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Caring for Children with Autism in Low-Income Malaysian Families

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Abstract: Objective: Low-income parents raising children with Autism Spectrum Disorder (ASD) experience complex and overlapping challenges that extend beyond daily caregiving to encompass emotional distress, financial strain, limited access to services, and social stigma. In Malaysia, although parental stress and economic burden have been documented, studies that integrate both parents' and teachers' perspectives, particularly within Muslim and low-income contexts, remain limited. To explore the challenges faced by low-income parents in managing and caring for children with ASD through the integrated perspectives of Malaysian teachers and parents. **Methodology:** An exploratory qualitative research design was employed. Semi-structured interviews were conducted with seven participants, comprising two Muslim Malaysian teachers from an early intervention centre and five low-income Muslim parents of children diagnosed with ASD. Interviews were conducted in Bahasa Malaysia, audio-recorded with participants' consent, and transcribed verbatim. The data were then subjected to thematic analysis. **Key Findings:** Six interrelated themes emerged: (1) early recognition and prolonged diagnostic pathways; (2) emotional and psychological distress; (3) daily caregiving burden and behavioral management; (4) disrupted family relationships and social participation; (5) financial strain and limited access to services; and (6) coping through meaning-making. Results indicate that caregiving challenges are intensified by socioeconomic vulnerability, institutional barriers, and social stigma, with teachers' professional observations corroborating parents' lived experiences. **Conclusions:** The study concludes that caregiving among low-income families raising children with ASD is a multidimensional and structurally embedded experience. The cumulative burden of caregiving is a shared social responsibility exacerbated by systemic constraints and poverty, rather than merely an individual issue. **Recommendations:** There is an urgent need to establish holistic, affordable, and culturally responsive support systems. Educational practices and social policies must be integrated to streamline diagnostic pathways, offer subsidized therapies, and provide targeted financial and mental health support for vulnerable families.

Keywords: Autism Spectrum Disorder, Caregiving Challenges, Low-income Families, Malaysia, and Qualitative study

رعاية الأطفال ذوي اضطراب التوحد في الأسر الماليزية ذات الدخل المحدود

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ملخص الدراسة

الهدف: يواجه أولياء الأمور ذوو الدخل المحدود الذين يقومون بتربية أطفال ذوي اضطراب طيف التوحد، تحديات معقدة ومتداخلة تتجاوز الرعاية اليومية، لتشمل الضيق النفسي، والعبء المالي، ومحدودية الوصول إلى الخدمات، والوصمة الاجتماعية .ورغم أن الدراسات في ماليزيا قد وثّقت الإجهاد الأبوي والعبء الاقتصادي، إلا أن الأبحاث التي تدمج بين وجهات نظر أولياء الأمور والمعلمين لا سيما في السياقات الإسلامية وذات الدخل المحدود لا تزال محدودة. استكشاف التحديات التي يواجهها أولياء الأمور ذوو الدخل المحدود في إدارة ورعاية الأطفال المصابين باضطراب طيف التوحد، من خلال دمج وجهات نظر المعلمين وأولياء الأمور الماليزيين. **المنهج :**تم استخدام تصميم بحثي نوعي استكشافي؛ حيث أُجريت مقابلات شبه منظمة مع سبعة مشاركين، شملت معلمين ماليزيين مسلمين من مركز للتدخل المبكر، وخمسة من أولياء الأمور المسلمين ذوي الدخل المحدود لأطفال شُخِّصوا باضطراب طيف التوحد. أُجريت المقابلات باللغة الماليزية، وسُجِّلت صوتياً بعد الحصول على موافقة المشاركين، ثم فُرِّغت حرفياً، وخضعت البيانات بعد ذلك للتحليل الموضوعي. **أهم النتائج:** أسفر التحليل عن ستة محاور مترابطة) :1 (التعرف المبكر ومسارات التشخيص المطولة؛)2 (الضيق العاطفي والنفسي؛)3 (عبء الرعاية اليومية وإدارة السلوك؛)4 (اضطراب العلاقات الأسرية والمشاركة الاجتماعية؛)5 (العبء المالي ومحدودية الوصول إلى الخدمات؛ و)6 (التكيف من خلال بناء المعنى .وتشير النتائج إلى أن تحديات الرعاية تشتد حدتها بفعل الهشاشة الاقتصادية والاجتماعية، والعوائق المؤسسية، والوصمة الاجتماعية، وقد عززت الملاحظات المهنية للمعلمين التجارب المعيشية لأولياء الأمور. **االاستنتاجات :**تخلص الدراسة إلى أن رعاية الأطفال المصابين باضطراب طيف التوحد لدى الأسر ذات الدخل المحدود هي تجربة متعددة الأبعاد ومتجذرة هيكلياً. إن العبء التراكمي للرعاية هو مسؤولية اجتماعية مشتركة تتفاقم بسبب القيود النظامية والفقر، وليس مجرد قضية فردية. **التوصيات:** ثمة حاجة ملحة لإنشاء منظومات دعم شاملة، ميسورة التكلفة، ومتجاوبة ثقافياً .كما يجب دمج الممارسات

التعليمية والسياسات الاجتماعية لتيسير مسارات التشخيص، وتقديم علاجات مدعومة، وتوفير دعم مالي ونفسي موجه للأسر الأكثر احتياجاً.

الكلمات المفتاحية: اضطراب طيف التوحد، تحديات الرعاية، الأسر ذات الدخل المحدود، ماليزيا، دراسة نوعية.

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Background

Families play a central role in the care, development, and well-being of children with special needs, particularly within contexts of socioeconomic vulnerability. In Malaysia, household income remains a critical determinant of families' access to healthcare, education, and social support services. According to the Household Income Survey Report 2022, Malaysia recorded approximately 8.4 million households, of which 3.16 million fall within the low-income category, defined as earning less than RM5,250 per month (Department of Statistics Malaysia, 2023; Romeli, 2024). For families raising children with special needs, limited income often intensifies caregiving challenges, placing parents under sustained financial, emotional, and psychological strain.

As of January 2023, Malaysia recorded 637,537 registered persons with disabilities, including more than 80,000 children under the age of 12 with physical, sensory, intellectual, learning, or multiple disabilities (Department of Social Welfare, 2023). Many of these children come from low-income households, where parents must simultaneously manage the intensive demands of caregiving and the constraints of economic hardship. Empirical studies indicate that insufficient financial resources significantly limit parents' ability to afford medical treatments, rehabilitation services, transportation, and specialised educational support, thereby increasing stress and emotional vulnerability (Bahry et al., 2019; Sullivan & Stadtlander, 2020).

Early Caregiving Challenges for Parents of Children with ASD

Early caregiving for children diagnosed with Autism Spectrum Disorder (ASD) presents parents with complex and interrelated challenges that affect emotional well-being, social functioning, financial stability, and daily family life. Upon diagnosis, parents frequently experience emotional responses resembling a grieving process, characterised by shock, sadness, guilt, and uncertainty about the child's future (Galán-Vera et al., 2025; Abdullah et al., 2022). These emotional reactions are often intensified during the early caregiving phase due to limited parental knowledge about ASD and uncertainty surrounding effective intervention strategies.

Empirical evidence consistently reports elevated levels of parenting stress among caregivers of children with ASD compared to parents of typically developing children or children with other disabilities (Di Renzo et al., 2020; Ghanbari et al., 2025). Mothers, in particular, are found to be at heightened risk of anxiety, depressive symptoms, and emotional exhaustion, especially when caregiving demands are intensive and prolonged (Marbaniang & Saha, 2024; Yaacob et al., 2021). These emotional burdens are often compounded by social stigma and negative public perceptions of ASD, which may lead to social withdrawal and reduced informal support (Shattnawi et al., 2021; Ludlow et al., 2012).

Financial strain constitutes another significant early caregiving challenge. The high

costs of diagnostic assessments, early intervention programmes, and specialised therapies place considerable pressure on family resources, particularly among low-income households (Tathgur & Kang, 2021; Appah et al., 2024). Employment disruptions due to caregiving responsibilities further exacerbate economic vulnerability. Practically, parents also struggle with navigating fragmented service systems, long waiting periods for intervention, and managing challenging child behaviours such as aggression, sensory sensitivities, and resistance to routine changes (Battanta et al., 2024; Čusak et al., 2024).

Psychological and Emotional Burden among Low-Income Parents

Low-income parents caring for children with ASD experience a distinctive pattern of psychological and emotional burden shaped by the intersection of caregiving demands and socioeconomic vulnerability. Studies consistently show high levels of psychological distress, including anxiety, depressive symptoms, emotional exhaustion, and feelings of inadequacy, particularly during the early stages of caregiving (Solaiman et al., 2023; Khader et al., 2020; Lee & Barger, 2024). Financial strain plays a central role in intensifying emotional burden, as limited income restricts access to early intervention services, specialised therapies, and respite care, leading to prolonged stress and feelings of helplessness (Al-Farsi et al., 2013; Salama et al., 2025).

The caregiving burden among low-income parents is both objective and subjective. Objectively, parents devote extensive time and physical energy to caregiving tasks; subjectively, they experience chronic worry about their child's future, guilt over perceived inadequacies, and emotional fatigue (Picardi et al., 2018; Daharli et al., 2025). Limited social support and experiences of stigma further compound emotional distress, reinforcing feelings of isolation and marginalisation (Bromley et al., 2004; Wheeler et al., 2026).

ASD and Low-Income Caregiving in the Malaysian Context

In Malaysia, the increasing identification of autism spectrum disorder (ASD) and other developmental disabilities has drawn growing attention to the psychological and emotional burdens experienced by parents, particularly those from low-income backgrounds. Diagnostic uncertainties, including cases of pseudo-autism, have been reported to heighten parental anxiety and emotional distress during the early stages of caregiving (Samsudin et al., 2025). Malaysian parents consistently report elevated levels of stress, anxiety, and depressive symptoms associated with intensive caregiving demands, children's behavioural challenges, and concerns about long-term functioning and independence (Masuri et al., 2023; Chua et al., 2023). These pressures were further exacerbated during the COVID-19 pandemic, when service disruptions and social isolation significantly undermined parental well-being.

Despite the presence of governmental and non-governmental support initiatives, many low-income parents continue to encounter persistent structural and systemic barriers, including limited access to specialised healthcare, prolonged waiting periods for rehabilitation services, and high therapy costs (Ying & Kuan, 2021). In practice, these constraints often compel parents to make difficult decisions regarding their children's care, placing additional emotional and psychological strain on families. Within the Malaysian context, coping with these challenges is deeply shaped by cultural and religious values, with Muslim parents frequently drawing upon psychospiritual resources such as prayer, acceptance, and faith-based meaning-making to navigate caregiving stress (Mohamad et al., 2019).

Research Gap and Objective

Although existing literature has documented caregiving challenges among parents of children with ASD and other special needs, there remains a notable lack of qualitative

research in Malaysia that captures these challenges through both teachers' and parents' perspectives, particularly within low-income Muslim communities. Teachers occupy a unique and influential position as daily observers of children's learning, behaviour, and parental engagement within early intervention settings; however, their perspectives, alongside parents' lived experiences, remain insufficiently explored in an integrated manner. This gap limits a holistic understanding of how educational, emotional, and socioeconomic challenges intersect in the daily management and care of children with special needs.

Therefore, the main objective of this study is to explore Muslim Malaysian teachers' and parents' perspectives on the challenges faced by low-income parents in managing and caring for children with special needs. By foregrounding contextually grounded voices from both educational and familial settings, the study aims to contribute nuanced insights that can inform culturally responsive educational practices and psychosocial support interventions for vulnerable families.

Method

Study Design: This study adopted an exploratory qualitative research design to gain an in-depth and contextually grounded understanding of the challenges faced by low-income parents in managing and caring for children with special needs, as perceived by Muslim Malaysian teachers and parents. An exploratory qualitative approach is particularly appropriate when limited prior research exists on a phenomenon from specific perspectives and when the aim is to capture meanings, interpretations, and lived experiences rather than to generalise findings statistically (Creswell & Poth, 2018; Braun & Clarke, 2021).

Qualitative inquiry allows researchers to explore complex social realities embedded within cultural, institutional, and socioeconomic contexts. In this study, it enabled the examination of caregiving challenges as they are observed by teachers in early intervention settings and experienced directly by parents, thereby offering a richer and more nuanced understanding of low-income caregiving within the Malaysian Muslim context. The study aligns with a case-oriented qualitative approach, which emphasises depth, context, and analytic insight over sample size (Crowe et al., 2011).

Study population and Setting: The study population comprised Muslim Malaysian teachers and low-income parents of children with special needs, specifically children diagnosed with Autism Spectrum Disorder (ASD). Two distinct yet complementary participant groups were involved to capture both professional and lived caregiving perspectives.

The first group as shown in Table 1 consisted of Muslim Malaysian teachers (n = 2) employed at an early intervention centre that provides educational and therapeutic services for children with developmental disabilities. These teachers had a minimum of two years of experience working directly with children with special needs and maintained close, ongoing engagement with parents from low-income backgrounds. Their inclusion allowed the study to examine caregiving challenges from a professional and observational standpoint within an educational setting.

Meanwhile, Table 2 shows the second group which comprised low-income Muslim Malaysian parents (n = 5) who were the primary caregivers of children diagnosed with ASD. These parents were drawn from households classified as low-income, defined as earning below RM5,250 per month, in line with national income categorisation. Parents were included based on their direct, daily responsibility for managing their children's care, therapy attendance, and educational needs.

The study was conducted in Malaysia, specifically within the Klang Valley, an urban region that hosts a concentration of early intervention centres and public healthcare facilities serving diverse socioeconomic populations. Data collection took place in early

intervention centres that ensured participants' comfort and privacy. The setting is particularly relevant, as it reflects the realities of low-income families navigating caregiving within resource-constrained yet service-dense urban environments.

Table 1: Participants' Background Information – Teachers.

Pseudonym	Gender	Type of Early Intervention Centre	Position	Working Experience
Teacher 1 (I1)	Female	Private intervention centre for autistic children	Therapist cum Teacher	7 years
Teacher 2 (I2)	Male	Community-based rehabilitation centre for persons with disabilities	Manager cum Teacher	3 years

Table 2: Participants' Background Information – Parents.

Pseudonym	Gender	Age	Location	Occupation
Parent 1 (P1)	Female	35	Selayang Bharu	Mother: Housewife Father: Store Keeper
Parent 2 (P2)	Female	33	Serendah	Mother: Self-Employed Father: Grab Rider
Parent 3 (P3)	Female	31	Sg Choh,	Mother: Self-Employed Father: Factory Supervisor
Parent 4 (P4)	Male	39	Serendah	Mother: Policewoman Father: Self-Employed
Parent 5 (P5)	Female	26	Serendah	Mother: Coway Service Lady Father: Grab Rider

Study Sample: A purposive sampling strategy was employed to ensure the selection of information-rich participants who possessed direct experience with the phenomenon under investigation.

Teachers were selected based on the following inclusion criteria: (a) Muslim Malaysian nationality, (b) a minimum of two years' experience teaching children with special needs, and (c) regular professional engagement with low-income families of children with ASD. Parents were included if they were (a) Muslim Malaysian, (b) classified as low-income based on national income thresholds, and (c) primary caregivers of a child formally diagnosed with ASD.

The sample size was deemed appropriate for an exploratory qualitative study, where depth of understanding and contextual richness take precedence over generalisability. Data saturation was achieved when no new themes emerged from subsequent interviews, indicating sufficient coverage of participants' experiences.

Data Collection Procedures: Data were collected using a semi-structured interview protocol, which was developed to elicit in-depth accounts of participants' experiences, perceptions, and challenges related to caring for and managing children with ASD in low-income contexts. The use of semi-structured interviews allowed for flexibility in probing participants' responses while ensuring consistency across interviews (Creswell & Poth, 2018).

Two versions of the interview protocol were prepared: one for teachers and another for parents, with overlapping core questions to enable comparison across perspectives. The interview questions focused on caregiving challenges, emotional and psychological experiences, access to support and services, financial constraints, and coping strategies.

Each interview lasted approximately 40 to 60 minutes and was conducted in Bahasa Malaysia to ensure participants' comfort and facilitate rich, nuanced expression. With participants' informed consent, all interviews were audio-recorded and transcribed verbatim to ensure accuracy and depth of analysis.

Ethical approval for the study was obtained from the International Islamic University Malaysia (IIUM) Research Ethics Committee prior to data collection (IREC2023-135). Before participation, all participants were provided with an informed consent form and were fully briefed on the purpose and procedures of the study. Participants were informed of their right to decline to answer any question or withdraw from the study at any time without penalty, particularly if they experienced discomfort or emotional distress.

Validity and Reliability of the Instrument: In qualitative research, the rigor of a data collection tool is established through criteria of

trustworthiness, including credibility, dependability, and confirmability, rather than statistical validity and reliability (Lincoln & Guba, 1985).

Credibility was enhanced through the use of a semi-structured interview protocol that allowed participants to articulate their experiences in their own words while maintaining alignment with the research objectives. The interview protocol underwent expert validation by two experts in the field of educational psychology and qualitative research, who reviewed the relevance, clarity, and cultural appropriateness of the questions. Their feedback resulted in minor refinements to improve question wording and sequencing.

Dependability was supported by the use of a consistent interview guide across all participants and by maintaining a clear audit trail documenting interview procedures, transcription processes, and analytic decisions. All interviews were audio-recorded and transcribed verbatim to ensure accuracy and consistency.

Confirmability was strengthened through reflexive memo-writing and collaborative review of emerging codes and themes, reducing the influence of researcher bias. Verbatim quotations are presented in the Findings section to ensure that interpretations are grounded in participants' voices.

Together, these strategies ensured that the data collection tool was methodologically sound and appropriate for capturing in-depth qualitative insights.

Data Analysis: The interview data were analysed using inductive thematic analysis, following the six-phase framework proposed by Braun and Clarke (2006). This method is well suited for exploratory studies seeking to identify patterns of meaning across qualitative data.

The analysis involved: (1) familiarisation with the data through repeated reading of transcripts, (2) generation of initial codes, (3) searching for potential themes, (4) reviewing themes, (5) defining and naming themes, and (6) producing the final analytic narrative. To enhance trustworthiness, themes were reviewed collaboratively by the research team, and discrepancies were discussed until consensus was achieved. Reflexive memo-writing was also employed to minimise researcher bias and maintain analytic rigour.

Findings

This section presents the findings derived from interviews with two Muslim Malaysian teachers and five low-income Muslim parents of children diagnosed with ASD. Through thematic analysis, six interrelated themes emerged, reflecting shared yet differently positioned experiences of caregiving challenges. Teachers' perspectives provide a professional and observational lens, while parents' accounts reveal the intimate, lived realities of daily caregiving. Together, these perspectives offer a nuanced portrayal of the challenges faced by low-income families raising children with special needs.

Theme 1: Early Recognition and Diagnostic Pathways

Across both groups, early recognition of developmental differences emerged as a critical starting point in the caregiving journey. Teachers observed that most parents arrived at early intervention centres already burdened with worry, having noticed atypical behaviours long before formal assessment. They highlighted that many parents approached early intervention centres with concerns about delayed speech, poor eye contact, and atypical behaviours, often after noticing developmental differences at home. Teachers described parents as often saying that "something was not right," yet lacking clarity or confirmation:

"Usually when parents come to us, they already feel something is wrong. They notice the delay, but they don't know what it is or where to go." (Teacher 1)

Parents' narratives strongly echoed this observation. Parents described relying on intuition and close daily interaction to identify early red flags such as lack of eye contact,

delayed speech, repetitive movements, and withdrawal. One mother explained: *"At this age, when you call their name, they should already look at you… but Rayyan didn't." (Parent 1)*

Another parent recalled the emotional moment of realisation: *"At one and a half years old, suddenly he didn't want to look at us at all, even when we were right in front of him." (Parent 3)*

Fathers shared similar concerns: *"After he turned two, it felt like he had his own world… when we called him, he just ignored us." (Parent 4)*

Despite these early concerns, both teachers and parents described lengthy and fragmented diagnostic pathways, particularly within public healthcare systems. Teachers noted parents' frustration with repeated referrals and long waiting periods: *"Parents get very tired of going from one place to another. They wait months, sometimes years, just to get an answer." (Teacher 2)*

Parents' accounts revealed the emotional toll of these delays: *"It took almost a year just to do the hearing test because government hospitals take so long." (Parent 2)*
"From age two, we kept going to Hospital Selayang… it took more than four years before the doctor finally confirmed ASD." (Parent 5)

For low-income parents, these prolonged pathways intensified uncertainty and distress, as they lacked the financial means to pursue faster private diagnoses.

Theme 2: Emotional Impact and Psychological Distress

Emotional burden was a dominant and deeply shared theme across both teachers' and parents' narratives. Teachers frequently described parents as emotionally overwhelmed, sensitive, and easily distressed, especially mothers. Teachers observed parents expressing sadness, fear, and anxiety, particularly concerning social judgment and the child's future. One teacher shared: *"Some parents become very sensitive and easily offended. They are already emotionally exhausted." (Teacher 1)*

Teachers observed parents struggling silently, particularly when they felt judged by others or unsupported by family members. Parents' accounts revealed the depth of this emotional turmoil. Many described shock, denial, and confusion upon hearing or anticipating the diagnosis. One mother stated: *"I didn't want to hear it… I felt the doctor was talking nonsense." (Parent 1)*
Another parent reflected: *"At first I felt very blur… confused, and honestly very down." (Parent 5)*

For some parents, emotional distress escalated into severe psychological crises, including suicidal ideation. *"At one point, I felt like killing myself… I was too stressed." (Parent 1)*

Teachers confirmed witnessing such emotional breakdowns from a professional distance: *"Some parents come to us already broken. They cry easily, and they don't know where else to turn." (Teacher 1)*

Both perspectives illustrate the cumulative emotional burden carried by low-income parents, shaped by caregiving demands, financial strain, and limited psychosocial support.

Theme 3: Daily Caregiving Burden and Behavioural Management

Both teachers and parents described daily caregiving as physically exhausting and emotionally draining, particularly in managing children's behaviours and ensuring safety. Teachers emphasised behavioural challenges and constant supervision needs: *"Parents have to be extremely careful. Even one moment of carelessness can be dangerous." (Teacher 1)*

Teachers recounted alarming real-life incidents: *"One child was found in a paddy field, the water almost reaching his nose. Another was found in a chicken coop. One was found naked at a mini mart." (Teacher 1)*

Parents described the same burden from within the home, particularly sleep disruption: *"As long as he doesn't sleep, I don't sleep." (Parent 2);*
"The earliest he sleeps is midnight, and then he wakes up again at dawn." (Parent 5)

Physical exhaustion affected both mothers and fathers: *"I hardly get enough rest… I wake up at 4.30 in the morning to prepare everything." (Parent 4)*

Feeding difficulties further compounded stress. Parents described extreme food selectivity and sensory sensitivities:

"Out of 100 percent, 95 percent of the time he refuses to eat." (Parent 1);
"He doesn't eat rice… he only wants spaghetti and pizza." (Parent 4)

Teachers acknowledged how these daily struggles drained parents' energy: *"Taking care of a special child requires double or triple the effort." (Teacher 1)*

These accounts reveal how behavioural challenges translate into continuous physical exhaustion and emotional strain for caregivers.

Theme 4: Family Relationships, Social Withdrawal, and Stigma

Both groups highlighted how caregiving responsibilities disrupted family dynamics and social life. Teachers reported that many parents lacked extended family support and were reluctant to return to their hometowns due to judgment and misunderstanding: *"Support usually comes only from the mother or father. When they go back to their hometown, there is no support. They are afraid to go back during festive seasons because family members don't understand." (Teacher 1)*

Teachers also observed marital breakdowns and lack of spousal support, sometimes resulting in single-parent caregiving: *"There are cases where the partner is not supportive, and it leads to divorce." (Teacher 1)*

Parents' experiences reinforced these observations, describing marital conflict, disrupted employment, and social withdrawal:
"Since Rayyan was born, we fight a lot because of him." (Parent 1);
"People shouted, 'Why are you treating your child like that?'… I just blocked my ears." (Parent 5)

Both groups highlighted stigma as a powerful force driving isolation and emotional distress.

Theme 5: Financial Strain and Limited Access to Services

Financial strain was consistently identified as the most pressing and persistent challenge. Teachers emphasised how therapy costs exceeded parents' financial capacity. They reported that therapy costs, transportation, and daily necessities exceeded what low-income parents could afford: *"RM150 for one physiotherapy session is very expensive for low-income parents. Even the RM120 allowance is usually spent on food, not therapy." (Teacher 2)*

Parents confirmed this financial strain, describing difficult trade-offs between therapy costs and basic needs: *"Sometimes we pay rent late because diapers have to come first." (Parent 4); "My salary is basically all spent on my child." (Parent 5)*

Affordable intervention centres were described by both groups as essential lifelines: *"There is no other place we can afford." (Parent 2); "If not for this centre, many parents wouldn't be able to send their children for therapy at all." (Teacher 2)*

Theme 6: Coping, Support, and Meaning-Making

Despite the severity of challenges, both teachers and parents described adaptive coping and resilience. Teachers recognised parents' need for emotional expression and described providing informal emotional support by listening and allowing parents space to share:
"Most parents felt better after sharing their stories with us." (Teacher 1)

Teachers also respected parents' need for "me time" as part of emotional self-care. *"Sometimes we tell them, it's okay to take 'me time'." (Teacher 1)*

Parents, in turn, described coping through religious meaning-making and acceptance:
"This is a trust from Allah… we have to help him." (Parent 3)

Small improvements in children's behaviour were described as powerful sources of hope by both teachers and parents:
"He can now follow instructions… outsiders can see the difference." (Parent 2)

Taken together, the integrated findings reveal that low-income parents' caregiving challenges are multidimensional and deeply interwoven, encompassing prolonged diagnostic uncertainty, emotional distress, physical exhaustion, strained relationships, financial hardship, and social stigma.

Teachers' professional observations validate and contextualise parents' lived experiences, while parents' narratives illuminate the emotional depth behind these observations. Despite these challenges, resilience is sustained through faith, supportive relationships with teachers, and hope derived from children's

developmental progress. Together, these integrated perspectives highlight the complexity of caregiving among low-income families and underscore the importance of holistic, affordable, and emotionally supportive systems.

Table 3: List of Themes, Teachers,' and Parents' Perspectives on the Challenges in Managing ASD Children.

Theme	Teachers' Perspectives	Parents' Perspectives
Early recognition and diagnostic pathways	Parents already worried before referral	Parental intuition guides early concern
Emotional impact and psychological distress	Observed sensitivity, exhaustion	Shock, denial, suicidal thoughts
Daily caregiving burden and behavioural management	Safety risks, behaviour issues	Sleep loss, feeding stress
Family relationships, social withdrawal and stigma	Lack of family/spousal support	Marital strain, stigma
Financial strain and limited access to service	Therapy & transport unaffordable	Basic needs prioritised over therapy
Theme	**Teachers' Perspectives**	**Parents' Perspectives**
Coping, support and meaning-making	Emotional sharing helps	Faith and child progress sustain hope

Discussion

This study examined the challenges faced by low-income parents in managing and caring for children with Autism Spectrum Disorder (ASD) through the integrated perspectives of Malaysian teachers and parents. Beyond documenting caregiving challenges, this discussion interprets the findings through structural, psychological, and sociocultural lenses to explain why such challenges persist among low-income families. Drawing on educational, caregiving, and psychosocial literature, the discussion critically examines the mechanisms underlying parental distress, highlights points of convergence and divergence with previous studies, and considers how cultural, socioeconomic, and institutional contexts in Malaysia shape caregiving experiences.

Early Recognition and Prolonged Diagnostic Pathways: While early parental recognition of developmental differences is well documented (Galán-Vera et al., 2025; Abdullah et al., 2022), the prolonged diagnostic pathways reported in this study point to deeper institutional and systemic constraints. Delays were not due to parental inaction but rather to fragmented referral systems, long waiting lists, and reliance on overstretched public healthcare facilities. Similar barriers have been reported in other low- and middle-income contexts (Battanta et al., 2024), suggesting that diagnostic delay is a structural rather than individual problem.

In contrast, studies from high-income settings report earlier diagnosis and more streamlined pathways due to better resourcing and integrated services (Ten Hoopen et al., 2022). This comparison highlights how socioeconomic position intersects with institutional capacity, leaving low-income Malaysian families disproportionately affected by diagnostic uncertainty. Prolonged ambiguity not only delays intervention but also amplifies emotional distress, reinforcing Di Renzo et al.'s (2020) assertion that uncertainty itself is a major psychological stressor for parents.

Emotional Impact and Psychological Distress: The emotional distress described, ranging from shock and denial to suicidal ideation, reflects a cumulative stress process, whereby emotional burden intensifies over time through repeated exposure to caregiving demands, financial strain, and social isolation.

From a stress-process perspective (Picardi et al., 2018), parental distress in this context is not episodic but structurally produced, suggesting that emotional well-being cannot be addressed without parallel systemic intervention. While similar levels of distress have been reported globally (Khader et al., 2020; Lee & Barger, 2024), this study reveals that low-income status magnifies vulnerability, particularly through reduced access to mental health services and social support. Cruz et al. (2025) demonstrated that income indirectly affects maternal mental health through perceived social support, a mechanism clearly reflected in the present findings. While studies in collectivist societies often suggest that extended family networks buffer caregiving stress (Turnage & Conner, 2022), the present findings challenge this assumption. In this context, disability-related stigma and moral judgement appear to override collectivist norms, transforming potential support networks into sources of stress. This suggests that culture alone does not guarantee support; rather, cultural meanings attached to disability play a decisive role.

Daily Caregiving Burden and Behavioural Management: Daily caregiving challenges such as sleep deprivation, feeding difficulties, and constant supervision, illustrate the invisible and gendered labour of caregiving, particularly for mothers. Behavioural dysregulation among children with ASD has been consistently linked to higher caregiver burden (Chua et al., 2023; Daharli et al., 2025), yet the present study demonstrates how this burden is intensified when parents lack access to respite care or specialised behavioural support.

Unlike studies conducted in resource-rich settings where professional support can mitigate daily stressors (Ten Hoopen et al., 2022), parents in this study relied primarily on personal endurance. Teachers' accounts of safety incidents further highlight how caregiving extends beyond routine tasks into constant risk management. These findings underscore that caregiving burden is not merely physical but also cognitively and emotionally taxing, particularly under conditions of scarcity.

Family Relationships, Social Withdrawal, and Stigma: The disruption of marital relationships and social withdrawal reported in this study reflects how caregiving intersects with cultural norms surrounding parenting, discipline, and family responsibility. Consistent with Bromley et al. (2004) and Ludlow et al. (2012), stigma emerged as a key mechanism driving isolation. However, in the Malaysian context, stigma was often compounded by moral judgement from extended family members, who interpreted children's behaviours as parental failure rather than disability-related differences.

While some studies suggest that religious or cultural communities may provide emotional support (Mohamad et al., 2019), the present findings complicate this assumption by showing how fear of judgement can lead parents to avoid social and religious gatherings. Teachers' observations of parents avoiding festive visits further reveal how stigma operates subtly, shaping social participation and emotional well-being.

Financial Strain and Limited Access to Services: Financial strain was not merely a background condition but a central organising force shaping caregiving decisions. Consistent with Tathgur and Kang (2021) and Appah et al. (2024), parents described constant trade-offs between therapy, food, housing, and transport. These findings resonate with Sullivan and Stadtlander's (2020) argument that poverty fundamentally restructures caregiving priorities.

These findings illustrate how poverty functions as a structuring condition, shaping

not only access to services but also parental decision-making and emotional priorities. Within the Malaysian context, where social protection for disability remains limited, economic survival often takes precedence over developmental ideals promoted by professionals. This contextual tension explains why parental choices may appear inconsistent with clinical recommendations yet remain entirely rational within lived constraints.

Coping, Acceptance, and Meaning-Making: Despite adversity, parents demonstrated resilience through religious meaning-making, framing caregiving as an *amanah* (trust from God). This finding aligns with Mohamad et al. (2019), who identified psychospiritual coping as a key adaptive strategy among Muslim parents in Malaysia. Faith provided emotional regulation, acceptance, and endurance, functioning as a culturally embedded coping mechanism.

However, reliance on spiritual coping should not obscure structural needs. While faith offered psychological comfort, it did not replace the need for accessible services, financial support, or mental health care. Teachers' roles as informal emotional supports further highlight gaps in formal support systems, positioning educators as unintended caregivers for parents' emotional needs.

Taken together, the findings suggest that caregiving challenges among low-income parents of children with ASD are not isolated or individual problems, but the outcome of intersecting structural, emotional, and cultural forces. Diagnostic delays, emotional distress, caregiving burden, stigma, and financial strain operate cumulatively, reinforcing one another within conditions of socioeconomic vulnerability. While religious meaning-making provides psychological resilience, it does not substitute for systemic support. These insights highlight the need for multi-level interventions that integrate educational, psychosocial, and structural responses, rather than placing responsibility solely on families.

Limitations of the Study

Several limitations should be acknowledged when interpreting the findings of this study. First, the small sample size, comprising two teachers and five parents, limits the transferability of the findings to broader populations. While the sample size is appropriate for an exploratory qualitative study aimed at achieving depth rather than generalisability, the experiences reported may not fully represent the diversity of low-income families caring for children with ASD in Malaysia.

Second, the study focused on participants from an urban setting (Klang Valley), where access to early intervention centres and healthcare facilities is relatively greater than in rural or remote areas. Consequently, the challenges faced by families in less resourced regions may be underrepresented.

Third, the study relied on self-reported data, which may be influenced by emotional states, recall bias, or social desirability. Although triangulation between teachers' and parents' perspectives enhanced credibility, observational or longitudinal data could have provided additional insight into caregiving dynamics over time.

Finally, as the study focused on Muslim Malaysian participants, the findings are culturally specific and may not be directly applicable to families from different religious or cultural backgrounds.

Recommendations for Future Research

Future studies are encouraged to include larger and more diverse samples, encompassing parents from different socioeconomic strata, ethnic backgrounds, and geographical regions to enable comparative analysis. Research involving rural and semi-rural communities

would be particularly valuable in uncovering context-specific caregiving challenges beyond urban settings.

Longitudinal qualitative or mixed-methods studies could provide deeper insight into how caregiving experiences, parental well-being, and coping strategies evolve across different stages of a child's development. Additionally, future research should explore the perspectives of fathers, siblings, and extended family members, as caregiving is often a shared yet unevenly distributed responsibility.

Further investigation into institutional practices, including healthcare and educational systems, would also be beneficial in identifying systemic barriers and informing policy-level interventions. Finally, more empirical work is needed to examine the effectiveness of psychospiritual and community-based support mechanisms for low-income parents of children with ASD.

Implications of the Study

The findings of this study have several important implications for practice, policy, and research. Practically, the results highlight the need for holistic, family-centred support services that address not only children's developmental needs but also parents' emotional, psychological, and financial well-being. Teachers and early intervention practitioners should be equipped with basic training in empathic communication and parental support, given their significant role as informal emotional anchors for families.

At the policy level, the study underscores the urgency of improving affordable and accessible diagnostic and intervention services, particularly for low-income families. Enhanced financial assistance, subsidised therapy programmes, and streamlined referral pathways could significantly reduce caregiving burden.

From a cultural perspective, the findings suggest that religiously informed coping strategies play a meaningful role in parental resilience. Integrating culturally and spiritually sensitive approaches into support programmes may enhance their relevance and effectiveness within Muslim communities.

Conclusion

This study provides an in-depth exploration of the challenges faced by low-income parents caring for children with Autism Spectrum Disorder in Malaysia, as viewed through the integrated perspectives of teachers and parents. The findings reveal that caregiving challenges are multidimensional and cumulative, encompassing prolonged diagnostic uncertainty, emotional and psychological distress, daily caregiving exhaustion, strained family relationships, financial hardship, and social stigma.

At the same time, the study highlights parents' resilience, particularly through faith-based meaning-making, supportive relationships with teachers, and hope derived from children's developmental progress. By foregrounding both professional observations and lived experiences, this study contributes to a more nuanced understanding of autism caregiving under socioeconomic constraint.

Ultimately, the findings call for systemic, culturally responsive, and economically inclusive support structures that recognise caregiving not as an individual burden, but as a shared social responsibility. Such efforts are essential to improving the quality of life for both children with ASD and their families.

Disclosure Statement

– **Ethical approval and consent to participate:** Ethical approval for this study was obtained from the International Islamic University Malaysia (IIUM) Research Ethics Committee (IREC). Participation in the study was entirely voluntary. All

participants were provided with informed consent forms in both English and Bahasa Malaysia, which clearly outlined the purpose and procedures of the study. Participants were informed of their right to withdraw from the study at any time without penalty. Confidentiality and privacy were strictly maintained throughout the research process; participants' identities were protected by assigning unique serial numbers to all interview records and transcripts.

- **Availability of data and materials:** The datasets used and/or analyzed during the current study are available from the corresponding author upon reasonable request.
- **Author contribution:** All authors listed have contributed to the work and approved it for publication. The authors have worked in an organized manner. A.H.A.K., S.S., M.A.M.I. & N.A.H.I. supervised the work. A.H.A.K. designed the study, communicated with the key people, and wrote the manuscript. S.K.K., H.R. & A.H.A.K. collected the data and did the statistical analysis. A.H.A.K. has reviewed the data and the final manuscript for approval. The author(s) read and approved the final manuscript.
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List of Abbreviations

ASD: Autism Spectrum Disorder

COVID -19: Coronavirus

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