

# Urban vs Rural: Parental Stress and Social Support of Parents of Children with Disabilities

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**Abstract.** Parents who care for children with disabilities are known to have higher levels of stress and greater obstacles compared to parents who care for children without special needs. However, this issue has received less attention and has not been studied much. This research is a correlational quantitative study that aims to see the relationship between parental stress and social support obtained by parents of children with disabilities, which also considers the factor of residence (urban vs. rural) as a moderator. The Parental Stress Scale (PSS) and the Medical Outcomes Study Social Support Survey - MOS-SS were administered to 107 parents with children with disabilities to determine the association between stress levels and social support received. Based on the results of the correlation test, a negative and significant correlation was obtained between parental stress and social support ( $p < .001$ ). This indicates that the higher the social support score, the lower the parental stress score. In addition, it was found that although it did not directly affect parental stress scores and social support partially, the location where participants lived moderated the influence of social support on parental stress..

**Keywords:** parental stress, social support, children with disabilities

## 1 Introduction

Based on data from the 2019 National Socio-Economic Survey (Susenas), the number of people with disabilities in Indonesia is 9.7 percent of the total population, or around 26 million people. Based on the 2018 Riskesdas report, as many as 3.3% of Indonesian children aged 5 to 17 years are in a disabled condition. When viewed from the age range, the majority of disabilities are in the range of 15 to 17 years, which is as much as 4.2%. Furthermore, as many as 3.5% aged 10 to 14 years and 2.5% aged 5 to 9 years. Naturally, from this prevalence, children with disabilities need utmost care from their parents and family.

Parenting a child with a disability specifically caused by rare disease brings unexpected demands and challenges for parents, with life-changing implications and long-term effects on the lives of the whole family (Simmernan, 2001). Many studies show that parents of children with disabilities experience higher levels of stress compared to parents of children without disabilities (Margarida, 2018; Padden & James, 2017; Kumar, et al., 2018; Sharma & Thapa,

2020). Stress experienced by parents also has an impact on children with disabilities that are multidimensional, reciprocal, affecting the entire family system, affecting relationships between family members (Guajardo et al., 2009; Raphael et al., 2010; Hsiao, 2017). Studies show that parents who experience higher levels of stress show different patterns of interaction and response with their children, compared to parents who experience lower levels of stress (Dervishaliaj, 2013). Parental stress and depression are strong predictors of actively managing and successfully coping with their child's problem behavior.

Parental stress, defined as parents' perception of the imbalance between parenting demands and available resources (Raphael, Zhang, Liu, & Giardino, 2010), is one of the many factors that contribute to parenting effectiveness (Guajardo, Snyder, & Petersen, 2009). However, when parents experience high levels of stress, their parenting effectiveness may decrease (Guajardo et al., 2009; Raphael et al., 2010); especially when a family has a child with a disability (Hsiao, 2017). Parental stress can cause parents to react negatively to their child's behavior, react in a less sensitive way, implement less effective coping strategies, or decrease their ability to seek appropriate support for their child, thereby affecting their child's physical and mental health (Hsiao, 2017).

Previous studies using a comparative study approach found that parents and caregivers of children with special needs have higher levels of stress, anxiety, and depression (Margarida, 2018; Padden & James, 2017; Kumar, et al., 2018) that are higher than the parents of non-disabled children. It is further known that the stress level of parents and caregivers in developing countries is higher than in developed countries. One of the triggers is the lack of resources, medicines, and medical equipment which can add to the stress of raising children with disabilities (Sharma & Thapa, 2020).

Hsiao (2017) states that parental stress is caused by at least three main factors, namely (1) child behavior problems, (2) parental coping strategies, and (3) parenting support in the family. The first factor is closely related to obstacles related to disability conditions experienced by children. Severe disability conditions and high care needs will increase stress on parents. The condition of disability also determines the dynamics of family life in various ways, such as recreational activities, educational activities, and sports activities, which in turn has the potential to limit the social activities of family members which leads to feelings of alienation.

The parents' coping strategy factors are related to how effective the parents' abilities are in overcoming the obstacles and burdens of parenting. Coping refers to behavioral or cognitive efforts that individuals use to minimize their level of distress or stress (Zablotsky et al., 2013). The worse the parents' coping abilities, the higher the reported stress level.

Parental support is an important factor in predicting parental stress. Parents who receive support from family and other support sources (friends, community, nurses, doctors) report lower levels of stress than parents who do not receive support.

Social support refers to the material and psychological resources considered available by a person through his interpersonal relationships. Satisfaction with social support is related to the perception that resources and relationships with other people are in accordance with expectations and needs (Rodriguez & Cohen, 1998). Pfeifer et al. (2014) argues that perceived social support helps more with stress than actual social support or the number of people who support it.

The social support perceived by parents with children with disabilities is an important variable for understanding the impact of disability on parental stress. Understanding the relationship between parental stress and perceived social support can increase knowledge about the barriers to and support needed by parents and caregivers of children with special needs and can provide a basis for the formulation of more effective public policies and services that target this population in the future. Based upon this urgency, this research explores the stress level of parents and the social support that has been received.

## **2 Methods**

This research is an explanatory research by providing a self-reported scale that measures the stress level of parents and caregivers with children with disabilities or rare diseases, and its relation to the social support they receive. This research data was collected online considering the conditions of the Covid-19 pandemic which were not yet fully conducive. The quantitative data obtained was analyzed using a correlation test to determine the relationship between the two variables, as well as moderated regression analysis with SPSS Statistics version 26 to determine the effect of the domicile variable (city or region) on the two variables. In addition, the data collected in this study will also produce descriptive data which includes socio-demographic data (gender, age, occupation, domicile, age of the child being treated), type or condition of the child's disability, forms of support so far received.

### **2.1 Sample**

The survey and provision of scales/measuring instruments in this study were conducted to 107 parents who have children with rare diseases or disabilities using the simple random sampling method. ), the minimum sample size for the linear regression test is  $N \geq 107$  (medium effect:  $f^2 = 0.15$ ) to 776 (small effect:  $f^2 = 0.02$ ) with an alpha level of 0.05 and a power of 0.95. In this experiment, with a medium effect, the minimum sample size is 107 respondents.

### **2.2 Research Instrument**

To measure the level of stress on parents and caregivers of children with special needs, this study used the Parental Stress Scale (PSS) developed by Barry & Jones (1995). The Parental Stress Scale (PSS) is an 18-item questionnaire that assesses parents' feelings about their parenting role, exploring the positive (emotional benefits, personal development) and negative aspects of parenthood (eg resource demands, feelings of stress).

Furthermore, social support was measured using the Medical Outcomes Study Social Support Survey - MOS-SS scale (Sherbourne & Stewart, 1991). This scale measures structural and functional social support consisting of 20 questions, 19 of which address perceived social support, such as: "How often have other people been able to help you when you needed them?" Respondents were asked to mark their answers on a Likert scale (never (1) - always (5)). This scale shows satisfactory indicators of reliability and validity (test-retest: .78; internal consistency: .91).

### **3. Research Procedure**

The research was conducted in three main stages consisting of preparation, data collection, and data analysis.

#### **1. Preparation Stage**

The preparatory stage as the first stage in this study includes: (a.) Transadaptation of research measuring instruments. Researchers transadapted two measuring instruments to be used in the study, namely the Parental Stress Scale (PSS) developed by Barry & Jones (1995) and the Medical Outcomes Study Social Support Survey - MOS-SS (Sherbourne & Stewart, 1991). Transadaptation is carried out in the form of translation and back translation by translators. The measuring instrument that has been trans-adapted will then be used in the trial phase. (b.) The researcher conducts a research try out which aims to determine the level of validity and reliability of the items that have been translated. The trial was conducted on research subjects, namely parents (within subject tryout). Within subject tryout were used considering that research subjects were not easy to obtain. (c.) The researcher revised the measuring instrument by retaining items that passed the validity and reliability tests and discarding items that failed and did not meet the qualifications. Items that have passed the validity and reliability tests will then be compiled into measuring instruments used in the data collection process.

#### **2. Data Collection Stage**

The data collection method in this study was carried out by distributing online surveys and measuring tools through the Google Form aimed at communities of parents who have children with rare diseases or disabilities, such as the Indonesian Rare Disorder Community.

#### **3. Data Analysis Stage**

Quantitative data obtained was analyzed by linear multiple regression with SPSS Statistics version 26. In addition, data analysis produced descriptive data including socio-demographic data (gender, age, occupation, domicile, age of the child being treated), type or condition of disability children, and the form of support that has been obtained so far.

### **4. Result**

The main hypothesis that we want to explore from this study is to determine the correlation between parenting stress and social support received by parents who have children with rare diseases or disabilities. The PSS scale (Berry and Jones, 1995) was used to measure parenting stress experienced by parents who have children with rare diseases or disabilities, while the MOS Social Support Survey scale (Sherbourne and Stewart, 1991) was used to measure the frequency of social support received by people parents with children with rare diseases or disabilities. Correlational analysis with Pearson Correlation was carried out to determine the closeness of the relationship and the direction of the relationship between the two variables. Pearson Correlation results show that there is a negative and significant relationship between parenting stress and social support of parents with children with rare diseases or disabilities ( $p=0.02$ ). This indicates that the higher the parenting stress score, the lower the social support score for parents of children with rare diseases or disabilities.

In addition to the correlation test, a simple linear regression test was also carried out to see the effect between variables, with an R squared value of 0.089, which means that the effect of the social support variable on the parenting stress variable was 8.9%.

Model Summary				
Model	R	R Square	Adjusted R Square	Std. Error of the Estimate
1	.298 <sup>a</sup>	.089	.080	6.47514

a. Predictors: (Constant), TotalMOS

In addition, the Moderated Regression Analysis (MRA) test was also carried out to consider other variables that could affect variable Y (parenting stress), namely domicile and whether or not you have accessed alternative medicine. The MRA model can be seen at the beginning below:

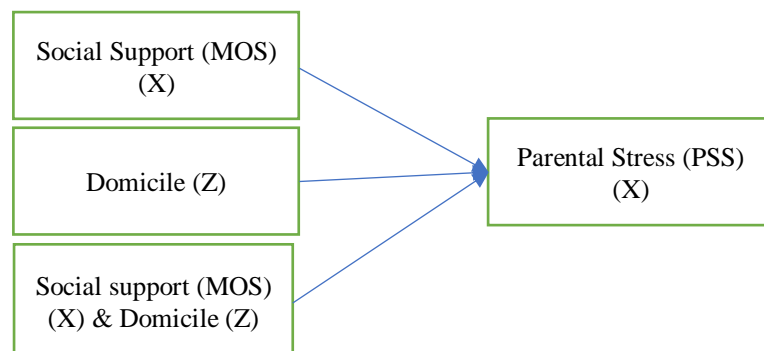


Image 5. Moderated Regression Analysis (MRA)

The results of the Moderated Regression Analysis show that there is a significant interaction between variables X (social support) and Z1 (domicile) ( $p=0.021$ ). Furthermore, it is known that the significance value of the interaction variable between social support and domicile is 0.034 ( $<0.05$ ) so it can be concluded that the domicile variable can moderate the influence of social support variables on parenting stress.

It is known that the R Square value is 0.232, which means that the contribution of the domicile variable to parenting stress is 23.2%. This indicates that the domicile variable can strengthen the effect of the social support variable on parenting stress.

Furthermore, it was also known through the one way ANOVA test that there was no significant difference in parental stress scores between participants who lived in big cities and those who lived in rural areas ( $p=0.486$ ,  $f=0.490$ ). In addition, there is also no significant difference in social support scores between participants who live in big cities and those who live in regions ( $p=0.411$ ,  $f=0.681$ ).

## **5. Discussion**

Support for parents with disabled children can vary depending on a number of factors, including the type and severity of the disability, the resources and services available in the community, and the individual needs and circumstances of the family. In general, parents of children with disabilities may face a range of challenges, including financial, emotional, and practical challenges related to caring for a child with special needs. They may also experience additional stress and feelings of isolation due to the extra responsibilities and demands of caring for a child with a disability.

There are a number of resources and supports available to help parents of children with disabilities. These can include financial assistance, educational resources, support groups, and professional support. Many countries have programs in place to provide financial assistance to families with disabled children, including disability benefits and financial aid for medical expenses. Schools and educational programs for children with disabilities may be available in the community, and there may also be resources available for parents to help their child learn and develop at home. Parents of children with disabilities may find it helpful to connect with other parents in similar situations through support groups or online communities (Riany & Ihsana, 2021). These groups can provide a sense of community, as well as practical advice and emotional support. Parents of children with disabilities may benefit from working with professionals such as therapists, social workers, and other specialists to help them manage the challenges of caring for a child with special needs. It's important for parents of children with disabilities to seek out the support and resources that are available to them and to take care of their own well-being as well as their child's.

Based on the findings, there were no significant difference on the score of social support of parents who live in the big cities and those who live in rural area. It's possible that social support may not be significantly different in urban and rural areas. Social support refers to the help, resources, and support that individuals receive from their social network, including family, friends, and community. Research has shown that social support can play a key role in promoting mental health and well-being, and can be especially important for managing stress and coping with challenges (Drogomyretska et al., 2020).

There are a number of factors that can influence the level of social support available to individuals in different areas. For example, people living in urban areas may have a larger and more diverse social network, with more opportunities to connect with others and access support. On the other hand, people living in rural areas may have a smaller, more tight-knit community, but may also have stronger social connections and a greater sense of community support.

The findings also revealed that there was no significant difference on the score of parental stress between parents who live in the big cities compared to those who live in the rural area. It's possible that parental stress may not be significantly different in urban and rural areas. Parenting can be a challenging and stressful experience regardless of where you live (Vazquez, et al, 2019). Factors that may contribute to parental stress include financial pressures, work-life balance, the demands of caring for children, and the overall responsibility of raising and supporting a family. These challenges may be present in both urban and rural areas and can affect parents in similar ways.

It's also important to note that there may be some unique stressors that affect parents living in different areas (Manimekalai et al., 2019). For example, parents living in a big city may experience higher levels of stress due to the fast pace of life and the challenges of living in a densely populated area. On the other hand, parents living in rural areas may face different

challenges, such as limited access to resources and support systems, or the isolation that can come with living in a more remote location.

## 6. Conclusion

Based on the results of hypothesis testing, although there was no significant difference between participants living in big cities (Jabodetabek) and those living in the regions, living area has a role in moderating the relationship between parental stress and social support. The level of stress experienced by parents of children with disabilities can be influenced by a variety of factors, including individual differences and personal circumstances, such as the severity of the disability, and the necessity of medical assistance. It's important for parents to find ways to manage stress and take care of their own well-being, regardless of where they live. It's important to recognize that the availability and effectiveness of social support can vary depending on the individual and their personal circumstances. Some people may have a strong support network regardless of where they live, while others may struggle to connect with others and find the support they need. It can be helpful for individuals to actively seek out and cultivate social connections and support, regardless of where they live.

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