2 shows that 25 items on the grandparent roles scale and 30 items on the Elderly Psychological Well-being scale were valid.

This study using the formula coefficient Cronbach's alpha for reliability test and Table 3 shows that the valid items shown in Table 2 had high reliability.

Descriptive statistics

Tables 4 and 5 used an analysis of the questionnaire results to categorize the contribution of the participants' roles as grandparents in families with child ASD sufferers and their level of psychological well-being. They show that the contributions of most of the grandparents were categorized as high; nearly over 80% of them had average or high levels of psychological well-being.

Inferential statistics

Correlation and contribution of grandparents' roles with elderly psychological well-being

Based on the analysis using SPSS 21.0, the value of product moment correlation coefficient shows the amount of 0.397 and *P*significance level of .000, which means that there is a positive, significant, and strong correlation between the roles of grandparents and elderly psychological well-being. The value of R-square from the simple regression analysis was 0.296, which shows that the roles of grandparents contributed 29.6% to elderly psychological well-being.

Correlation and contribution of each aspect of grandparents' roles to elderly psychological well-being

Table 6 shows the correlation and contribution of grandparents' roles with the elderly psychological well-being variables. Two of the grandparent roles variables show a relatively strong correlation with elderly psychological well-being, while others variables had weak and average correlations. The grandparents' role as financial and emotional support providers showed a 0.408 correlation with psychological well-being, and their role as the providers of childcare showed a 0.452 correlation. Other variables had weak or average correlations.

Discussion

The interaction of grandparent with their families usually had an effect on the family's psychological condition. A sur-

Table 1 Demographic characteristic of the research participants

Characteristic	Number
Age: 60-75/76-90	69/39
Sex: female/male	78/30
Age of grandchildren with autism:	
Toddler/6-12 years old	40/68
Married/widowed or divorced: yes/no	57/51

Table 2 Measurement tool validity pretest—grandparent roles and psychological well-being

Variable	No. of initial items	Range of validity	Range of validity	No. of valid items
Grandparents' roles	30	0.00-0.80	0.32-0.95	25
Psychological well-being	33	0.00-0.82	0.31-0.82	30

vey was conducted by Keeling³⁰, with 380 grandparents, focusing on their personality traits and the frequency of their interaction and activities with their grandchildren. It showed that of the 40% of the grandchildren who had daily or weekly contact with their grandparent, one-third stated that they engaged in regular activities with their grandparent and one-fifth of the subjects said that they had special relationship with their grandparent. This suggests that grandparents who frequently interacted with their grandchildren influenced to their grandchildren's life and development.

A quick review of the main conceptual idea and empirical findings on the relationship of grandparents with grandchildren suggested four main themes in understanding the relationship between generations: the historical context, the importance of the relationship, the individual changes over time, and variations in culture³¹. The dynamics within a family can give grandparents significant parenting responsibilities

for their grandchildren. These are related to the household system, social and environmental factors, beliefs, and the practice of culture³².

Parenting by the grandparents, surely, will affect their own well-being. Research by Gillian et al³³ in the United States showed that the parenting role has proven to be a significant source of stress for the elderly. In general, this study showed that caregivers have higher stress levels than non-caregivers. For women, the number of orphans and the adults who should be taken care of will result in stress. In families with special-needs children, including those with autism, the burden of parenting becomes heavier. Caregivers have to deal with the everyday reality of these burdens, which may include a child's difficulties in communicating and expressing desires, the inability to comprehend stimuli from the environment, and repetitive imitative or unusual behaviors. These become obstacles during the parenting process⁸.

The hypothesis of this study was that the roles of grandparents are associated with their psychological well-being in families having children with autism. Testing this hypothesis using product moment technique and simple regression analysis using SPSS 21.0 shows the value of $r_{xy} = 0.397$ with $P = .000$ ($p < .05$). This indicates a significant correlation between the roles of grandparents and their psychological well-being, where the extent of the role played by grandparents is directly proportionate to the psychological well-being they experience.

Psychological well-being is determined by the extent to which people feel a purpose in life, whether they realize their potential, the quality of their relationships with others, and the level of individual responsibility they have for their own lives where the evaluations or judgments of others act as an evaluation of their life experience²¹. According to Ryff which cited by Papalia et al³⁴, psychological well-being is very important for the elderly. With good psychological well-being, they will be happier, have life satisfaction, and experience no symptoms of depression.

Results of the current study indicate that the level of elderly psychological well-being in Semarang, Kendal and Jepara of 108 grandparents can be seen in Table 5. It shows that the psychological well-being of 36 participants (33.33%) can be categorized as high, 53 (49.07%) as average, and 19 (17.59%) as low. In general, those categorized as having high well-being were able to take active roles in fulfilling their individual needs as well as the needs of their grandchildren with autism. Those with high psychological well-being were autonomous, they could face social pressure and the burdens of caring for their grandchildren, and they showed positive attitudes toward themselves. The elderly with average well-being displayed positive acceptance and mastery in the family, are autonomous, had purpose in life and good

Table 3 Measurement tool reliability pretest—grandparent roles and psychological well-being

Variable	No. of items	Reliability
Grandparents' roles	25	0.92 (very reliable)
Psychological well-being	30	0.89 (very reliable)

Table 4 Frequency distribution of grandparents' role

Category	Frequency (%)
High	67 (62.4)
Average	25 (23.15)
Low	16 (14.81)
Total	108 (100.00)

Table 5 Frequency distribution of psychological well-being

Category	Frequency (%)
High	36 (33.33)
Average	53 (49.07)
Low	19 (17.60)
Total	108 (100.00)

Table 6 Summary of correlations and contribution of grandparents' roles with elderly psychological well-being variables

Variable	Correlation	Contribution (%)	Correlation interpretation
Role of grandparent and psychological well-being	0.397	29.6	Average
Culture transfer agent and psychological well-being	0.171	12.7	Weak
Moral and ethical provider and psychological well-being	0.312	21.8	Average
Financial provider and emotional support provider and psychological well-being	0.408	31.1	Fairly strong
Supporter of family member well-being and psychological well-being	0.199	13.9	Weak
Provision of childcare and psychological well-being	0.452	29.9	fairly strong

personal development, and had positive relationships with the family. This included taking care of the grandchildren. There were 19 participants with low levels of psychological well-being. They faced difficulties in improving and developing themselves, adapting their attitude and behavior to new situations, and having positive thoughts about the meaning of their life. Their responses showed that they are able to communicate, but are not able to take care of their grandchildren with autism because of their physical condition and because they do not receive adequate attention and support from their family.

Grandparents act as culture transfer agents, moral and ethical providers, financial providers, emotional support providers, supporters of well-being, and providers of childcare²⁷. The interaction between grandparents and their grandchildren with autism generates positive influences; for example, they can give additional attention to their grandchildren suffering from illness or accompany their grandchildren to therapy sessions or classes. Grandparents also contribute to family finances from their pension allowances or savings, often in the form of providing pocket money or supporting the cost of therapy for their grandchildren. Grandparents can support family needs such as food or clothes by cooking, sewing, or taking part in shopping. It can be concluded that grandparents provide significant parenting roles for their grandchildren with autism.

Grandparents who have a good role in the family, such as taking care and accompanying grandchildren at home, this will foster a positive psychological state. When a grandparent has an important role in the family, the positive understanding of feeling needed may improve their psychological well-being. Table 4 shows that around 62.04% of the 108 respondents had an important role in the family. The regression analysis results in Table 6 show a strong correlation between the grandparents' financial and emotional support and their provision of childcare. It suggests that grandparents provide financial, emotional, and childcare support for the family, thus stimulating grandparents to realize their potential and take an active roles in meeting individual, family, and the grandchildren's needs. The life satisfaction of grandparents who play a strong role in the family is higher than that of those living in nursing homes³⁵.

The coefficient of determination shown by R-square in the grandparent's roles variable was 0.296, meaning that the role of grandparents in this study contributed 29.6% to the elderly psychological well-being variable. Other contribut-

ing factors are outside the scope of this study, but may include socioeconomic status, relationships or social networks³⁴, individual competence, religiosity, personality traits and sex³⁶.

One limitation of this study is variations in the autism levels of different children may affect the level of parenting stress, which in turn would affect the psychological well-being of grandparents. This was minimized by limiting the inclusion criteria of the participants. Participants had to be in good physical condition and not suffer from chronic pain. Both measuring tools in the questionnaire, the grandparent's role and their psychological well-being, were tested for validity and reliability.

The survey results indicate a significant positive correlation between the roles of grandparents and their psychological well-being. The coefficient of determination shows that the roles of grandparents effectively contribute 29.6% to the variable of psychological well-being. This study found a relatively strong correlation between financial support and emotional support, also correlation between provision of childcare and psychological well-being. Variations in the autism level of children in different families may affect the level of parenting stress and thus the psychological well-being of the elderly. Further research could look more closely at grandparenting and the development of the children with ASD in the grandparents' families.

References

1. American Psychiatric Association. Diagnostic and Statistical Manual of Mental Disorders. fourth ed. Washington, DC: American Psychiatric Press; 1994.
2. Schopler E, Bourgonien MEV. (CARS™-2) Childhood Autism Rating Scale™. 2nd ed.; 2010. Available at: <http://www.wpspublish.com/store/p/2696/childhood-autism-rating-scale-second-edition-cars-2>.
3. Austin D. An epidemiological analysis of the 'autism as mercury poisoning' hypothesis. *Int J Risk Saf Med*. 2008;20:135-42.
4. Sun X, Allison C. A review of the prevalence of Autism Spectrum Disorder in Asia. *Res Autism Spectr Disord*. 2009;4:156-67.
5. Honda H, Shimizu Y, Imai M, Nitto Y. Cumulative incidence of childhood autism: A total population study of better accuracy and precision. *Dev Med Child Neurol*. 2005;47:10-8.
6. klinikautis.com. Angka kejadian autis di Indonesia dan di berbagai belahan dunia lainnya. 2015. Available at: <https://klinikautis.com/2015/03/24/angka-kejadian-autis-di-indonesia-dan-di-berbagai-belahan-dunia-lainnya/>.

7. Lismaya. Penanggulangan autisme. Menyongsong hari autisme sedunia. 2013. Available at: <http://www.melaticeria.or.id/2013/04/penanggulangan-autisme.html>.
8. Desiningrum DR. Psikologi anak berkebutuhan khusus. Yogyakarta: Graha Ilmu-Psikososains; 2016.
9. Lee IJ, Chen CH, Lin LY. Applied clip lets-based half-dynamic videos as intervention learning materials to attract the attention of adolescents with autism spectrum disorder to improve their perceptions and judgments of the facial expressions and emotions of others. *SpringerPlus*. 2016;5:1211.
10. Chan KK, Lam CB. Parental maltreatment of children with autism spectrum disorder: A developmental-ecological analysis. *Res Autism Spectr Disord*. 2016;32:106-14.
11. Gessa DG, Glaser K, Tinker A. The Health Impact of Intensive and Nonintensive Grandchild Care in Europe: New Evidence From SHARE. *J Gerontol B Psychol Sci Soc Sci*. 2016;71:867-79.
12. U.S. Census Bureau, American Community Survey: tables B05003, B10051, B10051B, B10052, B10053, B10054, B10056, B10057, B10058, B10059, B10061, and B16005, 2010. Available at: <http://factfinder2.census.gov>.
13. Drew LM, Richard MH, Smith PK. Grandparenting and its relationship to parenting. *Clin Child Psychol Psychiatry*. 2008;3:465-80.
14. Hillman J. Grandparents of children with autism: a review with recommendations for education, practice, and policy. *Educ Gerontol*. 2007;33:513-27.
15. D'Astous V, Wright SD, Wright CA, Diener ML. Grandparents of grandchildren with autism spectrum disorders: influences on engagement. *J Intergener Relatsh*. 2013;11:134-47.
16. Kahana E, Lee JE, Kahana J, Burk E, Barnes K. Advancing the field: Childhood autism and proactive family coping: Intergenerational perspectives. *J Intergener Relatsh*. 2015;13:150-66.
17. Ross MET, Kang DH, Cron S. Psychological profile, salivary cortisol, C-reactive protein, and perceived health of grandmothers with childrearing responsibility. *J Fam Issues*. 2015;36:1904-27.
18. Zohar AE, Garby A. Great-grandparents' role perception and its contribution to their quality of life. *J Intergener Relatsh*. 2016;14(3):197-219.
19. Poulin M, Cohen Silver R. World benevolence beliefs and well-being across the lifespan. *Psychol Aging*. 2007;23:13-23.
20. Ryff CD. In the eye of the beholder: views of psychological well-being among middle and old-aged adults. *Psychol Aging*. 2004;4:195-210.
21. Ryff CD. Happiness is everything, or is it? Explorations on the meaning of psychological well-being. *J Pers Soc Psychol*. 2002;57:1069-81.
22. Cavanaugh JC, Blanchard FF. Adult development and aging. Washington: Thompson Wadsworth; 2006.
23. Vakalahi HF. Tongan grandparents and grandchildren: the impact of grandparenting. *International Social Work*. 2011;54:580-98.
24. Azwar S. Metode penelitian. Yogyakarta: Pustaka Pelajar; 2010.
25. Azwar S. Dasar-dasar psikometri. Yogyakarta: Pustaka Pelajar; 2008.
26. Keyes CL, Magyar M. The measurement and utility of adult subjective well being. Washington D.C. American Psychological Association; 2003.
27. Goodfellow J, Laverty J. Grandparents supporting working families: Satisfaction and choice in the provision of care. *Fam Matters*. 2003;66:14-9.
28. Kemp CL. Grandparent-grandchild ties: Reflections on continuity and change across three generations. *J Fam Issues*. 2007;28:855-81.
29. Smith PK, Drew LM. Grandparenthood. In: Bornstein M, editor. *Handbook of parenting*. Vol. 3. Being and becoming a parent. Mahwah, New Jersey: Lawrence Erlbaum and Associates; 2002. p. 141-72.
30. Keeling S. Grandchildren's perspectives on grandparents in rural New Zealand. *J Rural Stud*. 2012;28:371-9.
31. Geurts T, Tilburg TV. Grandparent-grandchild relationships. In: Wright JD. *International encyclopedia of the social and behavioral sciences*. 2nd ed. Oxford: Elsevier; 2015. p. 336-40.
32. Kataoka-Yahiro M, Ceria C, Caulfield R. Grandparent caregiving role in ethnically diverse families. *J Pediatr Nurs*. 2004;19:315-28.
33. Gillian IH, Sadruddin, Aalyia FA, Amy V, Jaja Y, Elizabeth J. Stress associated with caregiving: an examination of the stress process model among Kenyan Luo elders. *Soc Sci Med*. 2012;74:2020-7.
34. Papalia DE, Old SW, Feldman RD. *Human Development*. 9th ed. Boston: McGraw Hill Companies; 2008.
35. Ferrand C, Martinet G, Durmaz N. Psychological need satisfaction and well-being in adults aged 80 years and older living in residential homes: using a self-determination theory perspective. *J Aging Stud*. 2014;30:104-11.
36. Santrock JW. *Life span development*. 13th ed. New York: McGraw-Hill Companies; 2011.