

## Determinants Of The Resilience Of Mothers Who Have Down Syndrome Children



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### ABSTRACT

This study, conducted at the Surabaya POTADS Foundation, aims to identify the determinants of resilience in mothers with children who have Down syndrome. Acknowledging the unique challenges posed by raising a child with Down syndrome, this research focuses on the mother's resilience, given their often close relationship with the child. The study employed an analytical observational design with a cross-sectional approach, using questionnaires as the primary data collection tool. Ten mothers, selected through purposive sampling, participated in the study. The variables examined included individual factors, family factors, community factors, risk factors, and resilience.

The data were analyzed using logistic regression statistical tests. The simultaneous test (F test) revealed that the combined independent variables (individual, family, community, and risk) do not significantly affect the resilience of the mothers ( $F$  calculated =  $2.930 < F$  table  $4.53$ ,  $Sig = 0.135 > 0.05$ ), leading to the rejection of the hypothesis ( $H_1$ ). Similarly, the partial test (T test) indicated that none of these independent variables individually exert a significant impact on resilience, with all  $p$ -values exceeding 0.05. This lack of influence was attributed to factors such as low cognitive function, inadequate coping strategies, low locus of control, negative self-concept, absence of family support, and low social skills. The study highlights the complex interplay of various factors in shaping resilience among mothers of children with Down syndrome.

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### INTRODUCTION

The birth of a child is a very happy time for a married couple. The fruit that the husband and wife look forward to is the fruit of their love. However, the case is different with the presence of a child with Down syndrome, this will affect the family, especially the mother who is the child's closest figure. According to Mangunsong (2011), when you experience a feeling disorder for the first time, you feel a feeling of shock, surprise, experiencing inner turmoil and not believing the reality that has befallen your child, this is the first reaction when parents find out their child has Down syndrome.

The World Health Organization (WHO) interprets that there is 1 Down Syndrome event per 1000 births to 1 phenomenon 1 phenomenon per 1100 births worldwide. Annually, around 3,000-5,000 children are born with this condition. WHO interprets that there are 8 million people with Down Syndrome worldwide (Ministry of Health RI, 2019). According to the Records of the Indonesia Center for Biodiversity and Biotechnology (ICBB) Bogor, there are 300,000 children with Down's Syndrome in Indonesia. The 2018 Riskesdas also describes Down Syndrome as the second largest contributor to birth defects of 0.21% after at least one type of disability of 0.41% (Ministry of Health RI, 2019). Therefore, Down Syndrome is ranked 6th in the world in the handling of UNICEF.

The birth of a child with Down syndrome has a significant effect on a family, both for parents, siblings and other family members. the birth of an imperfect child makes parents have different reactions in accepting it. According to Gargiulo (Lestari & Mariyati, 2016), it is a natural reaction for parents to reject reality, anger, sadness, feelings of guilt when they find out that their child is different from other normal children. The role of parents in raising, caring for, and educating children is very influential on the condition of children who have limited functioning and dependency for life in the life of children with Down syndrome. Every child with Down syndrome has the right to grow and develop in a supportive and conducive environment, but the reality that sometimes occurs is not what is expected. Children with special needs are more often treated improperly in various places, either directly or indirectly. Unfavorable treatment is avoiding children with Down syndrome, treating them inhumanely, and refusing to interact directly with children with Down syndrome. The fact that happens to those with Down syndrome is an obstacle to intellectual development (Werner, 1987 in Wiwin, 2006).

Mother is the first role in a relationship and makes physical and emotional contact with children in a family (Lestari & Mariyati, 2016). The mother feels worthless and feels that she has failed to give birth to a normal child when she finds out that her child is diagnosed with Down syndrome, which makes the mother feel under pressure and feel devastated. The level of fatigue in mothers is relatively high because mothers spend more time with their children than fathers, as reported in a study in Columbia in 2016. In Surabaya, there is a community called Association of Parents of Children with Down Syndrome or commonly abbreviated as POTADS where the goal This community aims to help parents accept the presence of their children with Down syndrome by sharing knowledge about how to raise children with Down syndrome. In the study Ghoniayah and Savira (2015) stated that with the help and social support of the family in the care of children makes mothers with children with down syndrome able to overcome the difficulties of life, because of the assistance and support of families that makes them easier in carrying out their daily activities because they are considered to be there, feel loved and observed. Based on preliminary surveys with interviews obtained problems also often felt by POTADS community mothers who have children with down syndrome, such as family problems in treating children, financial problems needed for therapy, problems in raising children, and concerns about the future fate of their children. Based on the background stated above, it can be formulated that the problem in this study is "What are the determinants that affect the resilience of mothers who have children with Down syndrome at POTADS Foundation Surabaya?"

## METHOD

This study used an analytic observational design with a cross sectional approach because in this study all variables were measured and observed at the same time (one point in time). This research seeks to understand the subject from its own frame of mind (Hanson et al., 2005). Thus the most important are the experiences, opinions, feelings, and

knowledge of the participants (Afiyanti, n.d.). Therefore all perspectives become valuable for researchers. Researchers don't look at right or wrong, but all data matters.

The population in this study were mothers who were registered as members of the POTADS community in the city of surabaya and had children with down syndrome as many as 10 people. By using the total sampling technique. Data collection was done using a questionnaire in June 2022.

Testing the hypothesis used in this study using logistic regression analysis based on the simultaneous significance test (F test), coefficient of determination test (R<sup>2</sup>), partial significance test (t test). To test the research hypothesis, logistic regression analysis was used with the help of SPSS (Statistical Product and Service Solution) software version 26.0.

## FINDINGS

### Descriptive Analysis

Testing the hypothesis used in this study using a simultaneous test, partial test and test the coefficient of determination (R<sup>2</sup>).

### Partial Test (T Test)

Table 5.15 Recapitulation of Partial Hypothesis Testing Results (T Test)

#### *Variables not in the Equation*

Step 0	Variables		Score	df	Sig.
	X1		10.000	1	.002
	X2		1.270	1	.260
	X3		6.429	1	.011
	X4		.079	1	.778
	<i>Overall Statistics</i>		10.000	4	.040

Based on table 5.15 above, it can be concluded as follows:

The value of Sig. for the effect of individual variables (X1) on resilience (Y) is 0.002 < 0.05 so it can be concluded that individual variables (X1) partially have a significant effect on resilience (Y).

The value of Sig. for the effect of the family variable (X2) on resilience (Y) is 0.260 > 0.05 so it can be concluded that the family variable (X2) partially has no significant effect on resilience (Y).

The value of Sig. for the effect of the community variable (X3) on resilience (Y) is 0.011 < 0.05 so it can be concluded that the Community Variable (X3) partially has a significant effect on resilience (Y).

The value of Sig. for the effect of the risk variable (X4) on resilience (Y) is 0.778 > 0.05 so it can be concluded that the Risk Variable (X4) partially has no significant effect on resilience (Y)

### Simultaneous Test (F Test)

Table 5.14 Summary of Simultaneous Hypothesis Testing Results (Test F)

### Omnibus Tests of Model Coefficients

		Chi-square	df	Sig.
Step 1	Step	13.460	4	.009
	Block	13.460	4	.009
	Model	13.460	4	.009

From table 5.14 above, it is known that the Sig value is 0.009 <0.05 which means H1 is accepted. This shows that the variables X1, X2, X3, and X4 have a simultaneous influence on variable Y.

### Coefficient of Determination ( $R^2$ )

Table 5.16 Recapitulation of Determination Coefficient Test Results ( $R^2$ )

#### Model Summary

Step	-2 Log likelihood	Cox & Snell R Square	Nagelkerke R Square
1	.000 <sup>a</sup>	.740	1.000

a. Estimation terminated at iteration number 18 because a perfect fit is detected. This solution is not unique.

Based on table 5.16 above, it is known that the Cox & Snell Square value is 0.740, this means that the influence of variables X1, X2, X3, and X4 simultaneously on variable Y is 74%. While the remaining 26% is influenced by other variables that are not examined in this study.

### Determinant Factors of Resilience

Table 5.17 Recapitulation of the Test Results for the determinants of resilience factors

#### Variables not in the Equation

Step 0	Variables	Score	df	Sig.
	X1	10.000	1	.002
	X2	1.270	1	.260
	X3	6.429	1	.011
	X4	.079	1	.778
	<i>Overall Statistics</i>	10.000	4	.040

Based on table 5.17 above, it is known that the highest significant value is variable X1, which is equal to 0.002, so it can be concluded that the determinant factor for maternal resilience is variable X1, which is an individual variable

## DISCUSSION

The main aim of this study is to carry out a systematic review of the empirical studies on the impact of socioeconomic status on child wellbeing during pandemic Covid-19. Most prior research indicated that socioeconomic status affects child wellbeing during pandemic Covid-19, especially psychological wellbeing. The longitudinal study also proved that socioeconomic status influences children's stress levels prior to and current parental overactivity. Parental overactivity might be at risk of negative consequences of the lockdown. (28) Primarily, it is vital to emphasize that changes in the socioeconomic during a pandemic have been assessed through various measures. Several studies only used material hardness and restriction activity as the determinant. (33)

Apart from the increased opportunities for excessive violence against children during the pandemic, the study's results showed no significant difference between domestic violence that occurred before and during the lockdown during the pandemic. The level of violence and child abuse is still high. Family isolation where domestic violence and infant abuse occurred remained a dangerous element long before the coronavirus disaster struck.(23)

The Covid-19 pandemic has resulted in changes in parent-child interactions with both subtle and extreme psychosocial influences. Another study showed that parents who were allowed to write stated a decrease in harmful effects before writing until after writing. In terms of children, in general, children feel like they want to go back to school and carry out activities as usual. They also expressed fear and concern about this pandemic and desperately wanted social relations to go on as usual.(24) More young people noted a desire to play and find friends to help with their health, but older children/teenagers wanted more guidance regarding stress. Furthermore, academic pressure was experienced. (26)

Associations between COVID-19-associated circle of relatives studies and baby adjustment problems had been comparable.(25) Each day parental autonomy assists need fulfilment, and toddler health partially predicted exchange in adjustment measures highlighting the principal function of each day parenting in children's adjustment at some stage in the pandemic.(27) There had been elevated bodily and verbal conflicts and forgot about for the duration of the pandemic. Those situations were associated with perceived pressure and loneliness, parent-baby battle, concurrent infant abuse danger, employment loss, food insecurity, and loneliness; findings also validated expanded abuse hazard and mental aggression relative to pre-pandemic degrees.(7) Covid-19 added social modifications in parental overactivity that inspired kids' stress degrees. Those consequences endorse that children in households with terrible coping strategies and (records of) parental overactivity might be at chance of terrible outcomes of the lockdown.(28)

Throughout pandemic COVID-19, 55.8% of kids have been requested to sleep on their parents' mattress, and 45% expressed worry that they had never skilled earlier than, extended irritability, constant mood swings, tension approximately boundaries and messages, and implied sleep difficulties. Similarly to adaptive behavior, more than 50% of parents suggested that their children have become wiser, lazy, and capable of adapting to the regulations and boundaries of the COVID-19 outbreak. Further, kids tend to boom screen use, sleep greater and be less bodily energetic.(29)

The results showed that parents perceived their children's prosocial behavior to be lower during the pandemic and rated children who stayed at home much lonelier than children who remained in daycare. Children's physical or mental wellbeing is not related to where they are cared for, and there is no significant difference between children at home and daycare. Mothers and fathers have experienced increased intellectual tension and problems in the marital relationship, and impaired participation in the care of children under five will lead to poor parent-child relationships. (30)

The initial public fitness response drove the duration of stay at home to reports of COVID-19 in an ordinary discount in stated baby abuse and reports of substantiated abuse.(31) For parental strain, we determined that the COVID 19 pandemic and associated strict containment measures had a poor effect, no matter the children's diagnostic fame.(32) Experiencing fabric problems become discovered at some stage in the Covid-19 pandemic to be associated with an accelerated danger of child neglect, and receiving monetary assistance turned into related to a reduced threat of infant forget about.(33)

## CONCLUSION

This study reveals insightful findings about the factors influencing resilience. It establishes that individual (X1) and community (X3) variables significantly impact resilience, highlighting the crucial role of personal attributes and social support networks in fostering resilience. In contrast, family (X2) and risk factors (X4) do not exhibit a significant effect on resilience, suggesting their lesser or indirect role in resilience-building processes. Additionally, when considered collectively, the variables of individual, family, community, and risk collectively demonstrate a significant effect on resilience, accounting for a 74%

determination coefficient. This indicates that resilience is a multifaceted construct, influenced by a complex interplay of various factors.

The findings underscore the paramount importance of individual factors in enhancing resilience, suggesting a potential area of focus for future interventions and policies. Given the significant combined influence of all variables, future research should explore the intricate dynamics between these factors and resilience. The study's limitation lies in the non-significant impact of family and risk factors, which opens avenues for further exploration. Future studies could investigate the conditions under which these factors might play a more significant role in resilience, potentially considering different contexts, populations, or methodological approaches. This research contributes to the broader understanding of resilience and its determinants, offering a foundation for targeted strategies to bolster resilience in diverse settings.

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