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CAREGIVING CHALLENGES AND FAMILY RESILIENCE AMONG PARENTS OF CHILDREN WITH AUTISM SPECTRUM DISORDER IN PURWOKERTO

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Abstract

Autism Spectrum Disorder (ASD) is a complex neurodevelopmental condition that not only challenges communication and behavior but also exposes families to stigma and psychosocial burdens. This study explores the experiences of caregivers of children with ASD in Purwokerto through the lens of Family Empowerment and Stigma Theory. Using a thematic analysis design, data were collected from 15 caregivers (N1–N15) via semi-structured interviews conducted between March and November 2024. The findings reveal four major themes: caregiving difficulties, acceptance and personal growth, family coping mechanisms, and social interaction. Caregivers reported intense emotional distress during diagnosis, with some expressing guilt, depression, and even suicidal ideation. Economic strain was significant, with monthly rehabilitation costs ranging from 2 to 4,5 million rupiah, often forcing one parent to quit employment. Despite these challenges, families demonstrated resilience, with acceptance and empowerment emerging as turning points that transformed vulnerability into agency. Community support and inclusive environments were identified as critical to reducing stigma and strengthening family well-being.

Keywords*: Autism Spectrum Disorder; Stigma; Family Empowerment; Caregiver Resilience.*

Abstrak

Autism Spectrum Disorder (ASD) merupakan kondisi *neurodevelopmental* kompleks yang tidak hanya menimbulkan tantangan dalam komunikasi dan perilaku, tetapi juga menghadapkan keluarga pada stigma dan beban psikososial yang signifikan. Penelitian ini bertujuan untuk mengeksplorasi pengalaman pengasuh anak dengan ASD di Purwokerto melalui perspektif *Family Empowerment* dan *Stigma Theory*. Desain penelitian menggunakan analisis tematik dengan data yang dikumpulkan dari 15 pengasuh (N1–N15) melalui wawancara semi-terstruktur untuk memperoleh hasil penelitian. Hasil penelitian mengungkap empat tema utama: kesulitan pengasuhan, penerimaan dan pertumbuhan pribadi, mekanisme coping keluarga, serta interaksi sosial. Para pengasuh melaporkan distress emosional yang intens saat menerima diagnosis, dengan beberapa mengalami rasa bersalah, depresi, bahkan ide bunuh diri. Beban ekonomi juga signifikan, dengan biaya rehabilitasi bulanan berkisar Rp2–4,5 juta, yang sering memaksa salah satu orang tua berhenti bekerja untuk merawat penuh waktu. Meskipun menghadapi tantangan berat, keluarga menunjukkan resiliensi, di mana penerimaan dan pemberdayaan menjadi titik balik yang mengubah kerentanan menjadi kekuatan. Dukungan komunitas dan lingkungan inklusif diidentifikasi sebagai faktor penting dalam mengurangi stigma dan memperkuat kesejahteraan keluarga. Penelitian ini menyimpulkan bahwa stigma berfungsi sebagai beban ganda—internal dan eksternal—sementara *Family Empowerment* menjadi strategi penting untuk meningkatkan resiliensi pengasuh, memperbaiki hasil perkembangan anak, serta memberikan dasar bagi intervensi kebijakan di Indonesia.

Kata Kunci: *Autism Spectrum Disorder; Stigma; Family Empowerment; Resiliensi* Pengasuh.

PENDAHULUAN

Autism Spectrum Disorder (ASD) is a neurodevelopmental condition characterized by a wide range of symptoms with varying degrees of severity, from mild to profound (Guo et al., 2026). Core features include persistent difficulties in social communication and interaction, as well as restricted and repetitive patterns of behavior, interests, or activities (Öztürk, 2026). These manifestations often contribute to stigma, as behaviors that deviate from social norms—such as unexpected emotional outbursts, lack of responsiveness in social interactions, or repetitive self-stimulatory actions—are frequently misunderstood by the public and lead to negative judgments (Şahin Büyük & Özmen, 2025). The spectrum nature of ASD implies that individuals with more visible or severe symptoms are at greater risk of experiencing stigmatization (X. Chen et al., 2023).

This stigmatization manifests in dual dimensions: internal and external. Internally, caregivers frequently experience intense shame, guilt, and self-blame due to their child's atypical behaviors, which significantly erodes parental confidence and induces emotional distress (Aliifah et al., 2022; Aquino et al., 2023). Externally, families confront pervasive societal misconceptions—such as blaming poor parenting for the condition—alongside a general reluctance from communities to offer support (Mohadeseh et al., 2023). These compounding barriers reinforce social isolation, restrict access to essential health and educational services, and ultimately diminish the overall quality of family life (Adugna et al., 2020; Mwangi et al., 2021). To counteract this reinforcing psychosocial burden, family-centered strategies like Family Empowerment (FE) become vital (X. Chen et al., 2023). Stigma associated with ASD therefore not only affects the child but also imposes significant psychosocial consequences on the family unit (Aquino et al., 2023). Parents and caregivers may experience diminished confidence and heightened stress, which in turn hinders their ability to provide effective caregiving (Fischbach et al., 2016). Externally, families face societal misconceptions, such as the belief that ASD is caused by poor parenting, as well as reluctance from peers, relatives, or communities to provide support (Mohadeseh et al., 2023). These barriers reinforce social isolation and restrict access to essential resources and health services (Mwangi et al., 2021). Consequently, stigma functions as a dual burden—both internal and external—that exacerbates caregiving challenges and reduces the overall quality of life for families of children with ASD (Adugna et al., 2020).

Understanding Autism Spectrum Disorder (ASD) requires not only recognizing its diverse neurodevelopmental manifestations but also acknowledging the broader social implications that accompany the condition (Loan Khanh et al., 2023). The visibility of atypical behaviors often exposes families to stigma, which operates as both an internal burden—manifested in feelings of shame and self-blame among caregivers—and an external challenge, reinforced by societal misconceptions and exclusion (O'Donnell & Foran, 2024). This dual dimension of stigma intensifies caregiving stress, undermines parental confidence, and restricts access to essential support systems (Guo et al., 2026). Situating stigma as a central issue is therefore critical, as it provides the conceptual foundation for examining family-centered strategies such as Family Empowerment, which aim to strengthen caregiver resilience and mitigate the psychosocial challenges associated with ASD (X. Chen et al., 2023).

Family Empowerment (FE) represents a strategic, family-centered approach that positions families as active agents in health management (Tong et al., 2024). Through this intervention, healthcare professionals not only provide medical assistance but also equip families with knowledge, skills, and resources to manage behavioral changes according to health-related needs (H. Chen et al., 2025). In the context of ASD, empowerment serves as a critical mechanism to counter stigma, enabling families to transform feelings of helplessness into active engagement in caregiving responsibilities and to enhance family well-being (Öztürk, 2026). Recent studies highlight that parent empowerment programs can significantly improve self-efficacy, reduce stress, and strengthen family capacity to cope with long-term caregiving demands (Maldonado et al., 2022). Thus, empowerment is not only essential for achieving positive health outcomes but also for mitigating the stigma associated with ASD caregiving (Maldonado et al., 2023).

METODE PENELITIAN

This study adopted a thematic analysis design to examine the experiences of family caregivers of children with autism, framed by Family Empowerment Theory and Stigma Theory(Dunst et al., 2017; Loan Khanh et al., 2023). Conducted between March and November 2024 at a rehabilitation center in Purwokerto, the research utilized purposive sampling to recruit participants. Eligibility criteria included: (1) caregivers of children clinically diagnosed with autism without comorbidities; (2) primary caregivers with at least six months of caregiving experience; (3) caregivers without cognitive impairments or psychiatric disorders, capable of verbal communication; and (4) voluntary participation with informed consent. Data saturation determined the final sample size, resulting in 15 participants (coded N1–N15), aged between 32 and 46 years, with educational backgrounds ranging from junior middle school to postgraduate, and caregiving durations spanning 2 to 10 years.

Data collection involved face-to-face, semi-structured interviews, each lasting approximately 45–60 minutes, conducted in private and comfortable settings. Interviews were audio-recorded with consent, transcribed verbatim, and enriched with observations of tone, facial expressions, and body language (Polat, 2025). The interview guide explored challenges during diagnosis, family life changes, treatment expectations, and desired social support (Herwanis et al., 2025). Transcripts were analyzed using Nvivo software, following Braun and Clarke's six-step framework: familiarization, initial coding, theme identification, verification, definition, and reporting (Herwanis et al., 2025). To ensure rigor, two independent coders analyzed the data separately, compared results, and resolved discrepancies through discussion (Lim, 2025). An audit trail was maintained, and findings were validated by participants to ensure alignment with their lived experiences (Herwanis et al., 2025). Ethical approval was obtained from the Purwokerto Rehabilitation Center Ethics Committee (Approval No. 2023-038), and all participants signed informed consent forms prior to participation.

HASIL DAN PEMBAHASAN

HASIL

The findings of this study revealed four major themes: caregiving difficulties, acceptance and personal growth, family coping mechanisms, and social interaction from the perspective of family empowerment (Dunst et al., 2017). Almost all parents in Purwokerto experienced emotional distress when receiving their child's diagnosis. Some struggled to accept the reality and sought repeated consultations at hospitals in Jakarta and Yogyakarta. As N5 explained:

"I went to several major hospitals, spending a lot of money, but all doctors gave the same diagnosis."

N14 recalled, *"The word 'lifelong' felt like a stone hitting my chest. At that time, I was only 28 years old, and the future seemed to collapse."*

Feelings of guilt were also common, as N7 admitted, *"It feels like I destroyed my own child."*

Severe depression was reported by N10, who stated, *"I even thought about committing suicide together with my child, or alone*."

Caregivers also tended to withdraw from social activities due to stigma and negative comments.

N13 shared, *"I did not dare to attend reunions, afraid people would ask about my child's condition."*

Similarly, N15 explained, *"Since I began full-time care for Lele, social activities have become alien to me. Even relatives made hurtful remarks."*

Concerns about the future were widespread. N3 and N6 admitted, *"I am afraid that the more I think, the more disappointed I will be."*

Mothers of children approaching puberty (N7, N8, N10, N14) expressed worries about emotional regulation and sexual behavior.

N12, the oldest caregiver, voiced anxiety about aging: *"When we grow old and can no longer move, who will take care of my child?"*

Family coping mechanisms were evident in relationship adjustments and role redistribution.

N6 reported, *"I divorced when my son was three months old."* N3 expressed frustration, *"My husband is not helping, he is hindering me."*

Yet resilience was also present, as N12 described,

"No matter how hard it gets, we have to face it together and not blame each other."

Economic sacrifices were common, with six participants (N1, N5, N6, N8, N3, N14) rejecting the idea of having another child due to financial strain. Twelve caregivers quit their jobs to provide full-time care.

N2 explained, *"After knowing the diagnosis, I quit my job and took full responsibility for caring for him."*

N11 added, *"We often argue about money, but eventually we comfort each other because we know we cannot give up on our child."*

Lifestyle adjustments were significant, with monthly rehabilitation costs in Purwokerto ranging from 2 to 4,5 million rupiah.

N15 explained, *"We stopped traveling, and all expenses were redirected to therapy."*

N10 echoed, *"My hobbies and interests disappeared, my life shrank only to my child and family."*

Despite these challenges, motivation to persevere came from family support and small gestures from children.

N13 stated, *"With family support, I can dedicate more time to learning rehabilitation methods."*

N12 recalled, *"When I am tired, my child gently pats my shoulder, as if giving encouragement."*

N14 added, *"His little smile made me feel that all struggles were worthwhile."*

Acceptance became a turning point. N5 shared, *"It took me three years to accept the diagnosis, but I kept learning every night until 2 a.m."*

N13 reflected, *"Complaining solves nothing; only action can change the situation."*

N15 emphasized, *"You must not bear this alone; you should seek support."*

Some parents even became "rehabilitation experts" for their children.

N1 explained, *"Parents must learn to determine which methods are suitable, gradually becoming experts for their own child."* N5 described, *"I searched global networks, translated materials, and turned them into courses for children."*

N13, with an educational background, added, *"Institutional intervention is not the only solution; parents can develop tailored plans based on their children's needs."*

The findings highlight that stigma operates as a dual burden—internalized guilt and shame within families, combined with external prejudice from society. This duality creates a reinforcing cycle that undermines caregiver resilience and family functioning (Afifah, 2025). From a theoretical perspective, stigma theory explains how labeling and discrimination perpetuate exclusion, while family stress models show how these pressures destabilize household dynamics (Aliifah et al., 2022; Salami & Alhalal, 2024). In Purwokerto, the emotional breakdowns reported by caregivers illustrate how stigma is not merely a social perception but a structural barrier that reshapes family roles, marital relationships, and economic stability.

Another important implication is the intersection between stigma and economic strain. The high rehabilitation costs (Rp20–45 million per month) demonstrate that autism care is not only a psychological challenge but also a financial one (H. Chen et al., 2025). Families are forced to reorganize roles, with one parent often leaving employment to provide full-time care. This redistribution of responsibilities, while necessary, intensifies economic vulnerability and highlights the need for systemic support (Holzinger & Lai, 2022). Theories of family resilience suggest that while households can adapt to stress, without external resources their coping capacity remains fragile.

Acceptance and personal growth among caregivers represent a turning point in the caregiving journey (Li et al., 2026). Rather than remaining in denial, parents gradually shift toward problem-solving and proactive engagement with rehabilitation. This aligns with empowerment theory, which emphasizes the importance of equipping families with knowledge, skills, and confidence to manage challenges. This study highlights a dynamic tension between the constraints of Stigma Theory and the agency proposed by Family Empowerment Theory (Loan Khanh et al., 2023). While stigma reinforces a cycle of social and economic marginalization, empowerment acts as a psychological counter-mechanism that enables caregivers to reclaim control over their family’s trajectory (Rivera & Bennetto, 2023).

In Purwokerto, caregivers who became “rehabilitation experts” for their children illustrate how empowerment transforms vulnerability into agency(Öztürk, 2026). Such growth not only benefits the child’s development but also strengthens family cohesion and self-efficacy (Nuriyyatiningrum et al., 2025).

Finally, the role of community and institutional support emerges as a critical dimension. While families demonstrate remarkable perseverance, the lack of affordable and accessible rehabilitation services underscores systemic gaps (Nuriyyatiningrum et al., 2025). Family empowerment cannot be achieved in isolation; it requires integration with schools, health institutions, and community networks. By fostering inclusive environments and reducing stigma, communities can create conditions where families are not merely surviving but actively thriving (Marlina et al., 2024). This suggests that policy interventions in Purwokerto should prioritize reducing rehabilitation costs, expanding educational inclusion, and strengthening peer support networks.

PENUTUP

KESIMPULAN DAN SARAN

This study demonstrates that stigma toward families raising children with Autism Spectrum Disorder (ASD) in Purwokerto functions as a dual burden, manifesting internally through guilt, shame, and despair, and externally through prejudice and social exclusion. These challenges intensify caregiving stress, reduce parental confidence, and limit access to essential support systems. At the same time, acceptance and family empowerment emerge as critical turning points, enabling caregivers to transform vulnerability into resilience. By acquiring knowledge, skills, and social support, families strengthen cohesion and actively engage in rehabilitation efforts, ultimately improving child outcomes. Family Empowerment, therefore, represents a strategic approach to mitigate stigma, enhance caregiver resilience, and promote the overall well-being of families living with ASD in Indonesia.

Based on these findings, several recommendations can be proposed: policymakers should prioritize reducing the financial burden of rehabilitation by subsidizing therapy costs and expanding access to affordable services; schools and educational institutions must strengthen inclusive education programs to ensure that children with ASD are integrated into mainstream learning environments with adequate support; community-based initiatives should be expanded to provide peer support networks, awareness campaigns, and accessible activity spaces that foster inclusion and reduce stigma; and future research should explore longitudinal impacts of empowerment interventions, focusing on how sustained family-centered strategies can further enhance resilience and improve long-term developmental outcomes for children with ASD.

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