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Social support, coping strategies, and resilience of families with neurodevelopmental disorder children

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ABSTRACT

Background: Neurodevelopmental disorder (NDD) in children can trigger feelings of sadness and low self-esteem in parents due to societal judgment. However, children still require treatment to improve their abilities and skills. Family resilience is needed to keep family functions optimally to support child's development.

Purpose: Analyze the effects of family characteristics, social support, and scoping strategies on resilience of family with neurodevelopmental disorder child.

Method: The study involved 95 mothers of children aged 6-13 years diagnosed with NDD. Instruments used in this study are Social Support Questionnaire, The Brief-COPE), and Resilience-Ga. This research was conducted offline at special need-child foundations and schools in Bogor City and Bogor Regency. Each respondent was interviewed based on questions from instruments used in this research.

Findings: A significant regression was found ($F(8,86)= 4.09$], $p= <.001$). The *adjusted* R^2 was 0.208, indicating that family characteristics, social support, and family coping strategies explained approximately 20,8% of the variance in family resilience. Study results show positive significant effect of fathers' education (β=0.168; p=0.092), social support (β=0.202; p=0.048), and coping strategies (β=0.275; p=0.010) on family resilience.

Implication: Provide inclusive and flexible policies and increase public awareness to support the resilience and well-being of families with neurodevelopmental children.

KEYWORDS
Caregiving; family resilience; neurodevelopmental disorder.

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Introduction

Families primarily expect their children to grow healthy and be able to fulfil their roles as successors to the family. However, some children develop disabilities alter their circumstances. One of the most common non-physical disabilities is neurodevelopmental disorder (NDD) (American Psychiatric Association, 2013). According to the Diagnostics Statistic Manual 5th Edition, neurodevelopmental disorder is a developmental deficits affecting neuro system and varies from a spesific limitations of learning or executive functional control to global impairments of social skills or intelligence (American Psychiatric Association, 2013). NDD includes intellectual disability (ID), mental retardation, communication disorder, autism spectrum disorder (ASD), attention-deficit/hyperactivity disorder (ADHD), and specific learning disorder (SLD) (American Psychiatric Association, 2013). Individuals with NDD may experience impairments in specific areas, such as social functioning, cognition, language, motor skills, and lack of engagement in activities (American Psychiatric Association, 2013; Sari et al., 2022). If these developmental deficits occur across the board, they can have a significant impact on daily functional abilities.

The prevalence of NDD is a concern because of its increasing trend. Data from the Indonesian Ministry of Health show 5,530 cases of developmental disorders in children were treated by health centers between 2020-2021 (Perwitasari, 2023). It is estimated 500 new cases of ASD are added each year (Kemenkes, 2022). ADHD cases in Indonesia showed in 2023, 15% of the total number of Indonesian school-age children had ADHD (Fakultas Kedokteran Kesehatan Masyarakat dan Keperawatan Universitas Gadjah Mada, 2019). Meanwhile, cases of ID in Indonesia are estimated to reach 6.6 million individuals, or 1-3% of the Indonesian population

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(Kemenkes, 2023).

Parents of children with NDD face significant challenges negatively affect couple dynamics (Baeza-Velasco et al., 2013; Desiningrum et al., 2020). The divorce rate of parents of children with ASD or ADHD is significantly higher than parents of typical children (Anchesi et al., 2023; Hartley et al., 2010). Typical children is a child who has grown and developed in line with the milestones that are expected to be reached at his or her age (Blums & Holloway, 2024). Lack of social support increases the risk of parental stress (Cavonius-Rintahaka et al., 2019). Social support comes from various sources, including spouses, family, friends, experts, or the surrounding community (Sarafino & Smith, 2011). Families receive social support are better able to adapt and achieve resilience (Caples et al., 2018).

Excessive fatigue and stress from caring for a child with NDD increase the rates of depression and the risk of family dysfunction (Anchesi et al., 2023; Cavonius-Rintahaka et al., 2019; Hartley et al., 2010; Kusumastuti, 2014; McConnell & Savage, 2015). When psychological stress is resolved and the family can function well, resilience is achieved (McConnell & Savage, 2015). Families need to achieve resilience to deal with pressure while caring for and assisting in the growth and development of children with disabilities (Amelasasih, 2018). Family resilience is a family's ability to survive and rise from crises or disruptive life challenges, such as adversity and homelessness (Sunarti, 2021; Walsh, 2016). In family with NDD children, it is essential, given that the family must still provide education, protection, and love for the child, regardless of the child's condition. An understanding oriented towards family resilience will focus on family adaptation when facing difficulties (Rahayu, 2019).

Family resilience is essential for families, especially those who have children with special condition such as neurodevelopmental disorders (NDD). Based on Walsh (1996, 2003, 2016) family resilience framework which emphasizes the interaction of ecosystemic view and developmental dimensions, this study explores how family characteristics, social support, and coping strategies interact to enhance family resilience. In families with children with NDD, coping strategies can manifest in specific forms, such as understanding children's habits, realizing what children can and cannot do, seeking alternative treatments as needed, increasing insight into NDD conditions, consulting with doctors and therapists, and following expert advice (Hidayah et al., 2017; Rachmayanti & Zulkaida, 2011; Yusmiati, 2016). However, research on the resilience of families with children with disabilities has mostly been conducted in Western countries (Das et al., 2017; Khan et al., 2017; Leone et al., 2016; McConnell & Savage, 2015; Rahayu, 2019; Safitri & Hapsari, 2013; Widyawati et al., 2022). This study aims to contribute to the understanding of the conditions in developing countries, such as Indonesia, which may have different challenges and resources in supporting families with children with NDD. No studies have examined families of children with NDD within a specific scope, namely ASD, ADHD, and ID, or explored how social support and coping strategies interact and coexist in affecting family resilience. This study fills this gap by analyzing the complex relationships between these factors.

Family resilience is inseparable from family's and parent's characteristics. As stated in Amelasasih's (2018) study that parent's resilience will differ based on their educational level, profession, and economic condition. This research hypothesizes that family characteristics, such as parents' educational level, income, and age, positively influence family resilience (H1). In line with the findings that older parents, higher education and higher economic conditions allow them to be more accepting of their child's NDD condition and be better able to fulfill their child's needs (Kristiana, 2016; Rachmayanti & Zulkaida, 2011). Second hypothesizes in this study is social support received by the family will positively influences their resilience (H2). Caples et al. (2018) stated in their writing that families who receive social support are better able to adapt and achieve resilience. The existence of support from the family makes the family atmosphere more pleasant (Rista et al., 2018). In the condition of children with disabilities, families get social support from various sources, including spouses, family, friends, experts, or even the

surrounding community (Sarafino & Smith, 2011). The third hypothesizes in this study is coping strategies done by the family will positively predict family resilience (H3). Achieving family resilience requires coping strategies, including problem-focused coping mechanisms and emotional strategies (Hidayah et al., 2017; Widyawati et al., 2022). An effort to strengthen family resilience realigns functional roles, reduces relational tensions, mobilizes extended kin, social, and financial resources, and increases support for the individual's effort (Walsh, 2016). The conceptual framework used in this study can be explained as show in Figure 1. This study contributes theoretically to the understanding of the resilience of families with children with NDD and provides practical implications for more effective interventions and policies to support these families in Indonesia.

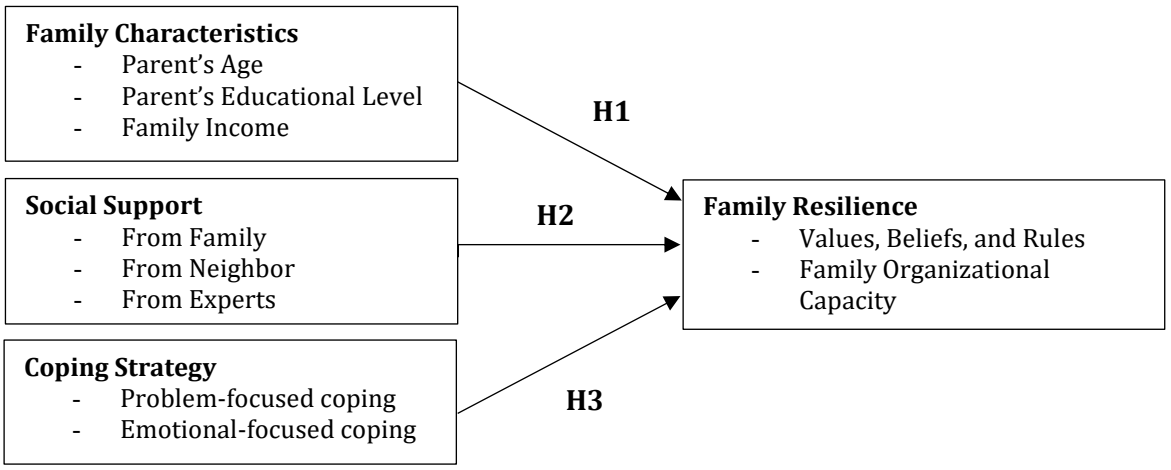

Figure 1. Framework

Method

Participants and Procedures

This study employed a quantitative approach with a cross-sectional design. The research began by identifying respondents in foundations, special schools, and inclusive schools located in Bogor City and Bogor Regency. The respondents were mothers of children diagnosed with neurodevelopmental disorder (NDD) aged 6-13 years, married, and taking care of the child with their husbands residing in Bogor City or Bogor Regency. To avoid self-claiming diagnosis, the respondent's child must have received an official diagnosis from a child growth and development doctor or psychologist. Data were obtained from relevant schools or foundations. The age of the children taken was 6-13 years old, accordance with the middle childhood and early adolescence developmental stage (Papalia & Martorell, 2021). The middle childhood phase was chosen because NDD conditions appear at an early age of child development or early childhood phase (American Psychiatric Association, 2013). Thus, it is expected that the diagnosis of the child's condition is final and will not change.

Data were collected from February to April 2024. This research was conducted offline at the foundation and school. The study population included family of children aged 6-13 years with neurodevelopmental disorder (NDD), represented by the mother. The research sample consisted of 95 people, obtained using a non-probability sampling technique through purposive sampling. This research managed to get 31 mothers of children with autism spectrum disorder (ASD), 30 mothers of children with attention-deficit/hyperactivity disorder (ADHD), and 34 mothers of children with intellectual disability (ID). The data collection process was conducted by filling out the questionnaires through interviews. All respondents were asked fill every item and explain their reasoning for selecting a specific answer. Each respondent was interviewed using questions from three instruments. Before filling out the questionnaires, every respondents were informed

of the research candidate's suitability and the study's description, including the interview process. After respondents had given their permission to proceed with the data collection process, they signed the informed consent form.

Instruments

Social support

Social support is described as psychosocial resources from significant others for an individual to implement coping strategies that the individual can rely on when dealing with stressors and life problems (Kort-Butler, 2017; Thoits, 1995). Support can come from various sources including partners, family, friends, experts, and the surrounding community (Sarafino & Smith, 2011). For parents of children with NDD, support can be obtained from partners, family, therapists, fellow parents of children with ASD, and the surrounding environment (Dewi & Widiasavitri, 2019). The research variables were measured using previous research instruments, which were modified according to research needs. Source of support asked in this study is from extended family, neighbors, and experts such as teachers, doctors, or therapist that handle the children. Social support variables were measured using a questionnaire modified by Sunarti et al. (2005) based on Sarafino (1990). In this study, expert support was asked instead of government support as asked in the Sunarti's questionnaire. This questionnaire uses a 4-point Likert scale (1 = strongly disagree, 2 = disagree, 3 = agree, 4 = strongly agree) with a Cronbach's alpha value of 0.895.

Coping strategy

Lazarus and Folkman (1984) defined coping as "a continually changing cognitive and behavioral effort to meet specific external and/or internal demands that are judged to burden or exceed one's resources" (p. 141). There are two coping strategies: problem-focused coping and emotion-focused coping. Problem-focused coping focuses on problem-solving or doing something to change the source of stress (Carver et al., 1989). Emotion-focused coping involves reducing or controlling emotional distress caused by a situation (Carver et al., 1989). The coping strategy variable was measured using the Coping Scale (Brief COPE) instrument by Carver (1997) with a 4-point Likert scale (1 = never, 2 = rarely, 3 = often, 4 = always). The questionnaire had a Cronbach's alpha value of 0.773. The inverse was performed on negative statements.

Family resilience

Family resilience refers to a family's ability to survive and rise or rebound from disturbing life challenges, such as adversity or loss (Sunarti, 2021; Walsh, 2016). The family resilience variable was measured using the Resilience-Ga questionnaire developed by Sunarti (2021) based on Walsh (2003, 2016). This questionnaire uses a 7-point semantic scale sequentially from the lowest point 1 to the highest point 7. The resiliency-Ga questionnaire had a Cronbach's alpha value of .961.

Data Analysis

The primary data obtained were processed and analyzed using Microsoft Excel 2019 and the Statistical Package for Social Sciences (SPSS) 26. This process included entry, editing,coding, cleaning, scoring, and data analysis. The total score for each variable is transformed into an index. Index results were then managed for data analysis, regression tests. A regression test was conducted using multiple linear regression tests. Before conducting multiple linear regression, a classical assumption test was carried out. The classical assumption tests indicate the regression model meets the necessary criteria for further analysis. The Durbin-Watson value is 2.176, which falls within the acceptable range of 1.5 to 2.5, suggesting no autocorrelation issues in the model's residuals. Multicollinearity was also assessed; all independent variables exhibit tolerance values

above .1 and VIF values ranging from 1.206 to 3.554 or below 10, indicating multicollinearity is not a concern, and the variables are sufficiently independent from each other. Additionally, the ANOVA results show an F-value of 3.053 with a significance level of .001, meaning the regression model is statistically significant at the 1% level. These results confirms the model adheres to classical assumptions, making it appropriate for further interpretation and analysis.

Result

Family and children characteristics

The respondents were mothers of children with neurodevelopmental disorders (NDD). Data were collected on three out of five types of NDDs. The three conditions are intellectual disability or ID (35.8%), autism-spectrum disorder or ASD (32.6%), and attention-deficit/hyperactivity disorder or ADHD (31.6%). Most of the respondents' children were males (74.7%). The age of most children diagnosed with NDD was 13 years (20%), with an average age of 10.26 years. All the children diagnoses were provided by specialist, such as child development specialists, psychiatrists, and medical rehabilitation professionals. More than half of the children had been diagnosed with NDD for more than five years (57.9%). Nearly half had received therapy for five years or less (45.3%). However, there were still children who did not receive therapy after learning the diagnosis of their condition (27.4%).

Half of the mothers were in the early adult group (50%), with an average age of 41.01 years. Mother's age ranges from 27 to 55 years old. The fathers' age was in the middle adulthood group (63.2%) with an average age of 44.68 years. Most of respondents, mothers (81.1%) and fathers (90.5%) of the diagnosed child are high school graduates or higher education. Most respondents' occupations were housewives (78.9%) and fathers were private employees (38.9%). The respondents' families resided in Bogor City (55.8%) and Bogor Regency (44.2%). The marriage age of three-fifths of the respondents was in the range of to 11-20 years (60%), with an average age of 16.48 years. The size of the nuclear family of children diagnosed with NDD was small which is 4 or less person in a family (61.1%). The average monthly family income was Rp8,722,894.74.

Social support

Table 1 shows the level of social support received by families based on the source of support. Most families of children diagnosed with NDD reported low levels of social support (49.5%), with an average support index of .59. Families received the highest level of support from professionals such as teachers, doctors, and therapists (.71). This support was typically provided during therapy sessions or school activities, which were accompanied by consultations between parents and therapists, doctors, or teachers. This opportunity was used by respondents to find out about their child's development as well as understand areas for improvement in parenting practices, including stimulation and nutrition.

Table 1.
Respondents' distribution on social support sources

Support Sources	Categories						Mean±*SD*
	Low		Moderate		High		
	n	%	n	%	n	%	
Extended Family	25	26.3	49	51.6	21	22.1	.65 ± .18
Neighbors	62	65.3	29	30.5	4	4.2	.50 ± .19
Professionals	23	24.2	30	31.6	42	44.2	.71 ± .17
Comp.	47	49.5	31	32.6	17	17.9	.59 ± .13

Note. SD=standard deviation

Coping strategies

More than half of the respondents reported using the coping strategies used by families while caring for children with NDD were high (55.8%) as shown in Table 2. The average coping strategy index was .80. In the problem-focused coping dimension, more than half of the respondents were in the high category (56.8%) with an average index of .80. This was reflected in their efforts to improve their children's abilities and independence through professional assistance. In the emotion-focused coping dimension, respondents were equally distributed between the medium (49.5%) and high (49.5%) categories with a mean index of .79, which is classified as medium. This was reflected in responses indicating that they had learned to accept their child's condition and consistently sought positive aspects of their current situation.

Table 2.
Respondents' distribution on coping strategies

Coping Strategy	Categories						Mean±*SD*
	Low		Moderate		High		
	n	%	n	%	n	%	
Problem-focused	6	6.3	35	36.8	54	56.8	.8 ± .13
Emotion-focused	1	1.1	47	49.5	47	49.5	.79 ± .10
Comp.	1	1.1	41	43.2	53	55.8	.80 ± .10

Note. SD=standard deviation

Family resilience

Table 3 shows the level of resilience of families with children diagnosed with NDD. More than half of the respondent families were in the high category with an index score of .8. This means most of the respondent families have been able to recover and adapt to live with the condition of a child diagnosed with NDD. The component with the highest average index is family atmosphere, which is .82. This reflects parents' willingness to make sacrifices for their families and the presence of strong emotional bonds among family members.

Table 3.
Respondents' distribution on family resilience

Family Resilience	Categories								Mean±*SD*
	Very Low		Low		Moderate		High		
	n	%	n	%	n	%	n	%	
VBR	0	0	2	2.1	30	31.6	63	66.3	.81 ± .14
FOC	0	0	5	5.3	37	38.9	53	55.8	.78 ± .15
FA	1	1.1	4	4.2	26	27.4	64	67.4	.82 ± .15
Comp.	0	0	4	4.2	34	35.8	57	60.0	.8 ± .14

Note. VBR= Values, Beliefs, and Rules; FOC=Family Organizational Capacity; FA=Family Atmosphere; SD=standard deviation

The influence of family characteristics, social support, and coping strategies onfamily resilience

The regression test results presented in Table 4 show a significant positive effect of fathers' education (β=.168; p=.092), social support (β=.202; p=.048), and coping strategies (β=.275; p=.010) on family resilience. These results indicate that the higher the father's education level, the higher the social support received by the family, and the more effective the coping strategies used, the higher the level of family resilience. The adjusted R-squared value for this model was .232. This suggests that all dimensions of social support and coping strategies explained 23.2% of the variance in family resilience, while the remaining 76.8% was influenced by other factors

not included in the model.

Table 4.
Influence between characteristics and variables

Variables	Estimate	*SE*	95% *CI*		*β*	*P*
			LL	*UL*		
Social Support	.383	.190	.004	.761	.202	.048
Coping Strategy	.999	.378	.247	1.751	.275	.010
Period since diagnosed (yr)	-.577	.796	-2.160	1.005	-.073	.470
Mother's Age	.872	.600	-.321	2.065	.219	.150
Father's Age	-.584	.501	-1.580	.413	-.172	.248
Mother's Education Level	2.515	6.174	-9.758	14.788	.040	.685
Father's Education Level	14.044	8.244	-2.345	30.432	.168	.092
Family income	1.341	.000	.000	.000	.074	.450

Discussion

The results of the multiple regression tests showed that fathers' education, social support, and coping strategies had a significant positive effect on family resilience. The father's education influences the level of involvement in parenting and plays a role in dealing with limitations in the family due to having children with disabilities (Febrianto & Darmawanti, 2016; Plaza et al., 2020). Fathers with higher educational levels use strategies that are involved in parenting and increase satisfaction (Plaza et al., 2020). Febrianto and Darmawanti (2016) show fathers with higher educational backgrounds will be more responsive in dealing with children and will always try to update knowledge about children's conditions via cell phones. Parents with higher education are able to access more reliable information, so when confronted with objective data and research results, parents can understand that their child's condition is not their fault so they can focus more on solving everyday problems, seeking support, and how to improve their child's condition (Demšar & Bakracevic, 2023). Results from Rachmayanti and Zulkaida (2011) shows that parents with lower education tend to reject and complain more often about their children's conditions. Thus, parents with lower education levels do not focus on ways to improve their children's conditions and abilities. Fathers' education is also related to social support sourced from extended families and family resilience. This is supported by research from Widyawati et al. (2022), which shows that the higher the father's education, the better the family's material conditions and social support.

Social support is an external factor that strengthens family resilience (Amelasasih, 2018). The influence of support from extended families and experts aligns with Flores-Builds and Andrés-Roqueta (2022) study, which explains the importance of emotional, instrumental, and informational support from these two sources. This shows that the better social support received by the family, the better its resilience. These results are in line with Amelasasih's (2018) research that social support is an external factor in strengthening family resilience. The findings of this research shows that biggest support perceived by family with NDD children is from the experts, such as doctor, therapist, and their child's teacher. support from experts helps families to adapt to their children's abilities and development. With their knowledge and skills, experts help families to train their responses in dealing with difficult situations or daily obstacles in caring for children with NDD (Flores-Builds & Andrés-Roqueta, 2022). The second biggest social support source is their extended family. In addition to patience and strength, support from a wider family also adds confidence for parents to accept the condition of the child and try to take care of the child who has been given by God (Aurellia & Ramadhana, 2022). Support from the extended family helps parents become stronger and do not feel alone because they can lean on the extended family (Sarasvati, 2004 in Rachmayanti & Zulkaida, 2011).

The biggest number of low-level supports is from the neighbours. Almost half of the family with NDD child received low support from neighbours. In the research process, many respondents shared their experiences after being asked about their child's condition. Even after the parents explain the child's condition, there are neighbour that made distance and avoided their children. This is in line with research by Yusmiati (2016) which states that neighbours will ask questions about the child's condition and make parents uncomfortable. From interviews with respondents, it was found that some NDD children still receive insults and bad words from neighbours even though their parents have explained their conditions. This led respondents to close and isolate themselves from interacting with neighbours, therefore they did not open the chance for help and support from neighbours. In line with Anantasari's research (2019) that stated negative attitudes from the community tend to make families isolate themselves.

The significant positive effect of coping strategies on family resilience aligns with research from Cantero-García and Alonso-Tapia (2018), which showed that the better positive coping strategies, both those that focus on emotions and problems, the better the level of family resilience. Coping strategies influence family resilience (Irzalinda & Sofia, 2019). This shows the better the family's coping strategy, the better the family's resilience. This is in line with Dewi and Widiasavitri (2019), who stated coping strategies are efforts to achieve resilience. Rajan and Romate (2022) stated that problem-focused coping is a protective factor that strengthens family resilience. Problem-focused coping carried out by respondents in this study included meeting experts; actively asking teachers, therapists, and doctors regarding child development; and planning for the continuation of education and treatment for their children diagnosed with neurodevelopmental disorders. The findings of this study also showed a significant positive relationship between emotion-focused coping strategies and family resilience. Cantero-García and Alonso-Tapia (2018) research also provides similar results, showing that the existence of positive emotion-focused coping can increase family resilience, namely by being calmer in dealing with children's conditions, being patient, thinking positively, and taking time to engage in other activities. Knowing the family's coping strategies can improve their level of resilience (Cantero-García & Alonso-Tapia, 2018).

Conclusion

Children diagnosed with NDD have been diagnosed for more than five years, while the average child has received therapy in the last 1-5 years. Most mothers are in early adult age group, and fathers belong to the middle adult age group. Most mothers were housewives, and fathers were the sole breadwinners. Most mothers and fathers are high school graduates or higher education The results showed that half of the respondents' families received social support in the low category. More than half of the respondents had high levels of coping strategies. Regarding the family resilience variable, three-fifths of the respondent families were in the high category. The results of the multiple linear regression tests showed a significant positive effect of social support variables and coping strategies on family resilience. This study can serve as a basis for increasing public care for families who have members with neurodevelopmental disorders. The government should play a role in providing more affordable therapy services, both in terms of cost and accessibility. In addition, education about the diversity of human conditions needs to start at an early age to create a more inclusive society. Positive support from neighbors and family is also very important so families with children with NDD do not feel excluded. Thus, children with NDD can receive optimal stimulation for their growth and development.

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