

**UNIVERSITI TEKNOLOGI MARA**

**UNDERSTANDING THE  
RELATIONSHIP BETWEEN  
SOCIAL SUPPORT, CAREGIVER  
BURDEN, RESILIENCE AND  
QUALITY OF LIFE AMONG  
MOTHERS WITH DOWN  
SYNDROME CHILDREN IN EAST  
KALIMANTAN: A MIXED  
METHOD STUDY**

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of the requirements for the degree of  
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## ABSTRACT

**Introduction:** One consequence of spending time with a child with Down syndrome is that parents may spend less time interacting with their surroundings. This behaviour has an impact on parents' resilience and quality of life. This study intends to evaluate the association between social support, caregiver burden, resilience and the level quality of life among mothers with Down Syndrome Children. **Materials & Method:** A sequential explanatory mixed-method design was employed between February and May 2023. The study involved 182 mothers selected through purposive sampling, and quantitative data were collected using validated questionnaires measuring social support, caregiver burden, resilience, and quality of life. Data were analyzed using ANOVA, Pearson correlation, and multiple regression, while the qualitative phase utilized semi-structured interviews analyzed thematically to enrich the quantitative findings. **Results:** Results indicated that mothers generally had a moderate quality of life, with sociodemographic factors such as age, education, and employment showing significant associations with caregiver burden, resilience, and quality of life ( $p < 0.05$ ). Caregiver burden was identified as the strongest predictor of quality of life ( $r = 0.67$ ,  $p < 0.001$ ;  $R^2 = 47.7\%$ ). Six key themes emerged from the qualitative analysis, including mothers' understanding of the child's condition, emotional responses, caregiving stressors, coping strategies, caregiving competence, and available support resources. **Conclusion:** Quality of life variables increase with decreasing caregiving burden and increasing social support that plays a role in maintaining resilience. There was a significant positive relationship between caregiving burden factors. However, only weak negative correlations were found between variables evaluating resilience in providing care and social support. Therefore, this study can provide guidance for the development of more effective intervention programmes in protective service providers by thinking about caregiving using this method as an early detection in maintaining and improving quality of life with a focus on reducing caregiving burden and increasing social support of parents with DS children.

**Keywords:** Caregiver Burden, Down Syndrome, Quality of Life, Resilience, Social Support

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# CHAPTER 1

## INTRODUCTION

### **Introduction**

Several studies have been conducted on resilience in children with Down Syndrome, which has a significant impact on the child's parents, especially on the health and function of the Social. Down syndrome is a disease caused by chromosomes, especially in the elderly; it tends to affect the cause significantly and affects a person of status, ethnicity, and socioeconomic status, and can even affect other social members (Caples et al., 2018). This chapter addresses the research overview, including the context, the description of the issue, the research goals, the research questions, and the research significance and hypothesis.

### **1.1 Background of Research**

Professional nurses have a responsibility to provide high-quality care. One of the roles of nurses is educators, because education is one of the ways nurses use so that clients and families can make decisions. The role of nurses as educators in community or hospital settings provides health education to clients and their families that can improve their health status. Nurses in providing health education to their clients should first assess the background and education of the client / parent so that the language conveyed can be accepted according to the level of education. The aim is to change the knowledge, attitudes and skills of individuals or communities in the field of health by making health something of value in society, helping individuals to be able to independently or in groups to carry out activities to achieve the goal of healthy living and encourage the development and proper use of existing health care facilities. The impact felt by parents with Down syndrome when their child is diagnosed with Down syndrome, parents are often sad and upset. Because families will be stigmatized by society due to restrictions on children with Down syndrome. So that the influence of prejudice against children with Down syndrome is still widely practiced in Indonesia which makes parents with Down Syndrome not optimal in providing support to help develop their child's potential