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Parents' Experiences of Occupational Therapy for Children with Autism Spectrum Disorder

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Abstract
Parents play a vital role in shaping occupational therapy (OT) outcomes for children with autism spectrum disorder (ASD), yet their experiences remain underexplored. This qualitative study at WQ Park Health and Rehabilitation Centre used Interpretative Phenomenological Analysis (IPA) to investigate parental perspectives. Semi-structured interviews with ten parents of children with mild ASD revealed three key themes: balancing hopes with therapy realities, fostering trust and collaboration with therapists, and overcoming systemic barriers such as cost and accessibility. Findings emphasize the importance of family-centered, collaborative OT practices that empower parents, enhance understanding, and ensure continuity of care beyond child-focused outcomes.

Keywords: Autism spectrum disorder, occupational therapy, parental perspectives, interpretative phenomenological analysis.

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1.0 Introduction

Autism spectrum disorder (ASD) is a neurodevelopmental condition characterized by persistent difficulties in social communication, restricted interests, and repetitive behaviors (American Psychiatric Association [APA], 2013). The Diagnostic and Statistical Manual of Mental Disorders (DSM-5) classifies ASD into three severity levels—mild, moderate, and severe—which guide healthcare professionals in tailoring appropriate interventions (APA, 2013). Globally, the prevalence of ASD has been steadily increasing. The U.S. Centers for Disease Control and Prevention (CDC) reported that as of 2022, approximately 1 in 54 children were diagnosed with ASD, reflecting a significant rise compared to previous decades (Maenner et al., 2022). Early diagnosis and structured interventions, including occupational therapy (OT), are essential to support functional independence, participation, and quality of life for children with ASD and their families (Case-Smith & Arbesman, 2008; Barton et al., 2014).

In Malaysia, early prevalence studies estimated ASD at 1–2 per 1,000 children aged 18 months to 3 years (Ministry of Health Malaysia, 2005), while smaller studies reported rates of 1 in 625 to 1.6 per 1,000 among toddlers aged 18–26 months (Rasalam et al., 2014). By 2014, approximately 47,000 Malaysians were reported to be living with ASD, with numbers rising at an estimated 3% annually (Bernama, 2014). More recently, government records indicate that the number of children registered with the Department of Social Welfare (JKM) increased from 6,991 in 2013 to 53,323 in 2023, a 663% increase (Parliamentary Reply, 2023). The prevalence of Autism Spectrum Disorder (ASD) among school-age children in Malaysia from 2018 to 2022, expressed per 1,000 children, shows a consistent upward trend across age groups, as shown in Table 1. A national analysis of school records revealed that overall prevalence among 5–17-year-olds increased from 6.34 per 1,000 in 2018 to 9.29 per 1,000 in 2022, with the preschool subgroup (5–6 years) rising from 4.44 to 5.95 per 1,000 during the same period (Shair et al., 2024). The primary school group (7–12 years) recorded the steepest increase, from 8.46 to 13.13 per 1,000, while the secondary group (13–17 years) showed a more modest rise, from 3.81 to 5.01 per 1,000. Although data for younger preschoolers (3–4 years) remain limited, current evidence indicates steady growth in ASD recognition and service needs across Malaysia. While prevalence statistics illustrate the rising demand for services, far less is known about the lived experiences of parents navigating occupational therapy for children with ASD. Parents play a crucial role in sustaining therapy progress, ensuring continuity at home, and advocating for their children within educational and healthcare systems (Karst & Van Hecke, 2012). However, in Malaysia, their perspectives remain underexplored—particularly for preschool-aged children (3–6 years old), when early intervention is most impactful. This study aims to explore parents' experiences in occupational therapy for children with ASD, focusing on their role in supporting children's progress and family well-being.

Table 1. Prevalence of ASD Among Malaysian Children (2018–2022)

Year	Preschool (5-6 yrs)	Primary (7-12 yrs)	Secondary (13-17yrs)	Overall (5-17 yrs)
2018	4.44	8.46	3.81	6.34
2019	4.51	9.40	3.99	6.87
2020	5.28	10.26	4.49	7.65
2021	5.72	11.22	4.66	8.18
2022	5.95	13.13	5.01	9.29

Source : Data adapted from Shair et al. (2024)

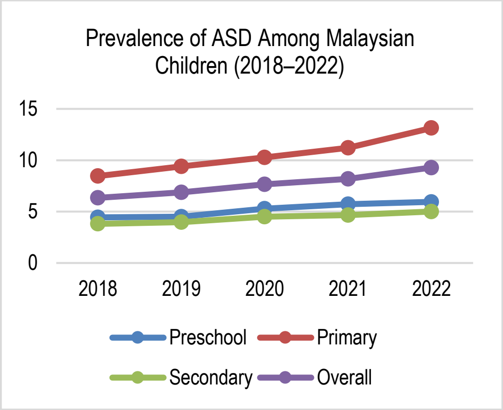

Fig.1 : Prevalence of ASD Among Malaysian Children (2018–2022)

2.0 Literature Review

Occupational therapy (OT) is a core intervention for children with Autism Spectrum Disorder (ASD), targeting self-care, play, sensory regulation, and school readiness (Case-Smith & Arbesman, 2008; Barton et al., 2014). Early and individualized OT interventions can enhance children's independence, communication, and engagement in daily routines. Given the heterogeneity of ASD, OT often combines sensory integration, behavioral strategies, and parent education, ensuring meaningful participation across home, school, and community contexts. The Occupational Therapy Practice Framework (OTPF-4) emphasizes a holistic approach, considering occupation, client factors, performance skills, performance patterns, and context in planning therapy. Parents play a central role in the success of OT, as their active involvement reinforces strategies in everyday life and enhances therapeutic outcomes (Karst & Van Hecke, 2012). Beyond caregiving, parents advocate for their child within healthcare and educational systems, coordinating services and navigating access to resources. When parents feel informed, guided, and supported by therapists, they demonstrate greater confidence and sustain their child's engagement in therapy (Brookman-Frazee et al., 2006). Active parental involvement not only improves children's functional skills but also contributes to enhanced family quality of life, reducing stress and promoting well-being.

Parental expectations and experiences are shaped by observing their child's progress and responding to developmental transitions (Smart et al., 2019). Expectations may be specific, such as improving communication, eating, or self-care, or broader, including behavioral regulation or overall well-being (Green, 2007). Satisfaction with OT is closely linked to whether parents perceive meaningful progress aligned with their hopes and the quality of collaboration with therapists (Schultz et al., 2011). Understanding parents' lived experiences provides critical insights into how therapy affects both children's development and family quality of life. In this study, the age group of 3 to 6 years was selected because it represents a critical developmental stage in which early intervention can have the most significant impact on cognitive, social, and functional outcomes. During this preschool period, children experience rapid growth in communication, play, and self-care skills, and neuroplasticity allows for optimal responsiveness to therapeutic input (National Institute of Child Health and Human Development [NICHD], 2024). Evidence suggests that initiating occupational therapy before school entry enhances adaptive behavior and long-term participation outcomes (Devescovi et al., 2023).

Quality of life (QoL) is an important consideration in occupational therapy for children with ASD, as therapy outcomes extend beyond skill acquisition to include family well-being and participation in meaningful daily routines. Although QoL is not directly measured in the present study, it is explored through parents' narratives, focusing on how therapy influences their child's functioning and overall family well-being. This approach aligns with qualitative research principles emphasizing meaning-making and subjective interpretation rather than numerical measurement (Smith et al., 2009). Previous research has emphasized that children's occupational performance is closely linked to the quality of life experienced by both the child and family (Nakai et al., 2021). Moreover, several QoL frameworks highlight the interconnection between child functioning, parental stress, and family adaptation within ASD contexts (Ghanouni et al., 2022; McStay et al., 2014).

Future studies may consider incorporating standardized QoL instruments to complement qualitative findings with measurable outcomes.While research in Malaysia has primarily focused on ASD prevalence, diagnosis, and intervention efficacy, few studies have explored parents' lived experiences and satisfaction with OT in relation to quality of life (Ministry of Health Malaysia, 2005; Shair et al., 2024). The present study addresses this gap by investigating parents' perspectives on OT for children with mild ASD using Interpretative Phenomenological Analysis (IPA), highlighting how therapy influences both child development and family quality of life. Core themes include navigating hopes and realities, building trust and collaboration with therapists, and overcoming systemic barriers, offering insights to guide family-centered practices that enhance overall well-being.

3.0 Methodology

This qualitative study employed Interpretative Phenomenological Analysis (IPA) to explore parents' lived experiences with occupational therapy (OT) for children with mild Autism Spectrum Disorder (ASD). IPA was chosen for its ability to provide in-depth insights into how individuals make sense of personal experiences (Smith, Flowers, & Larkin, 2009).

3.1 Participants and Sampling

The study included ten parents of children aged 3–6 years with mild ASD who had received consistent occupational therapy (OT) at WQ Park Health and Rehabilitation Centre, a one-stop health and rehabilitation center where approximately 80% of pediatric patients are diagnosed with ASD. Consistent with Braun and Clarke's (2013) guidelines for small-scale qualitative studies, a sample size of 6–10 participants were considered appropriate for IPA to allow detailed, case-by-case exploration. Participants were recruited through purposive sampling, enabling the researcher to select parents most likely to provide rich and relevant insights aligned with the study's objectives (Kumar, 2014). Eligibility was determined based on predefined inclusion and exclusion criteria (see Table 2).

Table 2. Inclusion and Exclusion Criteria

Inclusion Criteria	Exclusion Criteria
Parents of children aged 3-6 years old who have been diagnosed with Mild Autism Spectrum Disorder	Parents of children who have mental health problems such as anxiety disorders, depression, bipolar disorder, personality disorder, and schizophrenia.
Children with ASD who received consistent Occupational Therapy intervention for a minimum of 1 to 2 months	Children with ASD who come for assessment but have no follow-up for an intervention session.
Parents who understand and can speak in Malay and English	Parents who are not willing to participate in this study

3.2 Data Collection

Semi-structured interviews, each lasting approximately 45 minutes, were conducted to explore parents' expectations, lived experiences, and perceived impact of OT on both child development and family quality of life (Karst & Van Hecke, 2012). Interviews continued until thematic saturation was achieved (Guest, Bunce, & Johnson, 2006). All interviews were audio-recorded and later transcribed verbatim.

3.3 Data Analysis

The interview transcripts were analyzed using IPA procedures, following the step-by-step process outlined by Smith, Flowers, and Larkin (2009). This approach enabled the identification of emergent themes both within and across participants, allowing nuanced interpretations of parental perspectives.

3.4 Trustworthiness and Rigor

To enhance the credibility and trustworthiness of the findings, member checking and investigator triangulation were employed to ensure interpretations were grounded in participants' accounts. Member checking involved sharing key themes with participants for verification, while triangulation compared data across participants and integrated field notes and literature to strengthen study rigor (Lincoln & Guba, 1985).

4.0 Findings

This study explored parents' lived experiences regarding their expectations for occupational therapy (OT) for children with mild autism. A total of ten parents participated, sharing their personal perspectives, challenges, and reflections on their child's therapy journey. Through Interpretative Phenomenological Analysis (IPA), three main themes emerged, each capturing how parents made sense of OT in relation to their child's development, family well-being, and overall quality of life. The main themes and sub-themes are summarized in Table 3.

Table 3. Main themes and sub-themes emerged from the findings from this study.

Main Theme	Sub-themes
Navigating Hopes and Realities in Therapy Journeys	Aspirations for Growth and Future Confronting Challenges of Stigma and Uncertainty Reconciling Expectations with Acceptance
Building Trust and Collaboration in Parent–Therapist Relationships	Collaboration and Educational Role of Professionals Trust and Relational Support
Systemic and Logistical Barriers to Access and Continuity of Care	Access and System Navigation Personal and Temporal Constraints

4.1 Main Theme 1: Navigating Hopes and Realities in Therapy Journeys

The first theme reflects parents' aspirations for their children's growth and independence while also confronting stigma, uncertainty, and the emotional adjustment process. These experiences significantly shaped parents' psychological well-being and influenced their perception of the quality of their family life.

4.1.1. Subtheme- Aspirations for Growth and Future

Parents in this study shared their experiences of entering occupational therapy with high hopes for their children's growth and independence. Many viewed therapies as a way to improve functional skills, reduce their caregiving burden, and enhance family routines. This aspiration for progress was strongly tied to their quality of life, as achieving even small milestones provided hope and relief. One parent shared, *"I hope after a few months of therapy, my son can take care of himself, like dressing and eating properly without me helping all the time."* Such expectations reflected parents' desire for their children's autonomy, which, in turn, would allow families to experience greater balance and reduced stress in their daily lives.

4.1.2 Subtheme- Confronting Challenges of Stigma and Uncertainty

Alongside these aspirations, parents also confronted stigma and uncertainty about the future. Concerns about whether their children would be accepted at school or in society weighed heavily on their emotional well-being, often lowering their psychological quality of life. As one parent explained, *"Sometimes I worry… will he be able to go to school like other kids? What if people label him?"* These anxieties underscore how societal perceptions and external judgments profoundly impact parents' experiences, intensifying the pressure on their caregiving journey.

4.1.3 Subtheme- Reconciling Expectations with Acceptance

Over time, many parents described a process of reconciling initial expectations with acceptance of their child's unique developmental pace. This shift, although emotionally challenging, was a crucial step toward building resilience and enhancing quality of life. One parent expressed, *"At first, I expected fast progress, but slowly I learned to accept that he has his own pace. I cannot compare him with others."* Learning to adjust their perspectives allowed parents to manage frustrations more effectively, nurture patience, and foster more positive family dynamics. This acceptance reduced emotional strain and contributed to long-term psychological well-being.

4.2 Main Theme 2: Building Trust and Collaboration in Parent–Therapist Relationships

The second theme, "Building Trust and Collaboration in Parent–Therapist Relationships," emphasizes the crucial role of professional support in fostering confidence, alleviating parental stress, and empowering families. Collaborative and trusting relationships contributed positively to parents' sense of control and emotional stability, thereby enhancing their quality of life.

4.2.1 Subtheme- Collaboration and Educational Role of Professionals

Parents emphasized the central role of therapists in shaping their experiences of occupational therapy. Many valued the collaborative and educational role that professionals played, describing therapy not only as an intervention for their child but also as a source of guidance and reassurance for themselves. This collaboration enhanced their confidence, reduced feelings of helplessness, and contributed positively to their overall psychological and social well-being. One parent explained, "*The therapist can guide us, because sometimes we really do not know whether what we do at home is right or wrong."* Such guidance helped parents feel more competent in supporting their child, fostering empowerment, and lowering daily stress.

4.2.2 Subtheme- Trust and Relational Support

Trust and relational support also emerged as a vital component of parents' satisfaction. Parents highlighted how empathy, consistent communication, and emotional encouragement from therapists created a safe and supportive environment. This trust reduced anxiety, promoted engagement, and strengthened parents' sense of partnership in their child's journey. As one parent shared, *"I feel comfortable because the therapist always listens and explains patiently. It makes me trust that we are in good hands"*. Establishing this sense of trust not only improved the therapeutic alliance but also had a broader impact on parents' emotional stability and family well-being. Therapy became a shared journey rather than an individual burden, easing the pressures of caregiving and reinforcing a more positive outlook on life. Another parent reflected, *"When the therapist involves me, I feel like we are working together, not just me struggling."*

4.3 Main Theme 3: Systemic and Logistical Barriers to Access and Continuity of Care

The third theme, "Systemic and Logistical Barriers to Access and Continuity of Care," highlights the external constraints that families encounter, including healthcare navigation, financial strain, and time constraints. These challenges directly affected parents' environmental and social quality of life, often reducing the consistency of therapy and creating stress in daily routines.

4.3.1 Subtheme- Access and System Navigation

While parents recognized the benefits of occupational therapy, they also described significant systemic and logistical barriers that disrupted continuity of care. Access to services was often complicated by long waiting lists, high costs, and the need to navigate healthcare systems. These difficulties directly affected families' environmental quality of life, as financial strain and administrative challenges added to their stress. One parent explained, *“Sometimes the waiting list is so long. By the time we get the slot, my child has already lost the routine.”* Such interruptions not only delayed progress but also diminished parents’ sense of stability and control.

4.3.2 Subtheme- Personal and Temporal Constraints

Personal and temporal constraints were also frequently mentioned, as many parents struggled to balance therapy schedules with work responsibilities, other family needs, and commuting times. This balancing act often left them feeling overwhelmed and fatigued. As one parent shared, *“It is very hard to manage… I need to take leave from work, rush for therapy, then take care of the other kids. Sometimes I feel exhausted.”* These challenges, combined with systemic limitations, reduced psychological well-being as parents worried about their child’s missed opportunities for progress. However, many parents demonstrated resilience by seeking alternative strategies at home, reflecting their commitment to sustaining their child’s development even under challenging circumstances. As one parent expressed, *“If I can’t bring him to therapy, I try my best to do the activities at home, because I don’t want him to miss out.”*

5.0 Discussion

5.1 Navigating Hopes and Realities in Therapy Journeys

Parents in this study entered occupational therapy with strong hopes for their children’s independence, social participation, and school readiness. These aspirations align with previous studies, which have shown that parents of children with autism often prioritize functional skills such as communication, daily living, and peer interaction (Lau et al., 2012; Whitaker, 2019). Such expectations are tied to parents’ own quality of life, as progress in these areas reduces caregiving stress and offers hope for greater family balance. At the same time, parents described fears about stigma and uncertainty regarding their child’s future. This reflects findings by Kuhlthau et al. (2014), who noted that stigma contributes significantly to parental stress and lowers psychological well-being. Concerns about labelling and inclusion highlight the social domain of QoL, where external perceptions shape families’ experiences and opportunities. Over time, many parents reported shifting from unrealistic expectations to greater acceptance of their child’s developmental pace. This process aligns with research on parental adaptation and resilience, where acceptance is associated with improved psychological adjustment and family functioning (Luque Salas et al., 2017). In this study, acceptance allowed parents to reduce frustration, develop patience, and strengthen family relationships — factors that support a more sustainable quality of life.

5.2 Building Trust and Collaboration in Parent–Therapist Relationships

Parents in this study emphasized the importance of trust and collaboration with therapists, describing professionals as educators, guides, and emotional supports. This reflects the principles of family-centered practice, which highlight partnership and shared decision-making as critical for effective interventions (Dunst & Espe-Sherwindt, 2016). When therapists provided clear guidance and consistent communication, parents reported increased confidence in their caregiving role and a stress reduction, thereby enhancing both the psychological and social aspects of their quality of life. The findings align with previous studies, which have demonstrated that therapeutic alliances promote parental empowerment and enhance satisfaction with services (Basu et al., 2015). Trust in professionals not only facilitated parents’ engagement in therapy but also created a sense of emotional safety, which contributed to their overall well-being.

5.3 *Systemic and Logistical Barriers to Access and Continuity of Care*

Parents in this study reported that systemic barriers such as long waiting lists, high therapy costs, and fragmented service pathways disrupted their child’s continuity of care. These challenges mirror findings from global and local research, which highlight inequities in access to autism services and the financial strain on families (McConachie & Robinson, 2016). Such barriers reduced parents' quality of life by creating stress, uncertainty, and frustration in navigating the healthcare system. In addition, personal and temporal constraints, such as juggling work commitments and family responsibilities, often left parents feeling exhausted and overwhelmed. This resonates with Kuhlthau et al. (2014), who reported that the time demands of managing therapy schedules negatively impact parents’ psychological well-being and family routines. Despite these barriers, many parents demonstrated resilience by adapting therapy strategies at home, which reflects findings by Simpson et al. (2018) on parental resourcefulness in sustaining child development. However, the persistence of systemic and logistical obstacles underscores the need for more accessible, affordable, and family-centered service delivery models.

5.4 Implications for Practice and Policy

This study highlights the importance of adopting a family-centered approach in occupational therapy, where parents are actively involved in goal setting, provided with clear guidance, and supported through consistent collaboration with therapists. Strengthening trust and communication can reduce stress and empower parents in their caregiving role, while practical training and home-based strategies help sustain progress beyond therapy sessions. At the policy level, reducing waiting times, improving affordability, and enhancing service coordination are essential for continuity of care. Flexible approaches such as telehealth and parent education programs can further alleviate logistical challenges. Addressing both clinical and systemic needs allows occupational therapy to enhance children's functional outcomes and improve families' overall quality of life. Understanding parents' experiences is vital, as they play a central role in implementing and sustaining interventions for children with ASD. Research shows that parental satisfaction is closely linked to perceptions of their child's developmental progress (Ong et al., 2019) and that mothers and fathers experience the impact of ASD differently depending on the child's adaptive skills and behaviors (Pereira et al., 2021). Exploring these experiences enables therapists to refine family-centered practices that promote both child development and family well-being.

6.0 Conclusion & Recommendations

This study highlighted that parents of children with mild autism perceive occupational therapy as a process of balancing hopes, building trust with therapists, and overcoming systemic barriers, all of which influence their family's quality of life. The findings suggest that strengthening family-centered practices, fostering collaborative parent–therapist relationships, improving the accessibility and continuity of care, and providing home-based strategies to support parental well-being can enhance therapeutic outcomes. However, this study has several limitations. As an Interpretative Phenomenological Analysis (IPA), the findings reflect the subjective interpretations of a small group of parents and cannot be generalized to all families of children with ASD. The interpretative process may introduce researcher bias despite efforts to maintain reflexivity and credibility through member checking and triangulation. Participants were also recruited from a single center, which limits cultural diversity. Future research should therefore include larger and more varied samples, examine long-term changes in parental expectations and satisfaction, and explore cross-cultural perspectives to inform more inclusive, sustainable, and family-centered occupational therapy practices.

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Paper Contribution to the Related Field of Study

This paper makes a significant contribution to the field by revealing how parents experience occupational therapy for children with mild ASD, linking therapy outcomes to family quality of life, and informing strategies for more effective, family-centered interventions.

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