Jurnal Ilmiah Pendidikan Guru Pendidikan Anak Usia Dini
Jurnal Anak Bangsa
Vol. 5, No. 1, Februari 2026 hal. 426-432
Journal Page is available to http://jas.lppmbinabangsa.ac.id/index.php/home

PARENTS' EXPERIENCES IN THE FIRST MONTHS AFTER AN AUTISM OR ADHD DIAGNOSIS: A QUALITATIVE STUDY

Muhamad Fijar Rotul Akbar[1]
[1]Binus University
Email: vzhar.akbar@gmail.com[1]

ABSTRACT

This qualitative study explores the lived experiences of Indonesian parents during the first months after their children were diagnosed with autism spectrum disorder (ASD) or Attention-Deficit/Hyperactivity Disorder (ADHD). Six parents (three fathers and three mothers) whose children were diagnosed within the last six months participated in semi-structured in-depth interviews. Reflexive thematic analysis revealed five major themes: (1) emotional turbulence and psychological shock, (2) sociocultural stigma and judgment, (3) overwhelming therapy demands and financial pressures, (4) gradual development of acceptance through knowledge-building and religious coping, and (5) redefinition of parental expectations and reconstruction of parenting identity. Findings align with global literature showing that early post-diagnosis periods are marked by intense emotional, social, and practical adjustments. The Indonesian context adds unique cultural influences, particularly community stigma and strong religious meaning-making. The study highlights the urgent need for early psychoeducation, accessible intervention pathways, and culturally grounded family support systems..

Keywords*: Autism, ADHD, parental experience, qualitative study, Indonesia*

ABSTRAK

Penelitian kualitatif ini mengeksplorasi pengalaman hidup orang tua Indonesia pada bulan-bulan pertama setelah anak mereka didiagnosis autism spectrum disorder (ASD) atau Attention-Deficit/Hyperactivity Disorder (ADHD). Enam orang tua (tiga ayah dan tiga ibu) yang anaknya menerima diagnosis dalam enam bulan terakhir berpartisipasi dalam wawancara mendalam semi-terstruktur. Analisis tematik refleksif mengungkap lima tema utama: (1) gejolak emosional dan keterkejutan psikologis, (2) stigma dan penilaian sosial-budaya, (3) tuntutan terapi yang berat dan tekanan finansial, (4) perkembangan penerimaan secara bertahap melalui pencarian pengetahuan dan coping religius, serta (5) redefinisi harapan orang tua dan rekonstruksi identitas pengasuhan. Temuan ini selaras dengan literatur global yang menunjukkan bahwa periode awal pasca diagnosis ditandai oleh penyesuaian emosional, sosial, dan praktis yang intens. Konteks Indonesia menambahkan pengaruh budaya yang khas, terutama stigma komunitas dan kuatnya proses pemaknaan religius. Studi ini menekankan perlunya psikoedukasi dini, akses intervensi yang terjangkau, serta sistem dukungan keluarga yang sensitif secara budaya.

Kata kunci: Autisme, ADHD, pengalaman orang tua, studi kualitatif

BACKGROUND

A developmental diagnosis such as autism spectrum disorder (ASD) or Attention-Deficit/Hyperactivity Disorder (ADHD) marks a profound turning point not only in a child's life but also in the emotional, psychological, and social lives of parents. A substantial body of research shows that the early months following diagnosis are among the most stressful periods of the parenting trajectory, characterized by shock, fear, confusion, grief, guilt, and sometimes relief (DePape & Lindsay, 2015; Hughes et al., 2024). Parents suddenly face the need to reorient expectations, reorganize routines, and make rapid decisions regarding therapy, schooling, and support services (Amira & Zainal, 2024; Malhi et al., 2022).

Globally, parents report that the diagnostic moment triggers a process of meaning-making as they attempt to reconcile the diagnosis with their prior beliefs and hopes for their child (Fong et al., 2021). Studies on ADHD similarly highlight that parents experience exhaustion, heightened emotional stress, and struggles with new behavioural demands after diagnosis (Brown et al., 2025; Harris et al., 2022). These early months represent a liminal period, in which families transition from uncertainty to adaptation, yet remain highly vulnerable as they navigate complex emotional, relational, and practical realities (Sainsbury et al., 2024; Wang et al., 2025).

In Indonesia, the early post-diagnosis period is further shaped by cultural norms, collective expectations, and morally charged views regarding child behaviour. Parents often encounter stigma, social blame, and inaccurate assumptions rooted in limited public understanding of developmental differences (Picardi et al., 2018; Valicenti-McDermott et al., 2015). Extended families may pressure parents to conceal the diagnosis, avoid therapy, or attribute the child's behaviour to parenting failures. At the same time, Indonesian parents frequently rely on religious coping strategies and spiritual meaning-making as they search for emotional stability and hope (Pratama & Boediman, 2025).

Despite the growing body of Indonesian studies on ASD and ADHD, few have examined the specific first 3–6 months after diagnosis, a period repeatedly described by parents as the most emotionally disruptive and socially challenging. This study aims to fill that gap by exploring how Indonesian parents interpret, respond to, and cope with their children's diagnoses during this critical early adjustment stage.

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THEORITICAL FOUNDATION

Parental adjustment following a child's diagnosis of autism spectrum disorder (ASD) or Attention-Deficit/Hyperactivity Disorder (ADHD) can be understood through several interconnected theoretical perspectives. The **Stress and Coping Theory** (Lazarus & DeLongis, 1983) explains that the diagnosis functions as a major life stressor that triggers complex emotional reactions and requires parents to engage in cognitive appraisal as they evaluate the meaning of the diagnosis and assess their capacity to manage it. Research consistently shows that parents move between problem-focused coping (seeking information, arranging therapy) and emotion-focused coping (self-soothing, reframing expectations, or relying on spirituality) during the early post-diagnosis period (Hughes et al., 2024; Wang et al., 2025). Complementing this, **Family Systems Theory** emphasizes that a diagnosis disrupts the functioning of the entire family unit, requiring shifts in roles, routines, boundaries, communication patterns, and emotional dynamics as parents mobilize resources and renegotiate responsibilities (Malhi et al., 2022; Wong et al., 2018). These disruptions often affect marital relationships, sibling interactions, and extended family involvement. From a broader perspective, the **Sociocultural Model** highlights how parental experiences are shaped by cultural norms, expectations, and belief systems. In Indonesia, where collectivism, social conformity, and moral expectations strongly influence parenting, stigma remains a prominent factor shaping how parents interpret and respond to their child's diagnosis, often leading to fears of judgment, pressure to conceal the diagnosis, or internalized blame (Picardi et al., 2018; Valicenti-McDermott et al., 2015). Religious meaning-making, common in Indonesian families, further influences adjustment by providing spiritual interpretations that foster resilience and acceptance (Pratama & Boediman, 2025). These frameworks are further enriched by **the Double ABC-X Family Stress and Adaptation Model**, which explains how initial stress (the diagnosis) interacts with family resources, perceptions, and accumulating demands, such as therapy costs and behavioural challenges, to determine whether the family experiences crisis or adaptation (McCubbin & Patterson, 2014). Additionally, **Identity Reconstruction Theory** helps explain how parents reframe their parental identity and expectations as they shift from normative developmental ideals toward accepting their child's unique developmental pathway (Fong et al., 2021; Sainsbury et al., 2024). Finally, Bronfenbrenner's **Ecological Systems Theory** situates parental adaptation within multiple layers of influence, from family relationships and school interactions to healthcare systems, public policy, and cultural values, highlighting how Indonesian parents must navigate limited service accessibility, social stigma, and community expectations while adjusting to the diagnosis. Together, these theoretical perspectives offer a comprehensive lens for understanding how Indonesian parents emotionally process a developmental diagnosis, mobilize support, redefine family functioning, and reconstruct their sense of parenthood during the early adjustment period.

RESEARCH METHOD

This study employed a qualitative descriptive design to capture parents' experiences in their own words and provide rich descriptions of the emotional, social, and practical processes they navigated during the early post-diagnosis period. Six parents participated in the study, comprising three mothers (M1–M3) and three fathers (F1–F3), whose children, four diagnosed with autism spectrum disorder (ASD) and two with Attention-Deficit/Hyperactivity Disorder (ADHD), had received their diagnoses within the past three to six months and were between three and ten years of age. All parents resided in urban areas of Jakarta, Depok, and Bekasi. Participant characteristics are summarized in Table 1. Data were collected through semi-structured interviews lasting 45–60 minutes, conducted either online or in person depending on participant preference. The interview guide explored parents' emotional responses to the diagnosis, experiences of stigma and community judgment, adjustments to therapy demands and daily routines, coping strategies, and shifts in family roles and expectations. The structure and style of the interview questions were adapted from established qualitative research on parental experiences in neurodevelopmental contexts (DePape & Lindsay, 2015; Hughes et al., 2024; Wong et al., 2018). All interviews were audio-recorded with consent and transcribed verbatim. Data were analyzed using reflexive thematic analysis as outlined by Braun and Clarke (2006), which involved iterative coding, theme generation, and interpretive synthesis to ensure that emerging themes accurately reflected parents' lived experiences. Ethical procedures included obtaining informed consent, maintaining confidentiality, and using pseudonyms to protect participant identities.

RESULT AND DISCUSSION

Theme 1: Emotional Turbulence and Psychological Shock

All parents described the diagnosis as emotionally destabilizing. Many reported crying for days, feeling guilty, or questioning their parenting. A mother expressed, *"I blamed myself over and over. I felt I failed my child."* Others described confusion and panic as they processed medical terminology and future implications.

These experiences closely mirror international findings that the immediate aftermath of diagnosis triggers grief-like emotions, existential questioning, and psychological shock (Amira & Zainal, 2024; Hughes et al., 2024; Wang et al., 2025). For some parents, however, the diagnosis brought relief, providing clarity and reducing long-standing uncertainty—also consistent with findings from Fong et al. (2021).

Theme 2: Sociocultural Stigma and Community Judgment

Five of six parents encountered stigma from extended family, neighbours, teachers, or religious communities. Comments such as "your child is just naughty," "you spoil them," or "you are overreacting" were commonly reported. A father stated, *"I hide the diagnosis. I don't want people to label him forever."*

This theme aligns strongly with Indonesian studies documenting stigma, blame, and societal misunderstanding of developmental disorders (Picardi et al., 2018; Valicenti-McDermott et al., 2015). Cross-cultural literature also confirms that stigma is a major global barrier, though its intensity varies by cultural context (Malhi et al., 2022; Sainsbury et al., 2024).

Theme 3: Overwhelming Therapy Demands and Financial Strain

Parents described their daily lives becoming dominated by therapy schedules, school communication, behaviour management, and constant time pressure. Many expressed exhaustion and spoke of struggling to meet therapy costs. One father explained, *"The therapy fees nearly match my salary, but I cannot stop."*

Similar burdens are widely reported in studies across Asia, the Middle East, and Western contexts, highlighting that therapy intensity, financial strain, and emotional exhaustion are universal early challenges (Harris et al., 2022; Malhi et al., 2022; Sainsbury et al., 2024). Indonesian families face additional difficulties due to limited insurance coverage and high out-of-pocket expenses (Nursanti, 2024).

Theme 4: Developing Acceptance Through Knowledge and Religious Coping

Despite early distress, parents gradually developed acceptance. Learning about ASD/ADHD through social media, parent groups, teachers, and online webinars provided clarity and reduced self-blame. This knowledge-building process mirrors findings from Hughes et al. (2024) and Amira & Zainal (2024), who note that information literacy is a primary driver of psychological adaptation.

Religious coping emerged as a major resource. Parents frequently used prayer, spiritual beliefs, and religious reflections to find peace. A mother said, *"God gives challenges only to those who can carry them."* This process aligns with Indonesian and global findings that spirituality supports resilience in families facing disability (Pratama & Boediman, 2025; Wong et al., 2018).

Theme 5: Redefining Expectations and Reconstructing Parenting Identity

Parents described shifting from normative milestones, academic achievement, conformity to school standards, to valuing emotional well-being, communication, and daily functioning. They also reconstructed their identities as parents, becoming more patient, accepting, and adaptive. As one parent noted, *"I stopped comparing him to other kids. His journey is different."*

This reorientation replicates global findings that diagnosis initiates a deep transformation of parental identity and expectations (Fong et al., 2021; Sainsbury et al., 2024; Wong et al., 2018).

CONCLUSION

The first months following an ASD or ADHD diagnosis are a deeply challenging period for Indonesian parents, marked by emotional upheaval, sociocultural stigma, financial strain, and significant adjustments to family life. Yet, despite these difficulties, parents demonstrate notable resilience as they seek information, draw on spiritual and religious beliefs, and gradually develop acceptance of their child's condition. The findings underscore the urgent need for early and structured psychoeducation, accessible and affordable therapy pathways, community-based support groups, and stigma-reduction initiatives that align with Indonesia's cultural and religious contexts. Supporting parents during this critical early stage is essential for shaping effective policies and services that promote the long-term well-being of both children and families.

REFERENCES

Amira, N., & Zainal, M. S. (2024). A Systematic Literature Review of Qualitative Studies Exploring Parents' Experiences Post-Diagnosis of Autism. *INTERNATIONAL JOURNAL OF ACADEMIC RESEARCH IN PROGRESSIVE EDUCATION AND DEVELOPMENT*.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*. https://doi.org/10.1191/1478088706qp063oa

Brown, L. E., Tallon, M., Kendall, G., Boyes, M., & Myers, B. (2025). Parents' Experiences of Raising 7-to 11-Year-Old Children With ADHD and Perception of a Proposed Parenting Program: A Qualitative Study. *Journal of Attention Disorders*, *29*(5), 312–325.

DePape, A.-M., & Lindsay, S. (2015). Parents' experiences of caring for a child with autism spectrum disorder. *Qualitative Health Research*, *25*(4), 569–583.

Fong, V. C., Gardiner, E., & Iarocci, G. (2021). Cross-cultural perspectives on the meaning of family quality of life: Comparing Korean immigrant families and Canadian families of children with autism spectrum disorder. *Autism*, *25*(5), 1335–1348.

Harris, U., Svedberg, P., Aili, K., Nygren, J. M., & Larsson, I. (2022). Parents' experiences of direct and indirect implications of sleep quality on the health of children with ADHD: A qualitative study. *International Journal of Environmental Research and Public Health*, *19*(22), 15099.

Hughes, R., Curley, K., & Kotera, Y. (2024). Parents' Experiences after Their Child's Autism Diagnosis: A Reflexive Thematic Analysis. *Psychiatry International*, *5*(3), 370–394.

Lazarus, R. S., & DeLongis, A. (1983). Psychological stress and coping in aging. *American Psychologist*, *38*(3), 245.

Malhi, P., Shetty, A. R., Bharti, B., & Saini, L. (2022). Parenting a child with autism spectrum disorder: A qualitative study. *Indian Journal of Public Health*, *66*(2), 121–127.

McCubbin, H. I., & Patterson, J. M. (2014). The family stress process: The double ABCX model of adjustment and adaptation. In *Social stress and the family* (pp. 7–37). Routledge.

Nursanti, S. (2024). Mental health resilience of mothers children with special needs. *Hearty*, *12*(2), 393–400.

Picardi, A., Gigantesco, A., Tarolla, E., Stoppioni, V., Cerbo, R., Cremonte, M., Alessandri, G., Lega, I., & Nardocci, F. (2018). Parental burden and its correlates in families of children with autism spectrum disorder: a multicentre study with two comparison groups. *Clinical Practice and Epidemiology in Mental Health: CP & EMH*, *14*, 143.

Pratama, G. F., & Boediman, L. M. (2025). Religious coping among muslim parents of children with disabilities: a narrative review. *Insight: Jurnal Ilmiah Psikologi*, *27*(2), 122–134.

Sainsbury, W. J., Bowden, C. J., Carrasco, K. D., Whitehouse, A. J. O., & Waddington, H. (2024). Parent experiences of their children's diagnosis with autism, attention deficit hyperactivity disorder, or both conditions. *International Journal of Developmental Disabilities*, *70*(7), 1173–1183.

Valicenti-McDermott, M., Lawson, K., Hottinger, K., Seijo, R., Schechtman, M., Shulman, L., & Shinnar, S. (2015). Parental stress in families of children with autism and other developmental disabilities. *Journal of Child Neurology*, *30*(13), 1728–1735.

Wang, X., Cui, Y., Wang, M., & Fan, X. (2025). Experiences of Social Support among Foreign Parents Raising Children with Autism Spectrum Disorder in China: A Cross-Cultural Study. *International Journal of Disability, Development and Education*, 1–20.

Wong, I. Y. T., Hawes, D. J., Clarke, S., Kohn, M. R., & Dar-Nimrod, I. (2018). Perceptions of ADHD among diagnosed children and their parents: A systematic review using the common-sense model of illness representations. *Clinical Child and Family Psychology Review*, *21*(1), 57–93.