Lived Experiences of Malaysian Parents Following Their Child's Autism Diagnosis: A Qualitative Study in Klang Valley

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ABSTRACT

Autism spectrum disorder (ASD) is a neurodevelopmental condition that affects communication, social interaction, and behaviour, and its rising prevalence has significant implications for families. In Malaysia, the number of children registered with ASD increased from 6,991 in 2013 to 53,323 in 2023, reflecting a substantial rise in diagnosed cases. This study explored the lived experiences of parents in Klang Valley following their child's ASD diagnosis, with attention to emotional adjustment, spousal relationships, and overall life satisfaction. Using a qualitative phenomenological design, semi-structured interviews were conducted with ten participants, three fathers and seven mothers, who had been primary caregivers for at least one year post-diagnosis. Participants were recruited through purposive and snowball sampling. Thematic analysis identified seven major themes: (emotional experiences, new challenges and growth, support systems, challenges faced by couples, strengthened relationships, redefined life satisfaction, and emotional resilience). Parents initially experienced intense emotional responses, including denial, sadness, anger, and disappointment. Over time, many transitioned toward acceptance and developed resilience. Major challenges included financial strain from therapy costs, limited access to services, societal stigma, and marital tension. Despite these difficulties, many parents reported personal growth, strengthened family bonds, and increased patience and empathy. Support from spouses, extended family, teachers, and the wider community, along with spiritual beliefs, particularly the concepts of *Reda* (contentment) and *Shukur* (gratitude), and self-care practices, contributed to emotional resilience. These findings offer a culturally grounded insight into the realities of raising a child with ASD in Malaysia and underscore the need for inclusive, family-oriented support services and greater societal awareness.

Keywords: Autism Spectrum Disorder (ASD), parents' experiences, spousal relationship, life satisfaction

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INTRODUCTION

Autism spectrum disorder (ASD) is a neurodevelopmental condition that affects communication, social interaction, and behaviour, with substantial implications for an individual's emotional, cognitive, and social functioning (Okoye et al., 2023). In Malaysia, ASD prevalence has risen notably over the past decade, with the number of children registered with the Department of Social Welfare (JKM) increasing from 6,991 in 2013 to 53,323 in 2023, indicating a significant escalation in diagnosed cases nationwide (Galen Centre for Health and Social Policy, 2024). This rapid rise underscores the need to understand the lived experiences of Malaysian families caring for children with ASD. While ASD directly affects the child, its impact extends to the family system, particularly parents who commonly take on the primary caregiving role (Goh et al., 2021; Safe et al., 2012). Globally, ASD prevalence has also increased, affecting an estimated 1–2% of the population, or approximately 50 million individuals (Neik et al., 2014; Hui et al., 2021). Collectively, these global and national trends highlight the importance of examining ASD within Malaysia's cultural and social context, where family dynamics and public awareness strongly shape parental experiences.

Parents of children with ASD frequently experience emotional distress, uncertainty about the future, and major disruptions to daily routines. Communication difficulties, repetitive behaviours, and sensory sensitivities often make public outings overwhelming, sometimes resulting in meltdowns and parental anxiety (Ludlow et al., 2011; Reddy et al., 2019). These challenges can lead to emotional exhaustion and social withdrawal (Wong et al., 2024; Yaacob et al., 2021). Financial strain is another significant burden, as specialised therapies, interventions, and medical services are costly and often lack adequate public support (Befkadu & Adamek, 2022).

Caregiving stress often affects marital relationships, requiring couples to adjust to shifting roles and increased emotional demands. Heightened tension, communication breakdowns, and reduced intimacy are commonly reported (Joyce, 2020; Adamus & Satinská, 2021). However, some parents demonstrate notable resilience over time, finding meaning and fulfillment through a deeper understanding of their child and through access to support networks (Kuhlthau et al., 2014). In the Malaysian context, cultural norms and limited public awareness further shape parental experiences, with stigma often delaying help-seeking and intensifying emotional strain (Arunasalam et al., 2024; Abdullah et al., 2022). These challenges highlight the need to explore the lived experiences of Malaysian parents following their child's ASD diagnosis, particularly in relation to emotional adjustment, spousal relationships, and life satisfaction. Accordingly, the study is guided by the following research questions:

1. How do Malaysian parents describe their experiences upon learning of their child's ASD diagnosis?
2. What changes do Malaysian parents perceive in their spousal relationship after their child's ASD diagnosis?
3. How do Malaysian parents perceive the impact of their child's ASD diagnosis on their overall life satisfaction?

BACKGROUND OF THE STUDY

According to the DSM-5, autism spectrum disorder (ASD) is characterised by persistent deficits in social According to the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), autism spectrum disorder (ASD) is characterised by persistent deficits in social communication and interaction, alongside restricted and repetitive patterns of behaviour, interests, or activities (APA, 2013). Globally, ASD has become more widely recognised, with the Centres for Disease Control and Prevention (CDC) estimating that one in 36 children is diagnosed with the condition (Maenner et al., 2023). In Malaysia, data from 2010 to 2021 indicate that approximately 19% of children aged 18 and below with disabilities were identified with ASD, reflecting a rising prevalence that mirrors global trends. This increase has heightened public awareness of autism and drawn attention to the critical role of parents, who bear primary responsibility for their child's daily care, education, and emotional well-being (Goh et al., 2021). As such, examining parental experiences within the Malaysian context is essential for understanding the broader social and cultural impact of ASD.

Research consistently demonstrates that parents of children with ASD experience heightened emotional, social, and financial stress. Managing behavioural challenges, sensory sensitivities, and uncertainty about the child's future are common concerns (Wong et al., 2024). In Malaysia, societal stigma and cultural expectations further intensify these challenges. Limited public awareness and social pressure to maintain conformity often contribute to delayed diagnosis and reduced access to appropriate support services (Teo & Lau, 2018; Arunasalam et al., 2024). The high cost of ongoing therapy and specialised education places additional strain on families (Befkadu & Adamek, 2022). Despite these difficulties, some parents report emotional growth, increased patience and empathy, and greater self-efficacy as they adapt to the demands of caregiving (Kuhlthau et al., 2014).

These pressures often extend to spousal relationships. Marital conflict, emotional distance, and reduced intimacy have been widely reported, particularly when caregiving responsibilities are unevenly distributed (Joyce, 2020; Adamus & Satinská, 2021). In many households, mothers assume a disproportionate share of caregiving tasks, which may lead to resentment and feelings of insufficient support (Chan & Leung, 2020). Combined with the ongoing demands of raising a child with ASD, these relational strains can undermine life satisfaction and emotional well-being (Lombardo et al., 2018).

This study is informed by Family Systems Theory (Bowen, 1978), which conceptualises the family as an interconnected emotional system in which stress experienced by one member influences the entire unit. Concepts such as differentiation of self, family projection, and triangulation provide a useful framework for understanding how parents respond to caregiving demands and relational stress (Gavazzi & Lim, 2023). Despite extensive international research, the lived experiences of Malaysian parents, particularly those residing in the diverse urban region of the Klang Valley, remain underexplored. This study addresses this gap by examining how parents interpret and manage their child's ASD diagnosis, with particular attention to emotional adjustment, spousal relationships, and overall life satisfaction, thereby informing culturally sensitive support services and policy development.

METHOD

Research Method and Design

This study employed a qualitative research method aimed at exploring the experiences of Malaysian parents following their child's ASD diagnosis. Using a phenomenological design, the research sought to understand how parents interpret and respond to the emotional, relational, and social challenges associated with raising a child with ASD (Ranjitkar, 2018). This design enabled the investigation of parents' lived experiences and the meanings they ascribe to them, focusing on the emotional toll, marital dynamics, and implications for life satisfaction within Malaysian culture.

Sample and Location

The study employed a purposive sampling method to recruit 10 married parents of children diagnosed with autism spectrum disorder (ASD) residing in the Klang Valley, Malaysia. Participants were between 35 and 60 years old and represented diverse ethnic backgrounds and caregiving roles. The participants were recruited based on the following criteria: (a) being the primary caregiver of a child diagnosed with ASD at least one year prior to the study, and (b) residing within the Klang Valley region. To expand the participant pool, snowball sampling was also utilized by encouraging referrals from initial participants. The Klang Valley was selected for its demographic diversity and access to specialised autism support services. While phenomenological studies typically include between five and 25 participants (Dahal et al., 2024), data saturation was achieved with 10 participants, as no new themes or insights emerged from subsequent interviews. Table 1 below summarizes the demographic characteristics of the participants and their children.

Table 1: Demographic background of participants

Participants' Characteristics		**Number of Participants**
Gender	Male	3
	Female	7
Age Range	35 - 40 years	4
	41-50 years	5
	51 - 60 years	1
Ethnicity	Malay	6
	Chinese	3
	Indians	1
Occupation	Nurse	1
	Business Manager	1
	Financial Coach	1
	Project Manager	1
	Housewife	4
	Chief Executive Officer	1
	Pilot	1

Table 2: Characteristics of Participants' Children

Participant's Children		**Number of Children**
ASD Child's Age	5–10 years	4
	11–20 years	5
	21 years and above	1
Severity Level of ASD	Level 1	2
	Level 2	2
	Level 3	4
	Not Yet Specified	2
Time Since Diagnosis	1-2 years	5
	3–4 years	1
	5 years and above	4

Data Collection

The data for this study were collected through semi-structured interviews with 10 Malaysian parents, focusing on the experiences of raising a child with ASD. Ethical clearance was obtained from the Research Management Centre at Asia Pacific University of Technology & Innovation, under reference number APUFE06/2025 prior to conducting the interviews to ensure adherence to research guidelines. Each interview lasted between 45 and 60 minutes and was audio-recorded with the participants' consent. Participants were fully informed about the purpose of the study, with an emphasis on voluntary participation, confidentiality, and their right to withdraw at any time. The interviews were conducted in a private, comfortable setting to facilitate open discussions, and all data were securely stored. Transcripts were anonymised to protect participants' identities, and thematic analysis was carried out to identify key themes. Participants were also given the opportunity to review and clarify their responses during the data analysis phase, ensuring the integrity of the findings.

Data Analysis

The data were analysed using Braun and Clarke's (2006) six-phase thematic analysis approach. All interview transcripts were read multiple times to ensure familiarity with the data, followed by systematic coding to capture key aspects of parents' experiences, including emotional responses to the ASD diagnosis, changes in spousal relationships, and impacts on life satisfaction. Data collection and analysis were conducted concurrently, with each transcript reviewed and coded immediately after the interview and emerging codes compared across participants. By the eighth interview, only minor variations of existing ideas were identified, and by the tenth interview, no new codes, categories, or meanings emerged. This indicated that data saturation had been reached, and further recruitment was therefore discontinued. The codes were subsequently grouped into broader themes that reflected shared patterns of meaning, and these themes were reviewed, clearly defined, and supported by verbatim participant quotations to enhance the credibility of the findings.

RESULTS

The results presented in this section highlight several factors identified in the analysis, as outlined and summarised in Table 3.

Table 3: Summary of Themes

Research Questions	Themes
1. How do Malaysian parents describe their experiences upon learning of their child's ASD diagnosis?	1.1 Emotional Experiences 1.2 New Challenges and Growth 1.3 Support
2. What changes do Malaysian parents perceive in their spousal relationship after their child's ASD diagnosis?	2.1 Challenges Faced by Couples 2.2 Strengthened Relationships
3. How do Malaysian parents perceive the impact of their child's ASD diagnosis on their overall life satisfaction?	3.1 Redefined Life Satisfaction 3.2 Emotional Resilience

To address the first research question on the experiences of parents following their child's ASD diagnosis, three main themes emerged from the data analysis: Emotional experiences, new challenges and growth, and support.

Theme 1.1: Emotional Experiences

The diagnosis brought several emotional responses for many parents, including sadness, disappointment, shock, and anger. Seven participants described the emotional turmoil that came with the realization that their child would not develop as expected. Whereas five participants struggled to accept the diagnosis at first, while two described being in denial, questioning how such a condition could affect their child. Although the initial emotional struggle, for six parents, the diagnosis ultimately confirmed their prior suspicions. Gaining a clear explanation for their child's behavior brought a sense of relief.

> *"It's a bit hard to believe. And like you, I would say maybe something like, you know, saying that it's not like that. How can it be like that, you know, those kinds of feelings?" (Participant 3, Male)*

> *"It confirms my suspicion because I had a doubt. When I got the diagnosis, I was relieved because I knew there was something wrong, and I knew what needed to be done from there on." (Participant 5, Female)*

In summary, parents' emotional experiences of their child's ASD diagnosis ranged from sadness and denial to eventual clarity and acceptance. While the initial shock was difficult, the diagnosis validated many parents' concerns, helping them to understand their child's behaviour and begin their journey toward planning for future care and support.

Theme 1.2: New Challenges and Growth

All parents reported significant difficulty understanding their child's needs, particularly due to limited speech, behavioural outbursts, and sensory sensitivities. These challenges created daily stress and required constant monitoring and adjustment to routines.

> *"Maybe at first, we don't really understand what my son needs because at first, at a very early stage, he's not really verbal much. So, he will cry, and there may be a tantrum. So, yeah, we have this challenge to understand what he needs So, yeah, we have this challenge to understand what he needs." (Participant 4, Female)*

Limited access to assessments and therapy services was a major concern, with long waiting times and inconsistent availability across settings. Financial strain was also reported by all parents, as therapy costs exceeded what many families could afford, adding substantial pressure on household budgets.

> *"So, the appointment was about 12 months of waiting time. I think somehow nearer to six months or so, I got a little bit impatient, and I hope that I could just see someone to assess my son. So, I checked around. Apparently, most of the doctors have a long waiting time. There was even one, the waiting time was about three and a half years." (Participant 3, Male)*

> *"My primary concern, I think, it's the budget-wise because attending this ABA therapy is not cheap, it's very expensive." (Participant 4, Female)*

All participants reported reduced social participation due to fears of meltdowns in public, resulting in isolation and avoidance of outings. Concerns about their child's long-term independence were common among eight parents, alongside experiences of lack of public awareness, stigma, and judgment from individuals who misunderstood autism.

> *"The children's side has a lot of children playing board games and mini-indoor playground. It's too loud. My son can't handle it. So, he ended up having a meltdown right in front of the children's area outside. And then he was biting and scratching my mother-in-law and I." (Participant 5, Female)*
>
> *"And the biggest thing I keep worrying about was what if I'm no longer around? Because, of course, obviously, parents, we don't live forever." (Participant 3, Male)*

Despite these difficulties, parents demonstrated growth through an adaptive process in which they developed new knowledge, skills, and perspectives in response to the challenges of raising a child with ASD. Six parents reported increased empathy and patience, both toward their children and toward other families facing similar situations. Many became proactive learners, seeking information through journals, online resources, and peer networks, while others developed understanding through close observation of their child's behaviour and needs.

> *"I mean, before him, I would never have known what autism was like. So, it was something new. I think he taught me so much in life. He taught me patience. He taught me passion." (Participant 2, Female)*
>
> *"I read a lot of journals. I read a lot of things, reading materials, not just medical, but also everything that I can find on the internet. And also, I did seek help from parents who have similar symptoms or main symptoms as mine, but my children do not seek help, ask around. Sometimes, because of social media, I have Facebook, and I tend to tell my problems online and my friends would give feedback." (Participant 5, Female)*

In short, parents faced major struggles in understanding behaviour, accessing services, managing financial burdens, handling daily caregiving demands, and participating in social activities. Concerns for their children's future and experiences of stigma further deepened their difficulties. Despite these challenges, many parents showed remarkable growth, developing greater empathy, patience, and knowledge through proactive learning and close observation of their children.

Theme 1.3: Support

Support from family members, teachers, and the broader community played a vital role in helping parents cope with the challenges of raising a child with ASD. Six participants shared that family acceptance eased the emotional burden of caregiving and made daily responsibilities more manageable. In addition to family support, public accommodations were also appreciated by many parents. Improved facilities, such as autism-friendly rooms in shopping malls, provided safe spaces during outings and reduced the stress of managing sensory overload in public areas.

> *"This year. I think they are building some centres to support, what do you call that, autistic learning. And we can also see in some shopping malls that they are also setting up space or membership for autistic individuals. And also, one thing, we were also given the tax relief for autism diagnosis, something like that. So, I mean, the government is also trying to promote this kind of awareness. Maybe other parents wouldn't know, yeah. And yeah, I have to mention that also, a few months ago, right, from the state government, we live in Selangor. So, they also have like a financial aid for parents who have children who qualify under the programme. I think it will open up for applications once a year. It's not a lot of money. It's just RM1,000 in Malaysia, but, you know, we never know whether it means a lot to someone or not." (Participant 3, Male)*

The results show that family support, community resources, and public initiatives played an important role in helping parents manage the challenges of raising a child with ASD. Support from relatives, schools, public facilities, and government programs provided parents with much-needed relief, flexibility, and encouragement in their caregiving journey.

Next, to address the second research question on the impact of an autism diagnosis on spousal relationships, two main themes were identified from the data analysis: Challenges faced by couples and strengthened relationships.

Theme 2.1: Challenges Faced by Couples
Six parents reported that the early period after diagnosis placed considerable emotional strain on their relationships, often leading to conflict, misunderstanding, and cycles of tension. Differences in coping styles and emotional responses contributed to temporary distancing between partners, with some couples experiencing persistent strain.

> *"It created more challenges. Definitely, some people may bring the family close together, but my family, it's no. It drove us apart." (Participant 5 Female)*

Balancing caregiving was also a common stressor for all participants, with mothers typically taking on a greater share of responsibilities due to fathers' work demands or limited involvement. While disagreements about therapy, behaviour management, and the financial cost of interventions created additional tension. These challenges were intensified by differing views on the level of support their child needed.

> *"Well, somehow, he didn't think that the OT was required, as he didn't see the benefits. And to me, I did see very direct benefits, but I do see sometimes the OT actually addresses some of my blind spots. And he is very open to the OT to tell he tell her his issues and stuff. So as of now, I think it's still necessary. But my husband didn't think that it was necessary, and we had an argument about stopping it." (Participant 2, Female)*

All participants reported that caregiving demands significantly reduced the time and emotional energy available for their marital relationship. Limited opportunities for communication, shared activities, or intimacy contributed to emotional distancing. In some cases, partners withdrew into separate routines, leaving the relationship neglected.

> *"I don't think there's a balance time between my husband and son. I think most of the time, 90% goes to the son. Only 10% goes to the husband." (Participant 4, Female)*

> *"She likes to talk with me mostly, and I prefer things like, like smoking. I like exercise. I like playing computer games. So, yeah. That's why we're different like that." (Participant 9, Male)*

In summary, couples faced emotional challenges, imbalanced caregiving roles, frequent disagreements over treatments, financial pressures, and differences in coping styles. The intense focus on the child's needs further limited time and emotional connection between partners, often leading to feelings of neglect and relationship strain.

Theme 2.2: Strengthened Relationships
Several parents described how raising a child with ASD strengthened their relationship, noting that shared caregiving routines and increased time spent together helped rebuild emotional bonds. For some, emotional intimacy improved through small gestures of support and mutual comfort. Many highlighted the importance of teamwork, explaining how spouses encouraged one another and managed stressful moments together. Additionally, most participants felt that caring for their child enhanced communication and helped them align their goals more clearly as a couple.

> *"We sent our son to his center, and we waited for him. So, we get to spend most of the time together now." (Participant 3, Male)*

Raising a child with ASD brought many couples closer together, strengthening their emotional bonds, communication, and teamwork. Despite the challenges, participants highlighted how mutual support, improved intimacy, and shared parenting goals helped them adapt and grow stronger as partners.

Finally, in answering the third research question in examining how parents perceive their life satisfaction following their child's ASD diagnosis, two key themes were identified: Redefined life satisfaction and emotional resilience.

Theme 3.1: Redefined Life Satisfaction

Five participants reported that their life satisfaction depended largely on their child's progress rather than their own achievements. Religious beliefs were also a significant source of comfort and acceptance for three parents, while two noted that external stressors like workplace issues affected their satisfaction more than the diagnosis itself. Social connections also changed, with five parents losing some friendships but forming new ones through schools or autism-related communities. Supportive friends and family remained essential for sustaining their emotional well-being.

> *"I not to said not the said satisfied. But uh yeah, but as a Muslim, we have to learn about Shukur, right? Uh, how is it? How bad is it? I have to accept that. Then when we try to accept that, uh, automatically, we have a Reda, yeah." (Participant 1, Female)*

In summary, life satisfaction among parents varied after their child's ASD diagnosis. Many found fulfillment through their child's progress and religious faith, while others faced ongoing struggles due to external stressors. Though social lives shifted, continued support from close friends and family helped maintain a sense of emotional balance and positivity.

Theme 3.2: Emotional Resilience

To maintain balance amid daily stress, parents developed emotional resilience through coping strategies to sustain their emotional and physical well-being. These strategies included carving out personal time, practising self-care, and setting boundaries between caregiving responsibilities and personal needs. Most participants emphasised that maintaining their own well-being was essential for continuing to care effectively for their child, describing activities such as exercising, maintaining hobbies, and preserving personal routines. Several parents highlighted the importance of retaining a sense of self despite caregiving demands, while others established clear boundaries to prevent burnout. However, a few parents prioritised their child's needs above all else, adapting their daily routines and lifestyles to ensure the child's comfort, sometimes at the expense of their own well-being.

> *"When I was on uh off duty, uh some uh such as Saturday, Sunday, early in the morning, I will take about two hours going for Jogging, going for my exercise, uh my me time for two hours. Have a family gathering. Because I have, I have told my husband that how or how bad it is, I still want the two hours for me to release my stress." (Participant 1, Female)*

> *"My priority is my kids. My spending is for them first, my priority. They eat first, then I eat." (Participant 6, Male)*

In short, parents developed emotional resilience by balancing caregiving with self-care, setting clear boundaries, and maintaining personal interests. Prioritising both their children's needs and their own well-being helped them sustain their life satisfaction.

DISCUSSION

This study explored the experiences of Malaysian parents following their child's diagnosis of autism spectrum disorder (ASD), with a focus on emotional responses, spousal relationships, and overall life satisfaction. Raising a child with ASD introduces substantial emotional, relational, and practical challenges that reshape family life and well-being. The findings showed that Malaysian parents experience a complex emotional transition following their child's ASD diagnosis, initially marked by denial, shock, sadness, and anger, before gradually progressing toward acceptance. This progression aligns with Kübler-Ross's (1969) stages of grief and Lazarus and Folkman's (1984) stress and coping theory. Despite early distress, many parents reported that the diagnosis validated their longstanding concerns and enabled access to appropriate services (Legg & Tickle, 2019; Karst & Van Hecke, 2012; Boshoff et al., 2016), shifting their experience from uncertainty to purposeful action.

Beyond emotional responses, parents faced substantial practical challenges in caregiving. Managing communication difficulties, behavioural outbursts, and sensory sensitivities frequently led to social withdrawal and emotional exhaustion (Gek & Kaur, 2024). Similarly, overstimulation, limited adult support, and technological constraints have also been shown to intensify stress among caregivers and educators, particularly when children require constant guidance during learning or daily routines (Arjumandi al., 2024; Thing & Zhooriyati, 2022). Structural barriers, particularly long waiting times for assessments and therapeutic services, further heightened frustration and delayed access to essential support (Chu et al., 2018; Fadare et al., 2021). Financial strain was another prominent concern, as intensive interventions such as applied behaviour analysis (ABA) could cost RM4,500–RM7,000 per month, in addition to fees for speech and occupational therapy (Befkadu & Adamek, 2022; Papadopoulos, 2021).

Daily caregiving demands, especially for children with severe sensory sensitivities or aggressive behaviours, required considerable physical and emotional effort, prompting many parents to avoid social outings to prevent public meltdowns, thereby increasing isolation (Broady et al., 2015). Compounding these difficulties, parents expressed concern about their child's long-term future, particularly regarding independence and safety. This persistent worry aligns with earlier research showing that families often fear what will happen when they are no longer around (Baker et al., 2005).

Stigma and social misunderstanding further exacerbated parental stress. Many parents reported experiencing judgment, blame, or uninformed commentary from the public, consistent with persistent misconceptions (Abdullah et al., 2022; Arunasalam et al., 2024). Yet, despite these adversities, many parents reported meaningful personal growth. Increased resilience and patience reflected patterns of post-traumatic growth (Tedeschi & Calhoun, 2004). Parents also engaged actively in learning through reading, workshops, online resources, and peer networks, which strengthened their caregiving competence and self-efficacy (Kuhlthau et al., 2011). Support systems played a central role in this adjustment process: Emotional and practical assistance from family members eased daily burdens, while supportive teachers and inclusive school environments reduced isolation. Some parents also noted improvements in public infrastructure such as autism-friendly spaces, financial aid, and tax relief, indicating a gradual increase in autism awareness in Malaysia (Neik et al., 2014).

Spousal relationships were significantly affected by caregiving demands. Many couples experienced heightened tension, communication difficulties, and disagreements regarding childcare responsibilities and financial decisions (Adamus & Satinská, 2021; Ludlow et al., 2011). Mothers often carried a disproportionate caregiving load, contributing to fatigue and relationship imbalance (Freedman et al., 2011). Divergent coping strategies, such as emotional withdrawal by one partner and active problem-solving by the other, further strained marital dynamics (Benson, 2009; Meadan et al., 2010). Nevertheless, some couples reported strengthened relationships through shared caregiving routines and improved communication, echoing findings by Sim et al. (2016) and Hickey et al. (2019). These patterns align with Family Systems Theory (Bowen, 1978), which emphasizes the interdependence of family members in coping with stress (Suppes, 2022).

Parents' life satisfaction was shaped by both the demands of caregiving and evolving personal values. Many parents described redefining success by celebrating small developmental achievements rather than normative milestones, consistent with prior findings on adaptive shifts in parental expectations (Musetti et al., 2021). Religious and spiritual beliefs, including the Islamic concepts of *Reda* (contentment) and *Shukur* (gratitude), provided emotional grounding and supported resilience, echoing previous work on religious coping (Tarakeshwar & Pargament, 2001; Ismail et al., 2024). Social support from extended family, school networks, therapy centres, and personal self-care practices also contributed to improved well-being (Graaf et al., 2023; Boshoff et al., 2016). However, persistent financial strain and employment instability continued to affect overall emotional stability and quality of life (Wang et al., 2023).

In short, raising a child with ASD in Malaysia presents multifaceted emotional, relational, and practical challenges. Parents demonstrate adaptability and resilience, negotiating caregiving demands, marital dynamics, and societal pressures while gradually finding meaning and redefining life satisfaction.

CONCLUSION

This study provides an in-depth understanding of the lived experiences of Malaysian parents following their child's autism spectrum disorder (ASD) diagnosis, revealing the profound emotional, relational and practical challenges they face. Parents initially struggled with shock, denial and sadness, but they gradually moved toward acceptance and resilience as the diagnosis provided clarity and direction for intervention. Their journey was marked by significant obstacles, including financial strain, long waiting times for services, behavioural challenges and societal stigma, all of which affected their daily functioning and emotional well-being. Beyond individual experiences, the diagnosis reshaped family dynamics, especially spousal relationships, where some grew closer through shared caregiving and improved teamwork, highlighting both vulnerability and strength within the family system. Despite the difficulties, parents demonstrated remarkable adaptability. Many redefined life satisfaction around their child's progress, embraced spiritual coping and prioritised self-care to maintain emotional balance. Support from family, teachers, communities and emerging autism-friendly initiatives also contributed to their resilience. Overall, the findings underscore the importance of culturally sensitive, family-centred support, increased public awareness, affordable early intervention and stronger social policies to enhance the well-being of families raising children with ASD in Malaysia.

IMPLICATIONS OF THE STUDY

This study offers theoretical and practical insights into how Malaysian parents adapt to raising a child with ASD. It extends Stress and Coping Theory (Lazarus & Folkman, 1984) by highlighting the role of spiritual coping, particularly the Islamic concepts of *Reda* and *Shukur*, in promoting acceptance and resilience, and expands Family Systems Theory (Bowen, 1978; Titelman, 2014) by showing how cultural expectations, extended family influence, and gendered caregiving shape family adaptation. In practice, the findings emphasize family-centred support, including parental mental health services, marital counselling, and education for extended family, alongside affordable early interventions, reduced waiting times, culturally competent professionals, and community awareness initiatives to reduce stigma. Parent empowerment through peer networks, training, and accessible resources further supports resilience and caregiving. These findings underscore the importance of culturally sensitive, systemic, and sustained support to enhance the well-being and long-term outcomes of families raising children with ASD in Malaysia.

LIMITATION OF THE STUDY

A key limitation of this study was the difficulty in securing participants due to caregiving demands, which led to scheduling issues and cancelled interviews. Fathers were underrepresented, as most participants were mothers, limiting a balanced view of both parents' experiences. Additionally, cultural stigma around topics like marital conflict and mental health may have led to social desirability bias, reducing the authenticity of some responses. Finally, the study was also conducted solely in the Klang Valley region, which may limit the transferability of the findings to parents of children with ASD in other parts of Malaysia.

RECOMMENDATIONS OF THE STUDY

To enhance future research on parents of children with ASD, recruitment strategies should be made more flexible and accessible by incorporating options such as online interviews, evening or weekend sessions, and modest incentives to accommodate caregivers' demanding schedules. Addressing the underrepresentation of fathers is also essential, and future studies should emphasise the inclusion of paternal perspectives through recruitment approaches that align with work commitments. Creating a psychologically safe and non-judgmental environment, supported by clear assurances of confidentiality and culturally sensitive interviewing practices, may help reduce social desirability bias and encourage more open sharing of experiences. Beyond research, the findings also suggest the need for more coordinated, family-centred service delivery, including accessible parental counselling, marital support, and affordable intervention services. Strengthening public awareness initiatives and culturally responsive support programmes may further reduce stigma and improve access to care for families of children with ASD.

DECLARATION OF STATEMENT

The authors declare that this manuscript is the author's original work, and the manuscript has not been published before this and is not under consideration for publication elsewhere.

AUTHOR CONTRIBUTIONS

SSE conceived the study, designed the methodology, prepared the ethical documents, collected and analysed the data, and drafted the manuscript. ZSM supervised the study, provided guidance throughout the research process, ensured ethical rigor, and contributed to the manuscript's review and refinement. Both authors read and approved the final manuscript.

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CONFLICT OF INTEREST STATEMENT

The authors declare no conflicts of interest.

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