JANH Journal of Applied Nursing and Health | Vol. 8, No. 1 (2026) p-ISSN: 2657-1609 | e-ISSN: 2809-3208

Original Article

Caregiver Resilience and Burden in Long-Term Care Family of Children with Developmental Disabilities: A Cross-Sectional Study

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ARTICLE INFO

Article History

Submit : November 24, 2025
Accepted : March 26, 2026
Published : March 30, 2026

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Citation:

Wulandari, S. K. ., Sriwahyuningsih, L. N. ., & Israfil, I. (2026). Caregiver Resilience and Burden in Long-Term Care Family of Children with Developmental Disabilities: A Cross-Sectional Study. Journal of Applied Nursing and Health, 8(1), 581–592. https://doi.org/10.55018/janh.v8i1.490

ABSTRACT

Background: A family with a child with special needs experiences a struggle to provide care and quality of life. However, empirical evidence on the relationship between resilience and caregiver burden in the long-term care of children with developmental disabilities (DDC) in low- and middle-income countries remains limited, with a family nursing perspective in Indonesia, especially in Bali. This study aimed to determine the relationship between caregiver burden and resilience in long-term care of children with developmental disabilities.

Methods: This study was reported in accordance with the STROBE guidelines. A cross-sectional study was conducted online using network sampling DDC in Denpasar City. The questionnaires were the Burden Scale for Family Caregivers (BSFC) to measure the family burden as the independent variable and the Resilience Scale for Adults (RSA) used to measure the resilience of the caregiver as the dependent variable. Spearman's rank correlation was used for data analysis.

Results: As many as 102 parents or siblings of DDC joined the research online. Data showed most caregivers were mothers (67,6%), with more than one child (65,7%), and with various types of DDC. A moderate negative correlation was observed between caregiver burden and resilience ($r = -0.294$, $p < 0.005$). The higher burden experienced by siblings (mean= 13.5), when fathers have the highest resilience (mean= 99.83), as they felt less burden (mean= 8.93).

Conclusion: The greater burden experienced by the family implied a lower capacity to express resilience. Coping skill training could be developed as a response to the burden to build better family coping and boost resilience.

Keywords: Caregiver burden; Developmental disabilities; Family nursing; Long-term care; Resilience

Implications for Practice:

- The study provides empirical evidence to inform the refinement of family-centered nursing guidelines in resource-limited and Low – and middle-income countries (LMIC) contexts.
- Resilience-based interventions may be culturally adapted and feasibly implemented in settings with limited health-care resources.
- The findings support the integration of resilience-focused family nursing interventions to reduce caregiver burden in long-term care of children with developmental disabilities.

Implications for Practice:

Introduction

Children with special needs are expected to receive more support from their families. These special needs can be divided into several types, such as physical, cognitive, behavioral (behavioral disabilities), language, and learning (CDC, 2025). A child with a special need or developmental disability (DDC) had an increasing demand for care from others, especially family. Mother as primary caregiver reported experiencing physical, emotional, and relational difficulties along the caring phase; moreover, in pubescent children (Joung, 2023). The latest survey showed a decrease in the number of DDC who joined the survey, about 29% (Badan Kebijakan Pembangunan Kesehatan, 2023). In the Southeast Asia region, the highest prevalence of DDC is after the African region (World Health Organization (WHO) and United Nations Children's Fund (UNICEF), 2023). As the global data reached, the number of people experiencing disability reached 1.3 billion people (16%) in the total population around the world (WHO, 2025). They requested care services from basic to advanced needs. As the inclusive group that vulnerable DDC have barrier to joint into the society (World Health Organization (WHO), 2025). Family, as the closest companion and caregiver, has many roles and duties in assisting DDC. Alongside the mother, father, sibling, and other members of the family, there could be a caregiver with broad duties.

Family conditions are reciprocally affected by assistance in a long-term care setting. The vulnerable condition of children with special needs makes them vulnerable to neglect, violence, and bullying problems that disrupt their health (Gilbert et al., 2024). These conditions make children with special needs one of the marginalized groups that need support and assistance, especially in LMIC. Global data shows that 300 million children aged 2-4 years experience violence from their caregivers (World Health Organization (WHO) and United Nations Children's Fund (UNICEF), 2020). Conditions with DDC will exacerbate this condition. As family crises also faced the struggle as members of the community to adapt and care with limited facilities. Lived with autistic children, family sense negative feelings due to difficult care, hopelessness, and lack of information (Carvalho et al., 2021; World Bank, 2024), as the evidence is needed to clarify how the situation affects caregiver resilience of DDC to build further access for this marginal group.

On the other hand, family played an important role in ensuring the continuity of a good life for each of their members. The family resilience framework explained how families are capable of bouncing back from crises and successfully overcoming life challenges (Kaakinen et al., 2018). The caregiver burden as a crisis in the family is important to assess how much it affects the family's resilience. Alan and Kaçan's (2024) study showed that the level of care burden felt by parents of children with special needs was greater compared to children with chronic illnesses, which was in the moderate to severe range. Resilience family ability with positive parenting enhances a good quality of life in a family with DDC (Widyawati et al., 2021). Resilience has negative associations with caregiving burden but has a positive correlation with optimism and social support, as the study proved in the elderly care setting (Hou & Chen, 2024). However, the burden and resilience of families need to be addressed in further research on DDC, which was limited. It can be used as a basis for developing services and assistance, particularly family nursing in special services for families with children with special needs.

The long-term caregiver burden for DDC has implications for the fatigue and quality of life of the caregiver. The use of the family resilience framework in this study seeks to explore the potential ability of families to bounce back during the long-term care process in DDCs who also experience caregiving burden. The burden, which is a stressor, requires adaptation by caregivers, which can ultimately impact the quality of life of the family, as Walsh (2016) had explained before, as the update of the family resilience (Kaakinen et al., 2018). What is desired is the caregiver's ability to adapt well, namely, having resilience in managing stressors during the long-term care period.

Nursing services, especially family health nursing, are provided to meet the needs in long-term care support. Information is needed on the condition of families with DDC. Therefore, researchers want to explore information related to these conditions with the aim of determining the relationship between caregiver resilience and the burden of families with DDC.

Methods

Study Design

A correlational design with an inferential quantitative method with cross-sectional approach was employed (Ghanad, 2023). The study reported accordance the STROBE guidelines to examine the relationship between caregiver resilience and burden in family with DDC. Primary data taken from caregiver of DDC who lived together.

Participants

Data collected from two special school based in Denpasar, Indonesia which were 1st and 3rd Denpasar general special school. These schools chosen because it serves large students with various DDC condition that match with target population of this study. The study population included parent/ caregiver from DDC who lived together and agreed to participate which capable filled self-complete questionnaires online. The exclusion criteria were respondent with unfinished questionnaire and has formal caregiver for the DDC at home.

Network sampling was used to optimize the reach of potential respondents across the city (Lavrakas, 2026). Although some DDC students are enrolled in special schools, attendance fluctuates significantly. The study obtained voluntary participation. The class teacher and staff share the recruitment information with the DDC family. Informed consent and approval were obtained in a Google Form before filling in the questionnaires. Participation invitation was announced three times by the class teacher to obtain optimum primary data from July to September 2024. The study reached 102 participants complete online survey through Google forms. Other family or caregiver did not respond to the study invitation.

Instruments

The questionnaires used were demographic information, the Burden Scale for Family Caregivers (BSFC), and the Resilience Scale for Adults (RSA). The Burden Scale for Family Caregivers (BSFC) Short Version was used to measure family or caregiver burden was developed by Graessel et al. (2014) and consists of 10 items with a 0- 30 total score, and the response options used a Likert scale (0-3) that Cronbach's alpha for the complete scale was 0.92. Indonesian version had Cronbach's alpha for the complete scale was 0.904 (Nurlaila et al., 2024). The higher score, the more burden felt by the caregiver. The Resilience Scale for Adults (RSA) was used to measure caregiver resilience which consist 33 items with 0- 99 total score. The higher the score, the more resilience caregiver was. The Cronbach's alpha for total RSA score was 0.88 within cross culture assessment and response options using Likert scale (0-3) that re-test by Hjemdal et al. (2015) after developed (Friborg et al., 2003) and re-test as the latest by Rossi, et al. (2021) that used in this study.

Validity and reliability results from the current study will report separately.

Data Collection

Data management in this study began with identifying potential respondents through the databases of the two special schools. Then accessible population was identified through school information and notifications via class teachers. Next, the collected information was combined. A team was prepared to follow up on questionnaires completion via text message and check compliance with sample criteria in the incoming data. Participants filled the questionnaire online by their own device for convenience reason. The research team conducted follow-ups every 1-2 weeks on data collection. Then, preparations were made for data cleaning until ready for analysis. Monitoring the data collection for duplication and error with weekly check. Re-contact the respondents to confirm and check the accuracy of misleading data. Descriptive analyses performed to summarize demographic and univariate data. Then, correlation analyses conducted to assess relationship between caregiver burden and resilience.

The study workflow followed five steps: 1) identifying potential respondents, 2) collected information from both school, 3) follow up on questionnaires completion, 4) data cleaning and preparation, and 5) statistic analysis.

Data Analysis

The study received 102 valid respondents. This sample size is sufficient to determine in correlation research (Pallant, 2020). The effect size with Cohen's d got -8.85 (large effect) (*Effect Size*, 2025). Data processing and analysis used SPSS version 25.0 (IBM Corp.) Descriptive analysis used to presented sample characteristics frequency distribution to represent the data. The statistical analysis used Spearman's rank correlation because the data did not meet the assumptions required. Data showed linear distribution.

Ethical Considerations

This study had approval ethical clearance number 04.0258/KEPITEKES-BALI/VII/2024 by Ethic Commission of Institute of Technology and Health Bali. The commission reviewed and determined it to be ethically appropriate in accordance with the WHO (2011) ethical guidelines. Participants were provided with clear written explanations informed consent about the purpose, objectives, methods, potential risks, and benefits of the study. Participation was voluntary with written informed consent was obtained from each participant before conducted any questionnaires. We also sent the approval letter to each school as we knew that the participants were in some condition being high risk group.

Results

Respondents came from parent/caregiver of DDC in two special schools that located in Denpasar City. Respondents had children with various types of developmental disorders. They lived with their families and most of them received total support in everyday life.

Table 1 Characteristics of Respondents (n=102)

Characteristics	n (%)
Relationship with DDC	
Mother	69 (67.6)
Father	29 (28.4)
Guardian/Sibling	4 (4.0)
Number of children	
1	25 (24.5)
2–3	67 (65.7)
> 3	10 (9.8)
Number of DDC	
1	100 (98.0)

Characteristics	n (%)
2–3	2 (2.0)
Types of special needs in children	
Autism	21 (20.6)
Physical disorders (disability)	19 (18.7)
Cerebral palsy	2 (2.0)
ADHD	19 (18.7)
Other disorders	41 (40.0)
Average age of respondents	43.3 ± 1.9 years
Employment status	
Housewife/Father (freelancer)	54 (52.9)
Civil servant/Private sector	18 (17.6)
Self-employed/Entrepreneur	26 (25.5)
Not working	4 (4.0)

According to **table 1,** with average age of respondent were 43,3 ± 1,9 years and most of them are mother with 69 respondents (67.6%) compared to 29 as father (28.4%), others were guardian/ sibling. As many as 67 respondents have 2-3 children totally, which parents who have >3 children less then 10 respondents. Number of DDC in the family mostly one with 100 respondents (98%). Respondents have children with special needs of various types, such as autism, physical disorders (disability), cerebral palsy, attention deficit hyperactivity disorder (ADHD), and others. Mostly, respondents are housewife/husband at home worked as freelancer with 54 respondents (52.9%), as self-employed/entrepreneurs with 26 respondents (25.5%), as civil servants/private sector with 18 respondents (17.6%), and four respondents were not working anymore with various reasons.

The resilience consists of five dimensions: (1) personal competence (PC) consists of 10 statements, (2) social competence (SC) consists of seventh statements, (3) family coherence (FC) consists of seven statements, (4) social support (SS) consists of eight statements, and (5) personal structure (PS) consists of five statements. The result in this study is shown in **Table 3.**

Table 2. Correlation analysis between resilience and caregiver burden in families with DDC

	RSA's score
BSFC's score	r = -0.294 p = 0.003 n = 102

Note: p<0.05 (two-tailed)

Tabel 3. Correlation analysis between five dimensions of resilience and caregiver burden

Variables	RSA_PC	RSA_SC	RSA_FC	RSA_SS	RSA_PS
None	Co. 1.000	Co. 0.433 (p < 0.001)	Co. 0.209 (p = 0.035)	Co. 0.272 (p = 0.006)	Co. 0.424 (p < 0.001)
Care burden	Co. -0.257 (p = 0.009)	Co. -0.265 (p = 0.007)	Co. -0.154 (p = 0.112)	Co. -0.214 (p = 0.031)	Co. -0.048 (p = 0.632)

Note: p<0.01 (two-tailed)

The result in **Table 2** of Spearman's rho analysis found p = 0.003 (p < 0.05) with a correlation coefficient of about – 0.294. Although statistically significant (p = 0.003), the correlation coefficient (r = -0.294) indicates a weak inverse relationship between caregiver burden and resilience, suggesting other moderating factors may also play a role. The higher family burden experienced by the family correlates with lower resilience.

The partial correlation used eliminates the confounding factor among the variables (Pallant, 2020). The correlation of BSFC for each RSA dimension showed in Table 3 an accurate indication that each dimension has significant correlation, except the RSA_FC, *p*= 0.112, and RSA_PS, *p*=0.632. The strongest power was RSA_SC with Co. -.265, then the lowest was RSA_PS with Co. -.048. Each dimension contributed to the resilience aspect of the caregiver and built coping support for the family.

Tabel 4. The difference in burden and resilience between caregivers in the family

Variables	Mean ± SD
Caregiver burden	
Mother	10.49 ± 4.1
Father	8.93 ± 5.1
Sibling	13.5 ± 1.7
Resilience	
Mother	94.2 ± 12.2
Father	99.8 ± 13.2
Sibling	85.0 ± 16.2

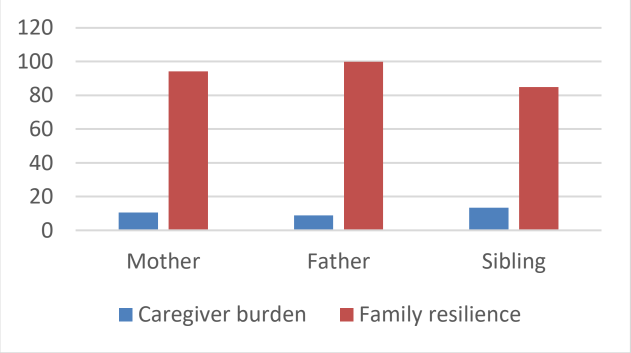

Figure 1. The difference in burden and resilience among caregivers of DDC

The result in **Table 4** indicates the mean of burden (M= 13.50) felt by the guardian/sibling was the highest among another caregiver. But for the resilience occur the highest score in father as caregiver (M= 99.83). The scores among caregiver group showed small difference in each variables score (**Figure 1**).

Discussion

The purpose of the study to determine the relationship between burden and resilience of caregiver with DDC which result show a significant negative correlation. Respondents were mostly DDC's mother (67%) and have more than one child (65%). Mother become primary caregiver in family and mostly also participation in paid work to support the family income. This family model may lead to a modernized male breadwinner (Lütolf, 2025). In this study, some of them worked as freelancers for flexible work hours and took care of the children. The DDC, who had complex care needs, led to burnout in caregiver. Some mentions occurrence of long-term care as nature, the development of stress symptoms into exhaustion, and distancing from others (Patty et al., 2024). Perceived stress and decline in physical condition among caregivers of children and adolescents with ADHD were lower than in those with intellectual disabilities that were studied in India (Dubey et al., 2023). Dlamini et al. (2023) described caregivers' experiences into 1) need for convenient health care facilities & accessible public space, 2) health care information and financial aid, 3) physical and psychological limitation, 4) stigma & social rejection, 5) burden of caring. In this study, siblings experience more care burden but limited access to the resources around. As the comparison with other low-middle-income countries remains limited, as known by the author.

Siblings, as the informal caregiver, also experienced burden and found it more difficult to adjust to the situation, as shown in Tabel 4. They felt more burden and lower resilience among mothers and fathers from DDC. Lee et al. (2025) described sibling experienced 1) encounter difficulties interaction to their DDC brother/sister, 2) intrapersonal response that struggle with their self as a complex feeling to their sibling, 3) interpersonal response, as they being advocate to their DDC sibling but also felt hesitance to disclose, 4) family dynamic, 5) develop strategies and support (take and give), and 6) accepting and adapting to the reality. In terms of dimensions, in this study, resilience shows the strongest correlation with personal and social competencies to anticipate the care burden. Hamama (2025) explains that in a family with an autistic child, responses from mother, father, and sibling differ, especially in the caring approach; mother and sibling openly perceive more social support than father. Parents who were married also have a chance to support each other in caregiving (Dey & Amponsah, 2020).

The finding showed the burden experienced by the caregiver family associated with resilience among them, even in a small connection, as the dimensions of resilience, such as personal competence, social competence, family coherence, social support, and personal structure, contribute to the ability of the family to cope with the burden. As individual willingness was important in responding to social support, not just the presence or absence of that support itself (Xin et al., 2025). This is proven by value of resilience dimensions separated between social competence and social support. Social interaction could become social support or social discrimination. Burden felt by the caregiver as a family member were intense. Some condition, caregiver of DDC still perceive from moderate to severe discrimination around them. The discrimination accured in group the oldest ones, with the multiple and/or mental disabilities (Leng et al., 2024). Social competence emerged as the strongest negative correlate with caregiver burden, suggesting that social interaction skills may buffer stress perception. In contrast, personal structure did not show significance, possibly due to cultural norms in caregiving.

As asians have greater concerns about providing care for their families (Tran et al., 2023). This increases their risk of experiencing a higher care burden. Another study revealed that the transactional model of depression through early life caregiving adversity could be a source of resilience for the family (Somers et al., 2024), and other developing resilience through faith in religion and social support (Lakhani et al., 2024). Resilience can be built within families through the following measures: development of resilience skills in parents, communication dynamics between parents and children, and the reinforcement of spiritual and moral values (Anggraini et al., 2024). As that possible in Indonesian characteristic with majority follow one of the religious or belief systems. Caregivers with less spirituality and lack of religious activity experience a higher level of burden (Maximiano-Barreto et al., 2022). Mostly, sibling lack of experienced on it and made them felt more burden in this study. Family health nursing could facilitate the build-up of family roles in early stage by identification of the caregiving adversity.

These findings highlight the need for targeted psychosocial support programs for families, especially mothers and sibling caregivers, to enhance resilience and reduce caregiver burden in long-term DDC care, as the results of this study refer to a negative correlation between caregiver burden and resilience of families with DDC. Therefore, it is important to identify the burden felt by caregivers (crisis occurs) as early as possible to develop better resilience (as a coping mechanism) and bring a matched support system. Better growth and resilience can outgrow the burden of the caregiver itself. As explained in The family resilience theory (Walsh, 2016). This can be done through comprehensive family nursing services for families caring for individuals with DDC.

Implications and limitations

The finding showed higher burden felt by caregiver resulting in lower resilience especially sibling of DDC. This is expected to provide space for families as informal caregiver to build resilience and optimize the quality of family life in the future. Nursing education also could put contribution by initiation integrated care support and facilitated for the special family care in long term care not just focus on the parent but also sibling.

However, this study has limitations that has not identified other confounding or supporting factors for the variables studied, such as community support and public policy. Which may shape the behaviors of communities in caring for family members with DDC. Small sample size might affect generalization in this group. Future research might use specific instrument for family as caregiver for both variable better assess, longer period of data collection, and collaborate with professionals in inclusive groups for wider reach.

Relevance to Practice

The result can expand as the base of the intervention in family nursing to get the intervention in family with DDC. Nursing care based on family as client approach without ignoring the role of other family members in DDC care besides parents, such as siblings who apparently experience a higher caregiver burden according to this study. As informal caregiver and spend most of the time with the DDC. Family nurses could explain to the family how to manage the care service and not to lose their self in the way of care. As in Indonesia family health nursing occasionally visiting the client home. Health care professional might explore how to create a confidence team as interprofessional collaboration in family center care orientation, such as involving cadres in accompanying DDC families.

Conclusion

Family experienced burden in various way and build resilience in care of their DDC and also the sibling who help the caregiving process. They had risk for caregiver burden even more and need of coping strategy to build their resilience among the family member. Further, parenting model could facilitate not only the DDC but the other children they have who also experienced being a caregiver in the future. Future research may explore longitudinal studies on family health nursing to observe changes in resilience over time as the family stage of growth, or intervention trials (coping skill training or family-centered care program), or other mediator analyses such as social support, economic burden, or mental health. Not only focus on the parents but also other family members such as siblings.

Funding

This research was funded by a grant from ITEKES Bali (Grant No.). The funding body had no role in the study design, data collection, analysis, interpretation, or manuscript writing.

CrediT Authorship Contributions Statement

Sar**ah Kartika Wulandari**: Conceptualization, Methodology, Investigation, Writing – Original Draft, Supervision

LG Nita Sriwahyuningsih: Validation, Formal Analysis, Writing – Review & Editing, Visualization

Israfil: Data Curation, Resources, Project Administration, Writing – Review & Editing

Conflicts of Interest

There is no conflict of interest.

Acknowledgments

The authors would like to express their sincere gratitude to the Institute of Technology and Health Bali for providing institutional support for this study. We also thank all respondents who participated in this research and contributed valuable data.

Appreciation is extended to colleagues and administrative staff who assisted in the research process and completion of this manuscript.

References

Alay, G. K., & Kaçan, H. (2024). Care burden and resilience in parents of children with special needs and chronic diseases. *Journal of Pediatric Nursing*, *76*(May–June 2024), 61–67. https://doi.org/DOI: 10.1016/j.pedn.2024.02.001

Anggraini, A. A., Harianto, M. I., Putri, S. N., Sholikah, N., & Anto, A. H. F. (2024). Family Resilience In Households Of Children With Disabilities: A Comprehensive Analysis. *Proceedings of International Conference on Psychology, Mental Health, Religion, and Sprirituality*, *2*(01), 25–43. https://doi.org/10.29080/pmhrs.v2i01.2194

Badan Kebijakan Pembangunan Kesehatan. (2023). Survei Kesehatan Indonesia 2023 (SKI). In *Kemenkes*. https://kemkes.go.id/id/survei-kesehatan-indonesia-ski-2023

Carvalho, C. M. S., Morais, I. C., Borges, J. da S., Oliveira, M. C. A., Carvalho, A. E. S. de, Amorim, F. C. M., Oliveira, A. D. da S., Magalhães, J. M., Sarisawa, E. A. L. S., & Araújo, A. S. de S. (2021). Experiences of Family Members of Children with Autism. *The Open Nursing Journal*, *15*(1), 367–372. https://doi.org/10.2174/1874434602115010367

CDC. (2025). *Developmental Disability Basics*. Child Development. https://www.cdc.gov/child-development/about/developmental-disability-basics.html

Dey, N. E. Y., & Amponsah, B. (2020). Sources of perceived social support on resilience amongst parents raising children with special needs in Ghana. *Heliyon*, *6*(11). https://doi.org/10.1016/j.heliyon.2020.e05569

Dlamini, M. D., Chang, Y. J., & Nguyen, T. T. B. (2023). Caregivers' experiences of having a child with cerebral palsy. A meta-synthesis. *Journal of Pediatric Nursing*, *73*(August), 157–168. https://doi.org/10.1016/j.pedn.2023.08.026

Dubey, M. J., Ray, P., Ghosh, R., Bhattacharyya, A. K., Dhor, P., Chatterjee, S., Dubey, S., Mitchell, A. J., & Benito-León, J. (2023). Health-related quality of life and perceived stress of informal caregivers of children and adolescents with intellectual disabilities and ADHD. *Neurology Perspectives*, *3*(2). https://doi.org/10.1016/j.neurop.2023.100120

Effect Size. (2025). Social Science Statistics. https://www.socscistatistics.com/tests/effectsize/calculator/

Friborg, O., Hjemdal, O., Rosenvinge, J. H., & Martinussen, M. (2003). A new rating scale for adult resilience: What are the central protective resources behind healthy adjustment? *International Journal of Methods in Psychiatric Research*, *12*(2), 65–76. https://doi.org/10.1002/mpr.143

Ghanad, A. (2023). Quantitative Research Methods. *International Journal of Multidisciplinary Research and Analysis*, *06*(08), 3794–3803. https://doi.org/DOI: 10.47191/ijmra/v6-i8-52

Gilbert, L. K., Annor, F. B., Brown, C., & Dube, S. R. (2024). Introduction to the child abuse and neglect special issue "epidemiology, risk factors, and impacts of adverse childhood experiences in low- and middle-income countries." *Child Abuse and Neglect*, *150*(March).

https://doi.org/10.1016/j.chiabu.2024.106748

Graessel, E., Berth, H., Lichte, T., & Grau, H. (2014). Subjective caregiver burden: Validity of the 10-item short version of the Burden Scale for Family Caregivers BSFC-s. *BMC Geriatrics*, *14*(1), 1–9. https://doi.org/10.1186/1471-2318-14-23

Hamama, L. (2025). Research in Autism Normalization and perceived social support among family members of children with autism spectrum disorder. *Research in Autism*, *126*(May), 202654. https://doi.org/10.1016/j.reia.2025.202654

Hjemdal, O., Roazzi, A., Dias, M. da G. B. B., & Friborg, O. (2015). The cross-cultural validity of the Resilience Scale for Adults: A comparison between Norway and Brazil. *BMC Psychology*, *3*(1), 1–9. https://doi.org/10.1186/S40359-015-0076-1

Hou, C. H., & Chen, P. L. (2024). Optimism, Social Support, and Caregiving Burden among the Long-Term Caregivers: The Mediating Effect of Psychological Resilience. *International Journal of Mental Health Promotion*, *26*(9), 697–708. https://doi.org/10.32604/ijmhp.2024.051751

Joung, W. J. (2023). Phenomenological Study on the Lived Experiences of Mothers Caring for Their Pubescent Children with Developmental Disabilities. *Asian Nursing Research*, *17*(4), 226–234. https://doi.org/10.1016/j.anr.2023.09.001

Kaakinen, J. R., Coehlo, D. P., Steele, R., & Robinson, M. (2018). *Family Health Care Nursing: theory, practice, and research* (Sixth Edit). F.A. Davis Company.

Lakhani, A., Ali, T. S., Kramer-Roy, D., & Ashraf, D. (2024). Informal social support for families with children with an intellectual disability in Karachi, Pakistan: A qualitative exploratory study design. *Heliyon*, *10*(20), e39221. https://doi.org/10.1016/j.heliyon.2024.e39221

Lavrakas, P. J. (2026). *Network Sampling*. Encyclopedia of Survey Research Methods. https://doi.org/https://doi.org/10.4135/9781412963947.n322

Lee, H., Kim, K., Kim, H., & Choi, E. K. (2025). Experiences of siblings of individuals with developmental disabilities: A meta-synthesis of qualitative studies. *Disability and Health Journal*, *18*(2), 101770. https://doi.org/10.1016/j.dhjo.2024.101770

Leng, L. L., Huang, S., & Zhou, L. G. (2024). Perceived discrimination among caregivers of children with disabilities in China: Unraveling the effects of social determinants. *Social Science and Medicine*, *351*(May), 116991. https://doi.org/10.1016/j.socscimed.2024.116991

Lütolf, M. (2025). *The Balancing Act of Working Mothers and Caring Fathers: Impact of Family Policy on Egalitarianism in Families in Western Democracies*. This Springer VS. https://link.springer.com/book/10.1007/978-3-658-47716-5

Maximiano-Barreto, M. A., Alves, L. C. D. S., Monteiro, D. Q., Gratão, A. C. M., Pavarini, S. Ic. I., Luchesi, B. M., & Chagas, M. H. N. (2022). Cultural factors associated with burden in unpaid caregivers of older adults : A systematic review. *Health and Social*

Care in Community, *January*, 1–14. https://doi.org/10.1111/hsc.14003

Nurlaila, A., Fikrie, & Quarta, D. L. (2024). Hubungan Caregiver Burden dengan Kualitas Relasi Orang Tua-Anak pada Orang Tua yang Memiliki Anak Austime. *Jurnal Psikologi*, *1*(4), 1–17. https://doi.org/https://doi.org/10.47134/pjp.v1i4.2979

Pallant, J. (2020). *SPSS Survival Manual "A Step by Step Guide to Data Analysis Using IBM SPSS"* (7th Editio). Rotledge- Taylor & Francis Group.

Patty, N. J. S., van Meeteren, K. M., Verdonk, M., Ketelaar, M., Schuengel, C., & Willemen, A. M. (2024). Conceptualizing burnout from the perspective of parents of children with complex care needs. *PEC Innovation*, *5*(July), 100325. https://doi.org/10.1016/j.pecinn.2024.100325

Rossi, R., Socci, V., Jannini, T. B., Collazzoni, A., Pacitti, F., Di Lorenzo, G., & Rossi, A. (2021). Validation of a brief version of the Resilience Scale for Adults on an Italian non-clinical sample. *Rivista Di Psichiatria*, *56*(6), 308–313. https://doi.org/10.1708/3713.37044

Somers, J. A., Querdasi, F. R., Chu, K. A., Gancz, N., Towner, E., & Callaghan, B. L. (2024). Transactional models of depression via caregiver-child interactions: Evaluating conflict resolution as a source of resilience in adversity-exposed families. *Children and Youth Services Review*, *166*(October), 107945. https://doi.org/10.1016/j.childyouth.2024.107945

Tran, J. T., Theng, B., Tzeng, H., Raji, M., Serag, H., Shih, M., & Lee, W.-C. (2023). Cultural Diversity Impacts Caregiving Experiences : A Comprehensive Exploration of Differences in Caregiver Burdens , Needs , and Outcomes. *Cureus*, *15*(10). https://doi.org/10.7759/cureus.46537

Walsh, F. (2016). Family resilience: a developmental systems framework. *European Journal of Developmental Psychology*, *13*(3), 313–324. https://doi.org/https://doi.org/10.1080/17405629.2016.1154035

WHO. (2025). *Disability*. https://www.who.int/health-topics/disability#tab=tab_1

Widyawati, Y., Scholte, R. H. J., Kleemans, T., & Otten, R. (2021). Positive parenting and its mediating role in the relationship between parental resilience and quality of life in children with developmental disabilities in Java Island, Indonesia. *Research in Developmental Disabilities*, *112*(August 2020), 103911. https://doi.org/10.1016/j.ridd.2021.103911

World bank. (2024). *How Indonesia is Including Students with Disabilities in School in Rural Indonesia*. https://www.worldbank.org/en/news/feature/2024/02/08/how-indonesia-is-including-students-with-disabilities-in-school-in-rural-indonesia#

World Health Organization (WHO). (2025). *A Global Research Agenda for Children with Disabilities* (Issue April). https://www.unicef.org/innocenti/media/10886/file/UNICEF-Innocenti-Disabilities-Global-Research-Agenda-Report-2025.pdf

World Health Organization (WHO) and United Nations Children's Fund (UNICEF). (2020). *Global status report on preventing violence against children 2020*. World Health Organization. https://apps.who.int/iris/bitstream/handle/10665/332394/9789240004191-eng.pdf%0Ahttps://www.who.int/pu blications-detail-redirect/9789240004191

World Health Organization (WHO) and United Nations Children's Fund (UNICEF). (2023). *Global report on children with developmental disabilities: from the margins to the mainstream*. http://apps.who.int/iris.

Xin, Z., Guo, Y., Zheng, J., & Xie, P. (2025). When giving social support is beneficial for well-being? *Acta Psychologica*, *255*(October 2024), 104911. https://doi.org/10.1016/j.actpsy.2025.104911