

Social Support, Caregiver Burden, Quality of Life and Resilience Among Mothers with Down Syndrome Children in East Kalimantan: A Mixed Method Study

Aries Abiyoga¹, Zamzaliza Abdul Mulud^{2*}

¹*Department of Nursing, Institute of Health Technology and Science Wiyata Husada Samarinda, Indonesia*

²*Departement of Nursing Studies, Faculty of Health Sciences, Universiti Teknologi MARA, Puncak Alam Campus, 42300 Puncak Alam, Selangor, Malaysia*

Authors' Email Address: ¹ariesabiyoga121186@gmail.com, ²zamzaliza@uitm.edu.my

Received Date: 30 May 2024

Accepted Date: 30 June 2024

Revised Date: 9 July 2024

Published Date: 31 July 2024

*Corresponding Author

ABSTRACT

One effect of spending time with children who have Down syndrome is that parents may spend less time interacting with their surroundings. Parents' resilience and quality of life will both be impacted by this behavior. The study sought to ascertain the relationship between quality of life, resilience, carer load, and social support in mothers of children with Down syndrome. This study employed a hybrid methodology, with two phases in February and May of 2023: quantitative and qualitative. In the initial phase, 135 parents with DS children were involved. The qualitative phase involved 8 individuals after that. The quality-of-life variable has a strong correlation; however, it is correlated negatively, meaning that the variable's resilience decreases as quality-of-life increases. However, the variables measuring the burden of caring and social support show a negligible connection with a negative direction. This implies that the resilience variable decreases with increasing stress and increases with social support. Six themes surfaced in the qualitative stage in the meantime. Social support, caregiver burden, and quality of life influence the strengthening of parents who have DS children; therefore, protection service providers can consider parenting using this method as early detection in maintaining the resilience of parents who have DS children.

Keywords: *caregiver burden, down syndrome, quality of life, resilience, social support*

INTRODUCTION

Down syndrome (DS) is a chromosomal disorder characterized by intellectual and physical disabilities. Historically, healthcare providers have often viewed its impact on individuals, families, and communities in a negative light. Mothers of a child diagnosed with Down Syndrome (DS) reportedly face an ongoing chronic condition that requires them to meet their child's multiple needs throughout their life (Van Riper, Cosgrove, & Fleming, 2023). It is reported that having a child with an unexpected

diagnosis is very emotional and stressful for some families. It is reported that having a child with a disability increases the risk of stress, fatigue, and worse health effects. The World Health Organization defines quality of life (QOL) as "an individual's perception of his position in life in the context of the culture and value system in which he lives and concerning his goals, expectations, standards, and concerns." It is considered a subjective evaluation embedded in the social, cultural, and environmental. It is "multidimensional" and combines the individual's physical perception of health, psychological condition, and social relationships with others (Bowling, 2017; Catalano et al., 2018).

The mother is the primary caregiver, helping the child's growth and development in the social environment. However, the presence of a child with special needs becomes a significant upheaval, especially for the mother, because having a child with special needs will take more attention, so it can affect the increasing various demands and needs of caring for children, ranging from emotional needs, tools to support their activities to improve financial needs. The pressures experienced by parents who have children with Down syndrome cover all fields. The stressful parenting process will be associated with low levels of cooperation and sensitivity and will impact the destruction of parenting styles (Alina Chiracu et al., 2023). The emergence of parenting stress in mothers with special needs children often causes depression, anxiety, health problems, social isolation, and low self-esteem. For children who suffer from genetic disorders, of course, parents will be faced with psychological issues, treatment, and uncertainty of the development and growth experienced, which in turn will cause stress (Alam El-Deen, Alwakeel, El-Gilany, & Wahba, 2021; Dias et al., 2022).

In addition, in Indonesia itself, much adverse treatment is still given by parents or people who have not been able to accept the existence of children with mental retardation, especially Down syndrome. The community embraced numerous adverse treatments and believes that Down syndrome is a curse on society. This belief is also a burden for parents with Down syndrome children. Down syndrome children need help with behavior, fulfilling daily activities, and direction and supervision in dealing with other people. It shows that parents' resilience is still weak in raising children with Down syndrome. Various efforts have been made to help parents by providing counseling methods, yet parents' resilience still experience higher levels of stress, depression, and anxiety. Based on research conducted suggests that resilience is often associated with a person's ability to adapt to the environment or face pressure or stress (Choi & Van Riper, 2020).

Genetic disorders experienced by children can be a stressor that causes psychological symptoms such as anxiety. A study conducted by (Lee, Neil, & Friesen, 2021). Showed that the quality of life (QoL) of Down syndrome children (DS) is related to social, which reflects positive aspects of social functioning that contribute to a better quality of life, and families that reflect negative aspects of social functioning contribute to a poorer quality of life. A study conducted by Choi & Yoo, 2020; (Choi & Van Riper, 2020) Identifying factors related to the social resilience of children with Down syndrome requires that social cohesiveness and communication skills be strongly related to social resilience and adaptation. However, not all families are placed in situations of non-adjustment. Some families adapt well to the problem, while others are more vulnerable. The differences depend on the level of resilience. Families of children with DS are reported to have higher stress levels, adjustment difficulties, and poorer coping than families of non-disabled children.

However, children with DS exhibit relatively few behavioral problems and higher levels of adaptive behavior than children with neurological issues or other developmental disabilities. Many families have chosen to care for children with DS at home rather than placing them in facilities because they have a higher developmental potential than children with other disabilities. Although the results suggest that nursing interventions to increase social resilience and adaptation should consider risk and protective factors, individual strategies that can strengthen and reduce protective factors should be implemented. This study still has limitations in that it is still carried out on parents of children under 17. In addition, this research is still conducted on parents who live in (Alam El-Deen et al., 2021).

Research in Indonesia on Down Syndrome is still minimal. Numerous studies (Andini & Nurrahima, 2017) have been conducted to describe the quality of life of parents of children with Down syndrome, to describe the quality of life of children with Down syndrome based on their age, gender, adaptive function, type of disease experienced, and behavioral problems based on parental support (Ayuningrum & Afif, 2020). Children with Down syndrome have many limitations that cause children to be unable to be independent, so they need parental help. Parents who spend time caring for children with Down syndrome can have an impact, such as reduced time for parents to interact with the outside environment and stress. If this is not handled correctly, it will cause the parents' quality of life to decline.

However, with the limitations of this study in Indonesia, special attention is needed to explore factors related to resilience, quality of life, social support, and caregiver burden for parents with children with Down syndrome. The researcher realizes that this research cannot be separated from several weaknesses or deficiencies in implementation and the research methods used. The researchers consider using two ways, both quantitative and qualitative, to be very efficient. In addition to obtaining subjective data, researchers can also develop new data obtained in concepts, behaviors, perceptions, or even human problems to be studied. This is very important to do because this research has never been done in East Kalimantan.

The most difficult things that the subject felt were the words of new people in public places and the views of other people who looked at their children strangely. So that makes the subject feel confused, stressed, sad, angry, and even afraid to imagine how his child's life in the future with his condition. In addition, parents and families also feel devastated by the condition of their children. Because of their shyness, they often avoid people they know. There is even a feeling of wanting to kill his child because he cannot accept the conditions he is in. In this case, it is evident that the parents experienced an excessive negative response; it was seen that there was a negative attitude that the parents revealed. Here, parents are required to be able to overcome the frustration they feel. Resilience is a natural process that occurs within the individual.

Parents who have children with Down syndrome need to make significant adjustments to get through the various difficulties they experience to rebuild their function correctly. Children with Down syndrome have the right to be treated equally and have equal opportunities in all aspects of life (Lee et al., 2021). Empowering parents to always be eager to help their unique child grow and develop to the fullest allows them to become independent individuals and excel so that the wider community can accept them. Individuals with good resilience are empathetic, calm, optimistic, and believe things can improve. Individuals have hope for the future and can control their life's direction. Optimism makes you physically healthier and reduces the chances of suffering from depression. Tuner argues that resilience is the mental capacity to bounce back from adversity and continue a prosperous functional life. So, it can be simplified that resilience is finding the positive side behind adversity and using it as a strength to get up. It shows that there are still parents who do not understand the function of resilience (A. Chiracu et al., 2023). Therefore, it is essential to have a well-designed study exploring factors related to resilience, quality of life, social support, and caregiver burden for parents with Down syndrome children.

RELATED WORKS

The Relationship Between Social Support

Social support functions as an adjustment process or adjustment from adverse events. Families with high perceptions of social support will rarely feel lonely (Kang et al., 2018). Families with a high level of perceived social support have favorable psychosocial profiles. In addition, the individual's perception of low social support can have an unfavorable impact. The common perception of social support can make individuals feel lonely, and then this low perception harms their quality of life. In addition, depressive symptoms can increase without the individual's perception of social support (Dağ & Şen, 2018).

The Relationship Between Caregiver Burden.

Carers of Down syndrome children face a problematic caring load since they must care for the ill individual while also meeting their own needs. The burden encountered is classified as an objective or subjective burden. The objective load is a realistic burden for carers due to different challenges in delivering care, such as disturbance of social interactions, limited time for themselves, and increased costs of daily necessities (AlShatti et al., 2021). Parents have the most significant burden of caring for Down syndrome children, both physically and mentally. When caring for children, older carers' body function deteriorates, leaving them exposed to exhaustion or physical health concerns.

In addition, parents who care for Down syndrome children frequently encounter mental health issues such as stress (Abdollahi & Rasoulpoor, 2024). The physical and mental components are indicators used to determine quality of life. Acceptance by parents, particularly moms who care for children with special needs, is a slow and gradual process that begins with denying the child's existence and ends with realizing that they accept it because they believe it is a trust and fortune for which they should be grateful (Takataya, Yamazaki, & Mizuno, 2016). Caregivers' self-acceptance when caring for children will make caregivers more likely to experience psychological well-being. So this means that the caregiver does not have physical, psychological, or social burdens; psychological well-being is not an easy thing to achieve; individuals are not only healthy physically but also psychologically (Jaramillo, Moreno, & Rodríguez, 2016).

The Relationship Between Quality of Life

Quality of life for parents with children with disabilities makes it an important and exciting thing to research. Referring to the parent's condition, who is the closest person to the child, it is directly affected by the pressures of education and the child's unique needs. On the child's side, the initial physical and psychological experience is an experience that must be passed on to his mother and father. The role and function of parents for children with unique characteristics are significant and prominent in developing the child, becoming a basis for the need to know the quality of life of parents with special needs children. Compared to families with children with other forms of disability, parents with ASD had worse quality of life and social functioning values (Pisula & Porebowicz-Dörsmann, 2017), due to the increased parental stress caused by the numerous challenges faced in caring for children with ASD, such as behavioral issues, emotional control, social problems, anxiety, and depression. The parent's physical and emotional health impacts their capacity and ability to care for their children. When parents' quality of life declines, it is feared that their ability to care for their children will deteriorate (Vasilopoulou & Nisbet, 2016).

The Relationship Between Resilience

Resilience entails more than surviving, enduring, or escaping a problematic experience. Survivors are not always strong; some may survive physically but suffer from post-traumatic stress disorder, agonizing sadness or anxiety, and an inability to love or thrive psychologically and interpersonally (Southwick, Bonanno, Masten, Panter-Brick, & Yehuda, 2014) Others remain locked in the victim role, nursing old wounds or unable to evolve. On the other side, the resilience process enables people to recover from traumatic situations, regain control of their lives, and continue to live and love effectively (Matheson, Asokumar, & Anisman, 2020). To comprehend and foster resilience, it is necessary to distinguish it from the typical hope of "bounce back" as well as the myths of "immunity" and "self-sufficiency." According to one study, resilience is built via hardship and struggle and is linked to our reliance on others (Ungar, 2021).

Over the last few decades, a rising body of research has contributed to our understanding of resilience. Resilient parents of children with ASD who achieved positive or desired outcomes despite high risk have been profiled. Resilience can assist parents of children with ASD who suffer unfavorable

symptoms in reducing the impact of the crisis and negative responses to the crisis, resulting in good individual adaptation (Kózka & Przybyła-Basista, 2018). Resilience requires seven capabilities. The first is the ability to understand negative attitudes that impede personal advancement. Second, avoid thinking about blaming yourself. Third, identify subconscious worries. Fourth, develop your problem-solving skills. Fifth, situate the problem in the proper context. Sixth, remain calm and focused when dealing with challenges. Seventh, the resilience concept should be immediately used (Choi & Van Riper, 2020). One of these skills can be learned through social assistance. Meeting and supporting other carers of children with Down syndrome is crucial for fostering emotions of empowerment (Beighton & Wills, 2019).

METHODOLOGY

Study Design, Setting, And Population.

The explanatory mixed method study approach was adopted to test and comprehend the aspects (social support, carer load, and quality of life) that influence the resilience of moms with Down syndrome. This mixed technique is also a methodology that provides philosophical assurance in directing or guiding data gathering and interpretation, as well as a combination of quantitative and qualitative methodologies throughout multiple stages of research. The quantitative method of cross-sectional analysis was utilized in the initial step of this study. The second stage of this research, which takes a qualitative approach and employs a structured interview, includes all data collection activities conducted in person with anyone who requires or desires to participate. This study was conducted from February to May 2023.

The participants in this study were parents, particularly women who belonged to the East Kalimantan Association of Parents of Children with Down Syndrome (POTADS). The names of all mothers with Down syndrome children were acquired from the POTADS registration list. We utilized the Raosoft sample size calculator to get a suitable sample size for this study. Given a population size of 207, a 95% confidence level, and a 5% margin of error, the calculator calculates that a minimum sample size of 135 people is required. After data collection, 135 people had completed the questionnaire (Raosoft, 2020). The random sample technique was employed based on criteria such as parents who have Down syndrome children, live together, and meet the conditions to participate in this study as inclusion criteria and parents who are unable to communicate or have cognitive issues as exclusion criteria. Randomly selected participants were contacted and invited to take part in the study. Following the completion of the quantitative research stage, the results of the first stage study will be used to choose participants for stage 2 (Jones, Gwynn, & Teeter, 2019). Participants with "poor quality of life, carer burden, low social support, and poor resilience" will be encouraged to participate, and qualitative data will be collected from eight moms. Researchers employed a series of Indonesian questionnaires developed by previous researchers that addressed each aspect (quality of life, carer load, social support, and resilience).

Parental-Developmental Disorder-Quality of Life (Par-DD-QoL), adapted from the Par-ENT-QoL questionnaire, has 18 items used to measure parents' quality of life. This questionnaire was translated into Indonesian by a previous researcher, Titis Nur Latifah, and has been tested for validity and reliability with Cronbach's reliability value of 0.903 and validity of 0.223 -0.692. The quality of life is assessed with scores: ≥ 66 high quality of life; 42-65 moderate quality of life; < 42 low quality of life. This scale has good consistency or reliability, with a Cronbach's alpha value of 0.903 and a validity level of 0.223-0.692 (Latifah, 2021). Previous researchers employed a modified ZBI questionnaire designed by Zarit, with 22 question items. This questionnaire contains four closed-ended answer options: 0 symbolizes never, 1 represents rarely, 2 represents occasionally, three represents frequently, and four represents practically always. With a score of 0-20, no or little load; 21-40, light to

moderate load; 41-60, moderate to heavy load; and 61-88, heavy load. Cronbach's Alpha (0.804) indicates that the test results are reliable and consistent (Andriani, 2019).

The questionnaire created by researchers was based on theories from Cutrona, Gardner, and Uchino regarding different sorts of social support. There are 27 question items, each with four option answers: strongly agree, agree, disagree, and strongly disagree. A score of 54 indicates low, 81 indicates medium, and 81 indicates high. Cronbach's Alpha result (0.911) suggests that the questionnaire is credible (Nuzula, 2018). The Resilience Scale has 23 items that use six alternative answers. The alternative answers are Very Unsuitable, Not Appropriate, Somewhat Unsuitable, Somewhat Appropriate, Appropriate, and Very Appropriate. Various scores assess resilience: > 138 very high resistance; 123-138 high resilience; medium resistance 108-123; 93-108 low resistance; < 93 meager resistance. This scale has good consistency or reliability with a Cronbach's alpha value of between 0.932 and a validity level of 0.302-0.770 (Reswara, 2023).

We distributed surveys to parents willing to participate while attending POTADS-organized activities. Mothers were given questionnaires to assess their quality of life in terms of resilience when raising children with Down syndrome. Quantitative data analysis considers the percentage and intensity of correlation direction. Given a sample size of 135, a Shapiro-Wilk normality test was performed, which revealed no evidence of non-normality in the data. Next, the Pearson correlation coefficient was calculated. P-values less than 0.05 were considered significant (Jones et al., 2019). Findings from audio recordings will be transcribed word for word from audio to text. The researcher will review and confirm each participant's quotes to ensure that they fit the context and purpose of the interview session. The qualitative data analysis process begins by organizing all the data collected from various sources. The data is then given codes (coding) and grouped according to the problem theme or research question. After being grouped into the same theme, the data is read, studied, and studied. Data with the same meaning is combined into one to avoid repetition. Data that is not relevant to the theme or research question and whose content is not very important is discarded or reduced (Jones et al., 2019). This research has received approval from the Health Research Ethics Committee of the East Kalimantan Health Polytechnic (Approval Number: DL.02.03/4.3/18851/2022) and the Research Ethics Committee of Universiti Teknologi MARA (UiTM) Malaysia (Approval Number: REC/01/2023 (PG /PAK)/20.

RESULTS

Phase 1

Table 1 explains that the Demographic characteristics of respondents in this study numbered one hundred and thirty-five. The research results show that the average age of parents is 26-25 years, while the education level of most is high school (n=74, 54.8%), and at the employment level, the largest percentage is in the No group. Working/Housewife category (n=88, 65.2%), and in the monthly income category, the average income was >1,000,001 – 3,000,000 (n=85, 63.0%).

Table 1. Socioeconomic characteristics

Sociodemographic	Response	Result	
		N(%)	Mean ± SD
Age			31,67 ± 8,94
	17-25	25 (18,5%)	
	26-35	55 (40,7%)	
	36-45	41 (30,4%)	
	46-55	14 (10,4%)	
Education	Primary School	4 (3,0%)	
	Junior High School	13 (9,6%)	
	High School	74 (54,8%)	
	College/University	44 (32,6%)	

Employment Status	Not Working/Housewife	88 (65,2%)	
	Private	41 (30,4%)	
	Government Officilas	6 (4,4%)	
Household Income/month (Rp)			1,10 ± 0,296
	< 1.000.000	38 (27,4%)	
	>1.000.001 – 3.000.000	85 (63,0%)	
	> 3.000.001	13 (10,4%)	

Note: ^a Column %, otherwise is row %; r, reference group.

Based on Table 2, there is a significant correlation. However, the direction of the correlation has a negative value, which means that the higher the quality of life, the lower the resilience variable. There is an insignificant correlation, and the direction of the correlation has a negative value, which means that the higher the carrier burden, the lower the resilience variable. There is an insignificant correlation, and the direction of the correlation has a negative value, which means that the higher the social support, the lower the resilience variable.

Table 2. Association between Quality of Life, Caregiver Burden, Social Support with Resilience

	Score Resilience	
	R	P-Value
Score Quality of Life	- 0.336**	0.000
Score Caregiver Burden	- 0.088**	0.311
Score Social Support	- 0.158	0.068

Note: Spearman's Correlation

Phase 2

The Interviews were conducted with eight parents of children with Down syndrome at the Association of Parents with Children with Down Syndrome. The following are some of the themes that were derived and emerged from the interview sessions.

(1) Mother's description of the characteristics of children with Down Syndrome.

Interviews were conducted with mothers who expressed their condition for the first time when they saw their child being born: *"How come his face is different, his face is wide, his nose is flat"* (P1), (P3). *"children who have less intellectual intelligence"* (P4). *"Weak immunity, weak mind, weak muscles"* (P5).

(2) Responses of mothers who have children with Down syndrome

Such expressions can be seen in this passage: *"Well, at first, I wasn't sincere because I was only able to move on after 3 years of walking"* (P4). *"At first I felt heavy, but mmmm yes, it's called destiny"* (P2), (P6). *"First, I didn't accept it, I felt disappointed, I had baby blues for 2 months"* (P1).

(3) Stressors for mothers who have children with Down syndrome.

In addition, an overview of This expression of feeling is an expression of feelings that arise from parents (mother). Expression of feelings obtained by parents' fear, from the following interview: *"There's not enough money, especially if you rely on your husband's salary"* (P2). *I have to fight... yes, I have to do extra for my child's condition in the future"* (P4). *"I often get sick because I have heart disease, epilepsy"* (P5, P6).

(4) Mother's coping strategies in dealing with children with Down syndrome

Of the mother participants who became the study's object, all received that there are several ways to maintain good coping. The above can be seen from the following interview results: *"Continuous efforts to survive, you have to be able and flexible, one day you will definitely be able to do it" (P4), "Yes you have to be able to appreciate and accept" (P3).*

(5) Mother's ability to care for children with Down syndrome

The following are some excerpts from participants. There are many things that must be considered when looking after children with Down syndrome: *"Children cannot eat carelessly; food must be chosen if they are allergic to cow's milk" (P2). ' Yes, the treatment is a little different" (P1), "My child is 6 years old but is still like 1 year old, can't walk or talk yet" (P5, P4)*

(6) Support Resources.

This support is a complementary ingredient that strengthens a relationship, especially when one of the family members needs support. The following are the results of interviews related to these categories: *"The family is very supportive, my brother and my husband are very supportive," (P2), "At first I was a little scared because I was separated from my husband, but my parents gave me a lot of support" (P4). "The neighbors are very attentive even though there are only one or two people who are indifferent" (P3, P5)." I was lucky because I joined the community, so it felt like there were lots of families who supported me" (P1, P6).*

DISCUSSION

Phase 1

There is no doubt that the quality of life, social support, and caregiving burden of parents with children with Down Syndrome (DS) are vulnerable to high levels of stress, considering that DS is a lifelong disorder and caregiver responsibilities increase as people with DS age. (Dias et al., 2022). However, quality of life, social support, and the burden of caregiving gradually develop specific personality attributes and skills essential in adapting to their life context.

In line with the aim of this study, the relationship between quality of life, social support, and caregiving burden for parents of children with DS was investigated. Descriptive analysis showed that participants reported moderate quality of life, social support, and caregiving burden. Statistical analysis shows that three dimensions of resilience negatively relate to quality of life, social support, and caregiver burden when discussing mediation analysis. Quality of life was a significant mediator in the relationship between self-resilience, hope, and well-being but not in the relationship between optimism and well-being (Dias et al., 2022; Faria Carrada et al., 2020). The total impact is positive and significant, and quality of life is an essential mediator in the relationship between parental resilience and caring for children with DS. Above-average results for quality of life can be attributed to education; 31.4 percent of mothers with higher education have a stable relationship with self-resilience.

Family demographics, family demands, and social support are essential factors that play a significant role in how families respond to the birth of a child with DS. Treatment of children with DS and their families may be more effective if professionals working with these families are aware of the factors that contribute to healthy family functioning (Hsiao, 2014). Social support is one factor that plays a role in shaping a person into a firm or resilient person. This is in line with research conducted regarding the relationship between social support and resilience, which shows that there is a positive correlation between social support and resilience (Afita & Nuranasmita, 2023). This indicates that the higher the social support an individual receives, the higher the individual's resilience. By getting social

support from an association for parents with children with the same condition, parents feel loved, valuable, and valued (Noroozi et al., 2024).

Parents who care for children with Down Syndrome (DS) have a more significant burden of daily activities, which can affect their health. Parents who are the primary caregivers of children with disabilities face many challenges in everyday life. In line with research concluded that mothers who have children with Down syndrome tend to have a high level of caregiving burden, and this is related to age at birth. Therefore, health service providers, including relevant authorities, are advised to carry out various programs to support nurses in reducing their burden as well as to increase awareness programs regarding Down syndrome prevention measures in the community (Mishra, Pandey, Bhujel, & Adhikari, 2023).

Resilience contributes to flexible adaptation to the demands of life in a precise, consistent, and persistent manner, both by adapting one's abilities and using environmental factors wisely. Positive adaptation is reflected in the fact that the person can cope positively with difficulties, failures, traumatic events, and also with increasing responsibility (Bonanno, Westphal, & Mancini, 2011). Thus, resilience reflects a person's ability to endure adverse events and return to an initial state of balance and functioning after experiencing these unfavorable events. People with a high level of resilience are characterized by self-confidence, independence, a sense of humor, patience, positive emotions, openness to new experiences, and determination in action, which contribute to improving the quality of life and well-being (Alina Chiracu et al., 2023).

Phase 2

The six themes that emerged from the in-depth interviews succeeded in providing a better understanding of parents' experiences in caring for children with DS. Qualitative findings showed five themes related to parents' strategies and abilities to maintain resilience in caring for children with DS. In this study, we aimed to assess the impact of having a child with DS on the parents' quality of life. Our results show that most caregivers reported strategies and efforts in caring for and sustaining the child's life, consistent with the investigation findings. Apart from that, many factors can contribute to a decrease in the quality of life of parents, social support, and the burden of caring for children with DS. This may include difficulty accepting their child's disability, changes in family routines, and difficulty getting needed support (Bull & Genetics, 2011; Uppal, Chandran, & Potluri, 2015). However, it should be noted that although many problems and difficulties have been reported for caregivers of children with DS, the estimated quality of life for the population included in this investigation does not appear to be significantly impaired (Uppal et al., 2015).

We have also assessed stressors for mothers of DS children. Our results show significant differences between different domains, where parents of DS children must be able to survive for the sake of survival for the future of their children. This may contribute to estimates of reduced quality of life among some caregivers. This can be attributed to the potential burden that having a child with DS places on the psychological, social, and physical parameters of their caregivers, which may be a direct cause of embarrassment, anxiety, and stress in their caregivers (Xanthopoulos et al., 2017). In the same context, we also found that the mother's ability to care for a DS child was associated with the child's health parameters, indicating a high burden in caring for a DS child; regardless of other conditions, the care provided was different from that of an average child, usually caused by weak immunity. Health in children with DS, so the role of parents is very large in maintaining the health of children with DS (Alexander & Walendzik, 2016).

In addition, supporting resources are urgently needed because caregivers are forced to spend more time with their children and provide more attention. In addition, evidence in the literature also shows that some caregivers report that it is challenging to handle health services for their children, who also take over other responsibilities from parents, thereby leading to a decrease in quality of life (Alexander

& Walendzik, 2016; Xanthopoulos et al., 2017). Therefore, adopting social integration by building a strong social network with caregivers of children with DS may contribute to beneficial resilience parameters for affected caregivers (Xanthopoulos et al., 2017). However, it should be noted that not all caregivers have access to such activities, which may be unaffordable for most of them, and therefore, raising their children may also be challenging and reduce the quality-of-life aspects. Thus, healthcare authorities should provide more facilitated access to these and home services to assist care providers and improve their quality of life and social integration.

Strength and limitation

This study has various advantages, one of which is using two techniques. This study used a combined strategy of quantitative and qualitative findings. Combining these two methodologies yields accurate data that can be used to construct a comprehensive nursing care model for maintaining resilience in parents of DS children. However, this study has drawbacks. The study's weaknesses stem from the small number of participants, which consisted of only 135 moms. It is advised that the number of difficulties is increased to include more parents. It is also vital to broaden the area of research by addressing contextual elements such as geographical location, sociodemographic linkages, and ethnic culture.

CONCLUSION

According to the objectives of this study, social support, carer burden, and quality of life influence the strengthening of older people; thus, nursing service providers can consider nursing care as an early detection strategy for preserving resilience. Good resilience is defined as the capacity to organize and focus attention effectively. When a woman has this resilience, she becomes more sensitive to her surroundings, which improves her ability to support her child's well-being.

ACKNOWLEDGMENTS

The authors thank the Faculty of Health Sciences, UiTM, for the support of this research. In addition, the author would like to thank the East Kalimantan POTADS organization for permission to conduct research and the Health Polytechnic of the East Kalimantan Ministry of Health.

FUNDING

This research uses scholarship funds from the Wiyata Husada Samarinda Institute of Health and Science Technology.

AUTHORS' CONTRIBUTION

Abiyoga, A. collected data, made a literature review/analysis, and wrote the manuscript and references. Zamzaliza Abdul Mulud contributed to studying conception and design, provided feedback, was critical, and helped shape the research, analysis, and manuscript.

CONFLICTS OF INTEREST

We certify that the article is the original work of the authors and co-authors. The article has not received prior publication and is not under consideration for publication elsewhere. This manuscript has not been submitted for publication, nor has it been published in whole or in part elsewhere. We testify that all Authors have contributed significantly to the work, validity, and legitimacy of the data and its interpretation for submission to Jurnal Intelek.

REFERENCES

- Abdollahi, R., & Rasoulpoor, S. (2024). Taking care of the children with Down's syndrome is a painful burden on their mothers. *Journal of Nursing Reports in Clinical Practice*, 2(4), 279-280. doi:10.32598/jnrpc.2403.1043
- Afita, L., & Nuranasmita, T. (2023). The Role of Social Support in Promoting Resilience and Mental Well-Being. *Bulletin of Science Education*, 3, 269. doi:10.51278/bse.v3i3.867
- Alam El-Deen, N., Alwakeel, A. A., El-Gilany, A. H., & Wahba, Y. (2021). Burden of family caregivers of Down syndrome children: a cross-sectional study. *Fam Pract*, 38(2), 160-165. doi:10.1093/fampra/cmaa097
- Alexander, T., & Walendzik, J. (2016). Raising a Child with Down Syndrome: Do Preferred Coping Strategies Explain Differences in Parental Health? *Psychology*, 07, 28-39. doi:10.4236/psych.2016.71005
- AlShatti, A., AlKandari, D., AlMutairi, H., AlEbrahim, D., AlMutairi, A., AlAnsari, D., . . . Ahmed, J. (2021). Caregivers' perceptions and experience of caring for persons with Down syndrome in Kuwait: a qualitative study. *Int J Dev Disabil*, 67(5), 381-390. doi:10.1080/20473869.2021.1910780
- Andini, D. C., & Nurrahima, A. (2017). *Gambaran Kualitas Hidup Orang Tua Anak Sindrom Down di Yayasan Persatuan Orang Tua Anak dengan Sindrom Down Jakarta*. Faculty of Medicine, Retrieved from <http://eprints.undip.ac.id/57897/>
- Andriani, N. P. A. S. (2019). Gambaran Beban Orang Tua (Caregiver Burden) Dalam Merawat Anak Retardasi Mental Di Slb Negeri 1 Badung. Retrieved from https://repository.itekes-bali.ac.id/medias/journal/Ni_Putu_Ayu_Sista_Andriani.pdf
- Ayuningrum, D., & Afif, N. (2020). Interaksi Sosial Anak Down Syndrome di TK Nusa Indah Jakarta. *IQ (Ilmu Al-qur'an): Jurnal Pendidikan Islam*, 3(01), 141-162.
- Beighton, C., & Wills, J. (2019). How parents describe the positive aspects of parenting their child who has intellectual disabilities: A systematic review and narrative synthesis. *Journal of Applied Research in Intellectual Disabilities*, 32(5), 1255-1279.
- Bonanno, G. A., Westphal, M., & Mancini, A. D. (2011). Resilience to loss and potential trauma. *Annu Rev Clin Psychol*, 7, 511-535. doi:10.1146/annurev-clinpsy-032210-104526
- Bowling, A. (2017). *Measuring Health: A Review Of Subjective Health, Well-Being And Quality Of Life Measurement Scales*.
- Bull, M. J., & Genetics, t. C. o. (2011). Health Supervision for Children With Down Syndrome. *Pediatrics*, 128(2), 393-406. doi:10.1542/peds.2011-1605
- Catalano, D., Holloway, L., & Mpofu, E. (2018). Mental Health Interventions for Parent Carers of Children with Autistic Spectrum Disorder: Practice Guidelines from a Critical Interpretive Synthesis (CIS) Systematic Review. *Int J Environ Res Public Health*, 15(2). doi:10.3390/ijerph15020341
- Chiracu, A., Cosma, G., Stepan, R., Cosma, A., Corlaci, I., Călugăru, E., . . . Avramescu, T. (2023). Psychological capital, quality of life, and well-being in mother caregivers of individuals with down syndrome. *Frontiers in Psychology*, 14, 1145104. doi:10.3389/fpsyg.2023.1145104
- Chiracu, A., Cosma, G. A., Stepan, A. R., Cosma, M. A., Corlaci, I., Călugăru, E. D. C., . . . Avramescu, T. (2023). Psychological capital, quality of life, and well-being in mother caregivers of individuals with down syndrome. *Front Psychol*, 14, 1145104. doi:10.3389/fpsyg.2023.1145104
- Choi, H., & Van Riper, M. (2020). mHealth Family Adaptation Intervention for Families of Young Children with Down Syndrome: A Feasibility Study. *J Pediatr Nurs*, 50, e69-e76. doi:10.1016/j.pedn.2019.03.010
- Dağ, İ., & Şen, G. (2018). The Mediating Role of Perceived Social Support in the Relationships Between General Causality Orientations and Locus of Control With Psychopathological Symptoms. *Europe's Journal of Psychology*, 14(3), 531-553. doi:10.5964/ejop.v14i3.1563

- Dias, C., Schwertner, C., Grando, D., Bidinotto, A. B., Hilgert, J. B., Schuch, J. B., . . . Hashizume, L. N. (2022). Caregiving of children with Down syndrome: impact on quality of life, stress, mental and oral health. *Special Care in Dentistry*, 42(4), 398-403. doi:<https://doi.org/10.1111/scd.12694>
- Faria Carrada, C., Almeida Ribeiro Scalioni, F., Abreu, L. G., Borges-Oliveira, A. C., Ribeiro, R. A., & Paiva, S. M. (2020). Caregivers' Perception of Oral Health-Related Quality of Life of Individuals with Down Syndrome. *J Dent Child (Chic)*, 87(3), 132-140.
- Hsiao, C. Y. (2014). Family demands, social support and family functioning in Taiwanese families rearing children with Down syndrome. *J Intellect Disabil Res*, 58(6), 549-559. doi:10.1111/jir.12052
- Jaramillo, S., Moreno, S., & Rodríguez, V. (2016). Emotional burden in parents of children with trisomy 21: Descriptive study in a Colombian population. *Universitas psychologica*, 15(1), 29-38.
- Jones, K. R., Gwynn, E. P., & Teeter, A. M. (2019). Quantitative or Qualitative: Selecting the Right Methodological Approach for Credible Evidence. *Journal of Human Sciences and Extension*.
- Kang, H. W., Park, M., & Wallace Hernandez, J. P. (2018). The impact of perceived social support, loneliness, and physical activity on quality of life in South Korean older adults. *J Sport Health Sci*, 7(2), 237-244. doi:10.1016/j.jshs.2016.05.003
- Kózka, A., & Przybyła-Basista, H. (2018). Perceived stress, ego-resiliency, and relational resources as predictors of psychological well-being in parents of children with Down syndrome. *Health Psychology Report*, 6(1), 50-59.
- Latifah, T. N. (2021). *Hubungan antara mindfulness trait dan kualitas hidup pada orang tua yang memiliki anak autisme*. Universitas Muhammadiyah Malang,
- Lee, E. Y., Neil, N., & Friesen, D. C. (2021). Support needs, coping, and stress among parents and caregivers of people with Down syndrome. *Res Dev Disabil*, 119, 104113. doi:10.1016/j.ridd.2021.104113
- Matheson, K., Asokumar, A., & Anisman, H. (2020). Resilience: Safety in the Aftermath of Traumatic Stressor Experiences. *Front Behav Neurosci*, 14, 596919. doi:10.3389/fnbeh.2020.596919
- Mishra, T. A., Pandey, K., Bhujel, B., & Adhikari, S. (2023). Burden of Care among Mothers Having Children with Down Syndrome. *J Nepal Health Res Counc*, 20(4), 977-982. doi:10.33314/jnhrc.v20i4.4415
- Noroozi, F., Farrar, Z., Gharibi, T., & Gashmard, R. (2024). Family Self-Support in Managing Down Syndrome Children: A Qualitative Study. *ScientificWorldJournal*, 2024, 9992595. doi:10.1155/2024/9992595
- Nuzula, M. A. (2018). *Hubungan antara Dukungan Sosial dengan Harga Diri Ibu yang Memiliki Anak Berkebutuhan Khusus*. Universitas Brawijaya, Retrieved from <http://repository.ub.ac.id/id/eprint/163311>
- Pisula, E., & Porębowicz-Dörsmann, A. (2017). Family functioning, parenting stress and quality of life in mothers and fathers of Polish children with high functioning autism or Asperger syndrome. *PLoS One*, 12(10), e0186536. doi:10.1371/journal.pone.0186536
- Raosoftware. (2020). Sample Size Calculator by Raosoftware Inc. Retrieved from <http://www.raosoftware.com/samplesize.html>. [(accessed on 16 September 2020)].
- Reswara, A. M. D. (2023). *Hubungan antara kebersyukuran dan resiliensi pada ibu yang memiliki anak berkebutuhan khusus*. (Volume 561, Edition 3)
- Southwick, S. M., Bonanno, G. A., Masten, A. S., Panter-Brick, C., & Yehuda, R. (2014). Resilience definitions, theory, and challenges: interdisciplinary perspectives. *Eur J Psychotraumatol*, 5. doi:10.3402/ejpt.v5.25338
- Takataya, K., Yamazaki, Y., & Mizuno, E. (2016). Perceptions and feelings of fathers of children with Down syndrome. *Archives of Psychiatric Nursing*, 30(5), 544-551.
- Ungar, M. (2021). *Multisystemic resilience: Adaptation and transformation in contexts of change*: Oxford University Press.
- Uppal, H., Chandran, S., & Potluri, R. (2015). Risk factors for mortality in Down syndrome. *J Intellect Disabil Res*, 59(9), 873-881. doi:10.1111/jir.12196

- Van Riper, M., Cosgrove, B., & Fleming, L. (2023). Adaptation at the Family Level in Families of Individuals With Down Syndrome: A Scoping Review. *Journal of Family Nursing*, 29(4), 324-347. doi:10.1177/10748407231163236
- Vasilopoulou, E., & Nisbet, J. (2016). The quality of life of parents of children with autism spectrum disorder: A systematic review. *Research in Autism Spectrum Disorders*, 23, 36-49. doi:https://doi.org/10.1016/j.rasd.2015.11.008
- Xanthopoulos, M. S., Walega, R., Xiao, R., Prasad, D., Pipan, M. M., Zemel, B. S., . . . Kelly, A. (2017). Caregiver-Reported Quality of Life in Youth with Down Syndrome. *The Journal of Pediatrics*, 189, 98-104.e101. doi:10.1016/j.jpeds.2017.06.073