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THE ROLE OF FAMILIES CARING FOR PEOPLE WITH MENTAL DISORDERS THROUGH FAMILY RESILIENCE AT EAST JAVA, INDONESIA: STRUCTURAL EQUATION MODELING ANALYSIS

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ABSTRACT

Families who have family members with Mental Disorders (ODGJ) have a decreased role in caring for ODGJ patients. This reduced role is felt by family members so that they will experience stress and bear a considerable burden. The purpose of this study is to develop a family role model in caring for ODGJ through family resilience by looking at the constructs and contributing indicators. Design research observational explanative, the first stage was to explain the constructs and indicators that contributed. The second stage was conducting FGD with the patient's family and health workers and conducting consultations with experts. The population was a family with diagnosed ODGJ with sample of 184 respondents using total sampling. The exogenous variables were patient, family, and environment. Endogenous variables were family resilience and family roles. Data were collected using research questionnaires and analyzed using structural model with SmartPLS (Partial Least Square) software. The results showed that family factors had no effect on family resilience with coefficient of 0.063, patient factors had positive effect on family resilience with coefficient of 1.121, environmental factors had negative effect on family resilience with coefficient of -0.430, and family resilience had positive effect on family roles with the coefficient of 0.821. Family factors do not affect family resilience, but patient factors can shape, encourage, and increase family resilience thus increasing the role of the family. While environmental factors have negative effect on the ability of family resilience. This means that environmental has more likely factor and greater effect to reduce family resilience.

Keywords: Role of Family; Family Resilience; Patients with Mental Disorders.

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INTRODUCTION

The role of families who have family members with Mental Disorders (ODGJ) is a major problem that occurs in society nowdays. Families caring for schizophrenic patients experience stress and a decreased ability to provide care so that mediation is needed in the form of family resilience [1]. Mental health is still one of the significant health problems in the world, including in Indonesia. The impact of mental health problems is also felt by the patient's family members. Family members of patients with serious mental disorders can be stressed and bear considerable burdens. This can endanger their health, quality of life, and interfere with family functions [2]. Based on the results of the Ministry of Health's 2018 Basic Health Research (Riskesdas) [3], the prevalence of households having ODGJ is recorded to have increased. The results of the 2013 Riskesdas, the prevalence of serious mental disorders in Indonesian population was 1.7 per mile. The prevalence of households having ODGJ from Riskesdas 2018 was 7 per household mile. Likewise, the prevalence of mental-emotional disorders in the population aged ≥ 15 years at East Java Province was 7.5 per 1,000 population. This figure has increased from the 2013 Riskesdes results, which was 6.82 per 1,000 population. The prevalence of depression based on Riskesdes 2018 in people aged ≥15 years at East Java Province was 4.53 per 1,000 population [3]. The closest prevalence of depression at East Java was Sidoarjo Regency, which was 4.5 per 1,000 population. The highest number of mental illness visits in Sidoarjo Regency Health Service Facilities in 2017 was at Puskesmas Taman, namely 22,591 people. A preliminary study by researchers at the Puskesmas Taman, Sidoarjo Regency, obtained 3 post-pasung ODGJ data of 3 men and 181 non-pasung ODGJ people consisting of 74 women and 107 men. All patients diagnosed with schizophrenia with varying family status. Some have the status of children, siblings, husbands, wives, mothers, and fathers in the family structure.

The increasing number of ODGJ can be caused by many factors. One of them is the role of the family. Family roles can be classified into two categories, namely formal or open

roles and informal or closed roles. The formal role of the family consists of the role and relationship of marriage, the role of women and men in the family, and the role of grandparents in the family [4]. The results of a preliminary study in Sidoarjo Regency, East Java, showed that underprivileged or lacking families have good skills to care for ODGJ who are shackled in terms of fulfilling self-care needs. Ideally, roles are based on prescriptions and role expectations which explain what the individual should do in a particular situation [5], [6]. Family role factors, namely social class, family form, cultural or ethnic background, family development stage, role models, and situational events, especially health problems or illness. This condition is to fulfill their expectations or the expectations of others regarding these roles [7]. The role of the family affects the adaptability of family members of ODGJ. The most relevant research that has been conducted regarding the role of the family in caring for ODGJ patients is research that shows strengthening the potential for increasing family roles through the ability of good recognition seekers, family nurses, providers, educators, and promoters. Strengthening the potential itself consists of assessment indicators and family empowerment. This study has limitations. The sample used is less representative of research type that uses modeling. A larger sample is needed to evaluate the influence of family roles on the adaptability of ODG patients [8]. The level of family resilience in caring for ODGJ is still low both in terms of belief systems, organizational patterns, and communication processes. The resilience of *family caregivers* for schizophrenia patients in Japan. This study used a qualitative descriptive based on the phenomenological method. Researchers conducted interviews with 12 *family caregivers* of schizophrenic patients. The results of the study showed that there were three themes related to resilience obtained from the data of the research subjects, namely: understanding related to disease description, learning coping skills, and understanding the gap between reality and social independence for patients [9]. Other studies described the burden of care and stigma as risk factors that family members must manage to survive, rise, and become better at caring for patients with schizophrenia. Nurses as health care workers have a central role in assessing the level of care burden and the stigma experienced by family members to help families achieve resilience. The description above shows that the family has not been able to care for family members who have mental disorders, even though the family is the basic service unit in the community who is also the main nurse for their family members. The family will play an important role, especially in determining the type of care needed by family members [10]. As a researcher, will offer the development of a family role model in caring for people with mental disorders through family resilience.

METHODS

Research Design

This research is *explanative observational* study through testing the structural model with *SmartPLS (Partial Least Square) software.* The first stage describes the test results based on the theory by looking at the constructs and indicators that contribute. The second stage then compiles a module on strategic issues that have been carried out by FGD with the patient's family and health workers and conducted consultations with experts.

Participants and Recruitment

Respondents consisting of 184 people using total sampling who were families with ODGJ family members and lived in Sidoarjo Regency, the working area of Puskesmas Taman. The inclusion criteria was the closest family member to a mental patient. Participants were family members of outpatients at Puskesmas Taman. The participants were recruited based on ethical principles. Participants who were involved in previous research have received a written explanation regarding the research objectives, procedures, rights and obligations, benefits, and disadvantages during the research. Only participants who had provided informed consent were included in the study. Before starting data collection, researchers conducted trials on 32 participants with the same characteristics, namely at the Krian Public Health Center, Sidoarjo Regency to validate the questionnaires. Furthermore, the data were collected by giving questionnaires to 184 respondents and testing the structural model with *SmartPLS (Partial Least Square) software.* The strategic issues obtained from the results of the *Structural Equation Modeling-Partial Least Square* (SEM-PLS) analysis were used as a reference for conducting *Focus Group Discussions* (FGD) with patient families and health workers as well as consultations with experts. The results of strategic issues, FGDs, expert consultations, and the results of the development of family role models in caring for people with mental disorders through family resilience serve as references for module development. The resulting module from the development of the model uses a family-centered approach so that it can be used as a guide by health workers or researchers in intervening to increase the role of the family in caring for ODGJ through family resilience.

RESULTS

Distribution Frequency

This research is *explanative observational* study through testing the structural model with *SmartPLS (Partial Least Square) software.* This research was conducted to determine the role model of the family in caring for ODGJ through family resilience by looking at the contributing constructs and indicators, then compiling a module on the strategic issues that have been carried out by the FGD with the patient's family and health workers then conducted consultations with experts. Description of study variables is shown to explain CONSTRUCTS research data according to measurable indicators for each construct research factors. The construct factors studied included family factors (X1), patient factors (X2), environmental factors (X3), family resilience (Y1), and family roles (Y2). The data scale used for statistical tests is the absolute value of each variable, but to facilitate the presentation of the data in the table used Likert scale.

Table 1. Distribution Frequency of Family Factors (Economic Status, Family Form, Family Development Stage, Structure and Function) in the Work Area of Puskesmas Taman

Item	N = Percentage of
Economic Status	
<UMR	125 (67.93)
≥ UMR	59 (32.07)
friendly form of	
Core family	126 (68.48)
Extended families	58(31.52)
Family development Stage	
new Family	0 (0)
Families with the birth of the first child	of 8 (4.34)
Families with pre-school children	6 (3.26)
Family with school children	0 (0)
Families with teenagers	2 (1.09)
Families with adults	164 (89.13)
Middle age families	2 (1.09) Elderly
Families	2 (1.09)
Structure and functions of	
Children	9 (4.89)
Siblings	7 (3.80)
Husband	2 (1.09)
Wife	2 (1.09)
Mother	155 (84.24)
Father	8 (4.35)
Brother	1 (0.54)
Age	
17-25years	2(1,09)
26-35 years	3 (1,63)
36-45 years	62 (33,70)
46-55 years	100 (54,34)
56-65 years	16 (8,70)
> 65 years	1 (0.54)
Genetic	
There are ODGJ family members	29(15.76)
There are no ODGJ family members	155 (84.24)
0-3 years	4 (2.17)
3-5 years	54 (29.35)
5-10 years	106 (57.61)
> 10 years	20 (10.87)
Relapse Frequency	
Never relapse	16 (8.70)
1-3 times	5 (2.72)
3-5 times	52 (28.26)
6-10 times	91 (49.45)
> 10 times	20 (10.87)
cultural or ethnic influence	
Javanese	176 (95.65)
Madurese	8 (4.35)
Situational events the	
family received	174 (94.57)
Families felt ashamed	10 (5.43)

Results of the study in table 1 showed that out of 184 respondents, it is known that based on the majority economic status as many as 125 families (67.93%) income <UMR Sidoarjo Regency. Based on the family form, 126 respondents (68.48%) were the main family. Based on the stage of family development, at the stage of new families and families with school children consisted of 0 respondents (0%), while the most at the stage of families with adult children were 164 respondents (89.13%). Based on the structure and function of the majority of mothers as the closest person to the patient were 155 respondents (84.24%). Results of the study in the table illustrate that the variable age of the patient started from the age range of 17-25 years, namely 2 people (1.09%) and the most in the range of 45-55 years, namely 100 people (54.34%). Based on genetic variables, there were 29 patients (15.76%) who in their family tree had experienced mental disorders. Based on the variable duration of illness, most in the range of 5-10 years, namely 106 patients (57.61%). Based on the relapse frequency variable, there were 16 patients (8.70%) who had never experienced recurrence and 91 patients (49.45%) who had experienced a relapse of 6-10 times. Based on results of study in the table illustrate that the variables influence culture or ethnicity. There were 8 families (4.35%) outside the Javanese Tribe, namely the Madurese Tribe. Based on the situational event variable, there were 10 families (5.43%)

who stated that they felt ashamed and considered very isolated by their neighbors while caring for family members with mental disorders.

Table 2. Distribution Frequency of Family Resilience in the Working Area of Puskesmas Taman

Indicator	Category		
	Good N =%	Enough N =%	Less N =%
Social Support			
Emotional	116 (63.04)	58 (31.52)	10 (5.44)
Informational	122 (66,30)	52 (28,26)	10 (5,44)
Instrumental	30 (32,07)	95 (51,63)	59 (16,30)
Award	114 (61,96)	60 (32,60)	10 (5.44)
Family Resilience			
Difficulty	123 (66.85)	Means56 (40.43)	5 (2.72)
Positive Outlook	110 (59.78)	66 (35.87)	8 (4.35)
Transcendence and spirituality	101 (54.89)	77 (41.85)	6 (3.26)
Flexibility	169 (91.85)	13 (7.06)	2 (1.09)
connectivity	149 (80.98)	35 (19.02)	0 (0)
Social and Economic Resources	131 (71.20)	52 (28.26)	1 (0.54)
Clarity	161 (87.5)	23 (12.5)	0 (0)
Emotional Expression	150 (81, 52)	34 (18.48)	0 (0)
Collaborative Problem Solving	146 (20.65)	38 (79.35)	0 (0)
Role of families			
Confession Seeker	148 (80.43)	36 (19.57)	0 (0)
Family Nurse	150 (83.70)	30 (16.30)	0 (0)
Provider	137 (74.46)	47 (25.54)	0 (0)
Family Coordinator	154 (83.70)	30 (16.30)	0 (0)
Harmonist	137 (74.46)	47 (25.54)	0 (0)
Entertainer	143 (77.72)	41 (22.28)	0 (0)
Educator	149 (80.98)	35 (19.02)	0 (0)
Encouragement	143 (77.72)	41 (22.28)	0 (0) The

The family said that praise and support from others for family decisions regarding the role of the family in caring is strength for families in accompanying ODGJ patients. Almost all circles get emotional support, informational, and well appreciation. Meanwhile, for instrumental support in terms of support for medical assistance and life support from other people, 59 families (16.30%) said it was lacking, 95 families (51.63%) said it was enough, and 30 families (32.07%) said it was good. The majority said that they only received medical assistance from the Community Health Centers. The results of the study in table 5 illustrate that the majority of family resilience is good on criteria and flexibility is the most dominant indicator. None of the indicators of connectedness, clarity, emotional expression, and collaborative problem solving have low resilience scores. Even though the indicators give the meaning of difficulty, positive outlook, transcendence and spirituality, flexibility, social and economic resources there are low resilience scores, all of them are not more than a score of 5%. Table 6 Frequency Distribution of Family Roles in the Working Area of Puskesmas Taman. The results of the study in table 6 illustrate that no indicator had a poor family role score. The family coordinator indicator was the most dominant indicator describing the role of the family in good criteria, namely as many as 154 respondents (83.70%). Meanwhile, in the category of the family role, it was sufficient for all indicators, not more than 26%. The results of the convergent validity test are presented in the following figure: showing that 2 indicators produce a factor loading value less than 0.5, namely X1.3 (family development stage) and X1.4 (structure and function), so that reduction is carried out and a model is obtained. The final result was as follows: The results of the convergent validity test after reduction showed that all *factor loading* values> 0.5 and a change in the value of *factor loading* X1.1 (economic status) became 0.990 and X1.2 (family form) became 0.991. The results of the significance test after reduction also showed changes, namely family factors to resilience into 0.063, patient factors to resilience into 1.121, and environmental factors to resilience into -430. The results of the test *R-square* after reduction also showed changes, namely the variable family resilience 0.615.

DISCUSSION

Family factors do not have a contribution to the ability of family resilience while caring for people with mental disorders. Family factors consist of economic status, family form, family development stage, structure and function. The results showed that the variables of economic status and family form were variables that formed family factors but had no effect on family resilience. The family's financial situation greatly determines the stability of the family. The results showed that more than half of them had income below the regional minimum wage, while the cause of the FGD process made family experienced fatigue and had limited time to work and socialize. Costs for schizophrenia patients were a burden in the family. Family financial needs in caring for mental patients were not significant. The family must meet the medical needs and daily needs of the whole family by working and arranging the time for patient care and outreach. Some of the respondent's families felt helped by the BPJS health insurance system, where families could control and get free medicine from mental health services, so that family finances could be focused on meeting the needs of patients and families every day.

Every family has a unique way to meet financial needs by optimizing the strengths which family has. Families who are

really limited in getting a regular income and have difficulty in finding additional income, try to manage their finances by setting aside money every day. The money is specifically to meet the daily needs of ODGJ patients. The ability of families to arrange agreements in terms of meeting financial needs stimulates families to be closer between one another and makes it easier for families to achieve resilience. The situation that was carried out by the resilience-based family therapy approach can foster self-confidence in the family to be able to arrange the resources owned by the family to solve problems [11]. The achievement is prioritized over descent so that family groups become less important to people in urban areas. Meanwhile, *The National Network for Family Resilience* in 1995 stated that the ability of individuals or families to exploit their potential in facing life's challenges, including the ability to restore family functions to their original levels in the face of challenges and crises affects family resilience [12], [13]]. Parents of children as the core family are family structures that have an important role in providing long-term care for family members who experience chronic illness, such as mental disorders. This situation is in line with research conducted in India that the core family in Asian families has a high moral responsibility in caring for sick family members [14]. The division of roles in the family is also given to family members who are not directly involved in caring and are not those closest to the patient, namely the role of taking control patients to the community health centers and the role of earning a living to make ends meet. However, conflicts often arise due to an imbalance in the division of roles in the family structure [15].

Based on the results of the study, most ODGJ patients were in the age range of 46-55 years which states that the elderly group is a population that is vulnerable to various disorders including those related to their mental status [16]. Most of the patients have had mental disorders for 5-10 years. The duration of illness shows a picture of the course of disease from the critical phase, relapse, stabilization to worsening the mental health condition of ODGJ patients. Family will give the best care and try to understand the patient's behavior. The behavior of each patients are greatly varies and require the family to accept the condition. Patients who have had mental disorders for a long time will make their families more resilient than those who have recently suffered from mental disorders. This could be due to the fact that the family's habits in caring ODGJ for long term have been compared to families who just learned how to care for their family members who have just been diagnosed with mental disorders [17]. The condition of ODGJ patients with varying numbers of relapses causes changes in the situation and conditions in the family. The family will try to provide the best care and try to understand the patient's behavior. When a family member experiences chronic illness, disability, including mental disorders, the family must provide long-term care, and have to support the patient so that patient can carry out their daily activities. The behavior of each patient varies greatly and requires the family to accept the condition. The family's ability to accept and tolerate the symptoms displayed by ODGJ patients in this study affects the level of family resilience so that the family as the closest person to the patient will carry out the role of caring for ODGJ patients properly and this results will make family is not feeling hopeless to the situation. Enthusiasm to support their family members who are sick. [18]. Environmental factors have a negative effect on resilience ability, so other factors such as social support are needed [19]. The response from family to family members who experience ODGJ, the majority of families receiving and caring for their family members is the resilience of the family. Almost all families who care for ODGJ patients have high resilience. Family resilience is the ability to survive, react and changes in family members and environments that are detrimental and oppressive so that they can recover by maintaining their integrity. Resilient families greatly contribute to the welfare of family members, especially individuals with mental disorders. [20]; [21]; [22]. The pattern of communication within the family can facilitate family expectations to be compact and flexible so that it can achieve the function of the core family where good communication within the family can help the family achieve family functions and meet the needs of family members [23]. The results illustrate that no indicator has low family role score. The family coordination indicator is the most dominant indicator describing the role of the family in good criteria. The role of a family coordinator can be carried out by organizing and planning family activities, which function to promote intimacy and struggle from pain [24], [25], [26]. The family will try to involve and invite all family members to think about what will be done to organize the future of the family. The family plans and concludes some steps that will be taken for the good of the family and patient. The findings of the research on family role models in caring for ODGJ through family resilience found that families who have high resilience are directly influenced by patient and environmental factors, thereby increasing the role of the family in caring for family members who experience ODGJ [27], [28], [29].

The patient factor can form, encourage, and increase family resilience thereby increasing the role of recognition seeker, family nurse, provider, family coordinator, harmonist, entertainer, educator, and promoter. High role of the family will make ODGJ clients feel more meaningful and have confidence and be able to adapt well. Meanwhile, environmental factors indicate that these factors have a negative effect on the ability of family resilience. This means that the environmental factor has greater effect more likely to reduce family resilience. The ability of families to modify their perspective on environmental factors is a provision for fostering family resilience abilities [30]. Based on the analysis of family theory and family resilience that has been done, the researcher integrated the role of the family and family resilience into theory of *Family-Centered-Nursing* or family practice as the center of nursing according to Friedman. The family as the basic unit of community and society shows the differences in culture, ethnicity, and socioeconomic conditions. In its application, this theory considers social, economic, environmental, family type, and cultural factors in conducting the assessment, planning, implementation, and evaluation. This model explains that the assessment stage in the nursing process views family as a sub-system of society [31]. The role in the family shows behavior patterns of all members of the family. The role in a family can be flexible so that family members can adapt to the changes that occur. Roles based on expectations or role assignments that limit what individuals should do in certain situations to fulfill self or others' expectations of them. The role of families who have family members with mental disorders in the work area of Puskesmas Taman, Sidoarjo Regency focused on recognition seekers, family nurses, providers, family coordinators, harmonists, entertainers, educators, and advocates. [32]. If a family is seen as a system, mental disorders in one family member will disrupt all systems or family conditions. This is one of mental disorders causes in family members. From two statements above, it is concluded about how important the role of the family is in the event of mental disorders and

readjustment process after completion of treatment program. Therefore family involvement in care greatly benefits the client's recovery process [33]. Based on the explanation of the research results above, it can be concluded that there was an influence of patient factors and environmental factors on family resilience, thereby increasing the role of the family in caring for family members with ODGJ. The following were the new findings based on the research results: first, patient factors were an important factor affecting the resilience of families who have ODGJ family members. Patient factors directly influence the resilience of families with ODGJ family members. Second, environmental factors negatively affect the ability of family resilience. The environmental factor will have greater effect to reduce family resilience. The ability of families to modify their perspective on environmental factors was a provision in fostering the ability of family resilience. Third, family resilience increases the role of families who have ODGJ family members. Family resilience directly affects the role of the family in caring for ODGJ family members [34].

Based on new findings, the concept of a family role model in caring for ODGJ through family resilience is as follows:

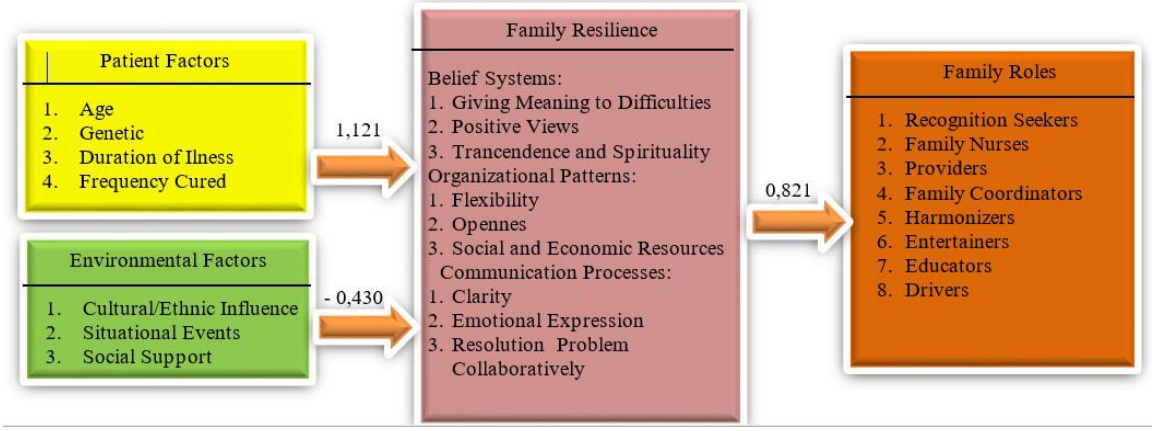

Figure 1. New Findings of Family Role Models in Caring for ODGJ through Family Resilience.

Based on findings above, the assessment process on family role models in caring for people with mental disorders through family-resilience is *centered on nursing* carried out on patient factors and environmental factors. Family factors were excluded from the model considering the effect of family factors on family resilience is too small, which is below 0.1, however, assessments of family factors, patient factors, and environmental factors remain the data to determine the ability of family resilience. Family and environmental factors are factors that must be studied in depth because family factors did not affect family resilience, while environmental factors negatively affect family resilience. [35]

The stages of determining the problem according to the theory were family-centered nursing carried out based on the data obtained in the assessment stage. Based on the research results, problem determination in the family role model in caring for people with mental disorders through family-based centered nursing family resilience was focused on the level of family resilience. The stages of intervention and implementation according to the theory of family-centered nursing is planning to interference using family-owned resources to overcome health problems, while implementation was carried out to address health problems in the family on the five family health tasks to stimulate family awareness and acceptance of health problems, to give the ability and confidence in caring of sick family members. So that the family can create a healthy environment and make maximum use of the available health facilities. Based on the results of research on the intervention and implementation stages of the family role model in caring people with mental disorders through family-based resilience, it was centered that nursing family focused on stimulating family strength to improve family resilience abilities consisting of belief systems, family organizational patterns, and communication processes. [35], [36].

The stages according to the theory of family-centered nursing were to assess cognitive, affective, and psychomotor related to the abilities that have been intervened. The evaluation in this study was aimed at assessing the role of the family in caring for ODGJ patients which includes roles as recognition seekers, family nurses, providers, family coordinators, harmonists, entertainers, educators, and promoters.

CONCLUSION

A family role model is formed in caring for ODGJ through family resilience composed of: patient factors, environmental factors, family resilience, and family roles. The patient factor can form, encourage, and increase family resilience thereby increasing the role of recognition seeker, family nurse, provider, family coordinator, harmonist, entertainer, educator, and promoter. The high role of the family will make ODGJ clients feel more meaningful and have confidence and be able to adapt well. Environmental factors indicate that these factors have a negative effect on the ability of family resilience. This means that the environmental factor is more likely have greater effect to reduce family resilience. The ability of families to modify their perspective on environmental factors becomes provision for fostering family resilience to increase the adaptability of family members with ODGJ.

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CONFLICT OF INTEREST

The authors stated that there were three conflicts of interest regarding the publication of this article.

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Others source

ETHICAL CLEARANCE
This study was approved by the institutional review board of Ethical Approval (NO: 1831-KEPK). The research received a certificate from the Airlangga University ethical permission.

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