

Occupational Balance and Caregiver Burden among Parents of Children with Autism Spectrum Disorder

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Abstract

This study explores occupational balance (OB) and caregiver burden among parents of children with Autism Spectrum Disorder (ASD) in Malaysia. A cross-sectional survey of 89 parents from the National Autism Society of Malaysia (NASOM) centres used the Zarit Burden Interview and Occupational Balance Questionnaire. Results showed significant demographic variations, with Malay parents reporting higher burden scores. However, no significant correlation was found between OB and caregiver burden. Findings emphasize the need for culturally sensitive support systems to alleviate caregiving stress. Future research should explore longitudinal and intervention-based studies to enhance parental well-being through targeted support programs and community initiatives.

Keywords: Autism Spectrum Disorder; occupational balance; caregiver burden: family support

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1.0 Introduction

Autism Spectrum Disorder (ASD) is a neurodevelopmental condition characterized by challenges in communication, social interactions, and repetitive behaviors. It affects individuals across all racial, ethnic, and socioeconomic backgrounds (Centers for Disease Control and Prevention, 2022). In Malaysia, ASD diagnoses have steadily increased over the past decade. The Malaysia Ministry of Health (MOH) reported a 5% rise in diagnosed cases in 2021, totalling 589 children aged 18 and below (CodeBlue, 2020).

Caring for children with ASD requires significant time, effort, and financial resources, leading to increased parental burden. The intensive and long-term nature of caregiving often results in physical and emotional exhaustion. As a result, many parents struggle to maintain occupational balance (OB), which is crucial for overall well-being.

OB is traditionally defined as a balance between work, play, rest, and sleep, but it now encompasses broader aspects of daily life. Research indicates that parents of children with disabilities report significantly lower OB levels than those with typically developing children (Dhas, 2021). The high demands of caregiving contribute to occupational imbalance, as parents often make personal sacrifices to meet their child's needs. Although caregiving is a fundamental parental role, the intensive care required for a child with ASD can negatively impact caregivers' physical and mental health. There is currently no study in Malaysia examining the impact of caregiving for children with ASD within the country's cultural and socioeconomic context. This study aims to investigate the level of OB among parents of children with ASD and its relationship with caregiver burden, addressing this critical research gap. The specific objectives of the study

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are: i) to examine the levels of occupational balance and caregiver burden among parents of children with Autism Spectrum Disorder (ASD) in Malaysia. ii) to analyze the relationship between occupational balance and caregiver burden, including the influence of demographic factors

2.0 Literature Review

Children with ASD frequently exhibit behavioral challenges, including meltdowns, frustration, and difficulty meeting daily demands. In addition, parental stress is often linked to their child's disruptive behaviors. Studies indicate that children with lower IQs exhibit higher levels of stereotyped behavior, aggression, and self-injury, further increasing caregiver stress. In addition to emotional strain, parents of children with ASD face financial burdens. Specialist treatments, therapies, and resources add to their economic stress. Research by Kamaralzaman et al. (2018) revealed that families of children with ASD in Malaysia spend an average of RM35,365.62 annually, making the financial strain significantly higher than for families with typically developing children. These expenses, including out-of-pocket therapy costs, often result in additional physical and emotional stress.

Parenting a child with ASD also presents emotional challenges, as many parents experience heightened levels of anxiety and depression, particularly those with limited social support. Over time, the emotional toll deepens due to the ongoing care demands, leading to significant psychological distress. Furthermore, parents of children with ASD report higher stress levels than those with other developmental disabilities (Solaiman et al., 2023). The physical toll of caregiving is another major concern. The demands of daily caregiving contribute to parental fatigue, in which most parents do not report severe physical symptoms, and many experience chronic fatigue Patel et al. (2022). Eng et al. (2024) further highlighted that caregivers often prioritize their children's needs over their own, neglecting self-care, which exacerbates exhaustion.

Social isolation is another challenge, as parents of children with ASD often feel disconnected from their friends, family, and broader social networks. The stigma surrounding autism, combined with the demands of caregiving, limits social interactions. Many caregivers struggle to access social support, leading to feelings of loneliness and stress. Additionally, safety concerns related to aggressive behaviors further contribute to parental withdrawal.

Occupational balance (OB) refers to the equilibrium between work, household responsibilities, leisure, and rest. Moreover, it is important in maintaining well-being. However, parents of children with special needs often experience disruptions in OB (Dhas et al., 2023). Caregiving responsibilities limit parents' free time and engagement in other activities. Mothers, in particular, face challenges in maintaining OB due to caregiving demands, social stigma, and the need for constant supervision of their children (Dhas et al., 2023). Ultimately, caregiving burdens contribute significantly to disruptions in OB, making it difficult for parents of children with disabilities to achieve balance (Dhas et al., 2023).

Limited studies have explored the relationship between caregiver burden and occupational balance among parents of children with ASD in Malaysia. Most existing research focuses on Western contexts and examines these concepts separately. This study addresses the gap by investigating both variables and their demographic influences within a local cultural context.

3.0 Methodology

This study employed a cross-sectional research design and was conducted at four branches of the National Autism Society of Malaysia (NASOM) in Puncak Alam, Gombak, Titiwangsa, and Pulau. The target sample size was 105, but out of 126 distributed questionnaires, only 103 were returned. Seven were incomplete, four involved parents with more than one child with special needs, and three had children older than 11 years. As a result, 89 respondents were eligible for analysis.

Purposive sampling was used, targeting parents of children with ASD. Participants completed a 19-item history and demographic questionnaire covering factors such as the severity of their child's ASD, age, gender, presence of other special needs or chronic conditions, parental demographics (age, marital status, race, education, income), and availability of a secondary caregiver (e.g., grandparents or a maid).

Caregiver burden was assessed using the Zarit Burden Interview (ZBI) (Domínguez-Vergara, Santa-Cruz-Espinoza, & Chávez-Ventura, 2023), while the occupational balance (OB) was measured with the Occupational Balance Questionnaire (OBQ), which evaluates individuals' experiences with various daily activities (Håkansson, Wagman, & Hagell, 2020).

The study received ethical approval from UiTM's Research Ethics Committee (REC) in June 2024 (FERC/FSK/MR/2024/00232). Data collection took place from July to August 2024. Before distributing the questionnaires, permission was obtained from NASOM centres, and parents were given four weeks to complete them. Centre management assisted in distributing the booklets, and the researcher collected and compiled the responses. Data were analyzed using SPSS version 27.0.

4.0 Findings

The study involved 89 parents of children with Autism Spectrum Disorder (ASD) who were categorized according to age, relationship status, race, marital status, education level, and family income. Most participants were mothers aged 31–40, identified as Malay, were married, had tertiary-level education, and came from middle-income households (Table 1).

Table 1. Sociodemographic data of the parents of children with ASD (n = 89)

Variable	Frequency (n)	Percentage (%)
Age		
21-30	9	10.1
31-40	56	62.7
41-50	24	27.0
Relationship Status		
Father	18	20.2
Mother	71	79.8
Race		
Malay	72	80.9
Non-Malay	17	19.1
Marital status		
Married	81	91.0
Separated	8	9.0
Education Level		
Primary	0	0.0
Secondary	12	13.5
Tertiary	77	86.5
Family income		
B40	26	29.2
M40	38	42.7
T20	25	28.1

A one-way ANOVA examined differences in caregiver burden and occupational balance (OB) among three age groups: 21–30, 31–40, and 41–50 years (Table 2 and Table 3). Although the 41–50-year group recorded the highest average caregiver burden (mean = 34.83, SD = 9.75) compared to the 21–30 (mean = 30.67, SD = 11.50) and 31–40 groups (mean = 29.45, SD = 13.66), the differences were not statistically significant ($F(2, 86) = 1.56, p = 0.271, \eta^2 = 0.035$). Similarly, no significant differences in OB were observed across age groups ($F(2, 86) = 0.65, p = 0.527, \eta^2 = 0.015$), even though the oldest group also showed a slightly higher OB (mean = 34.83, SD = 9.75) compared to younger groups (21–30 years: mean = 28.22, SD = 5.63; 31–40 years: mean = 28.66, SD = 4.38).

The analysis comparing relationship status used an independent t-test to evaluate differences between mothers and fathers (Table 2 and Table 3). Mothers (n = 71, 79.8%) reported a marginally higher caregiver burden (mean = 31.81, SD = 13.17) than fathers (n = 18, 20.2%; mean = 30.39, SD = 10.44), but this difference was not statistically significant ($p = 0.813$; 95% CI: -7.44 to 5.86). For OB, mothers scored slightly higher (mean = 29.27, SD = 4.42) than fathers (mean = 27.50, SD = 3.87); however, this difference also failed to reach statistical significance ($p = 0.125$; 95% CI: -4.03 to 0.50). Thus, both mothers and fathers experience comparable levels of caregiver burden and OB.

Regarding racial background, the study found significant differences in caregiver burden based on race (Table 2 and Table 3). Malay parents (n = 72, 80.9%) experienced a significantly higher caregiver burden (mean = 32.50, SD = 11.92) compared to non-Malay parents (n = 17, 19.1%; mean = 24.76, SD = 13.90), with the difference achieving statistical significance ($p = 0.022$; 95% CI: 1.14 to 14.33). In contrast, OB scores were nearly identical between Malay (mean = 28.93, SD = 4.13) and non-Malay parents (mean = 28.82, SD = 5.34), showing no significant difference ($p = 0.928$; 95% CI: -2.24 to 2.40).

The effect of marital status was also assessed (Table 2 and Table 3). Married parents (n = 81, 91.0%) showed a slightly lower caregiver burden (mean = 30.98, SD = 12.68) than separated parents (n = 8, 9.0%; mean = 31.05, SD = 12.74); however, the difference was not statistically significant ($p = 0.911$; 95% CI: -9.87 to 8.82). Similarly, married parents had marginally lower OB scores (mean = 28.86, SD = 4.46) compared to separated parents (mean = 29.38, SD = 3.29), with the difference remaining insignificant ($p = 0.753$; 95% CI: -3.73 to 2.71). Therefore, marital status does not significantly influence caregiver burden or OB.

When comparing education levels (Table 2 and Table 3), parents with tertiary education (n = 12, 13.5%) reported slightly higher caregiver burden (mean = 31.39, SD = 12.26) than those with secondary education (n = 77, 86.5%; mean = 28.65, SD = 15.05), though this difference was not statistically significant ($p = 0.490$; 95% CI: -10.53 to 5.08). For OB, parents with tertiary education also showed higher scores (mean = 29.22, SD = 4.07) than those with secondary education (mean = 26.92, SD = 5.66), but again, the difference was not significant ($p = 0.088$; 95% CI: -4.96 to 0.35). This suggests that although there is a tendency for higher education to be associated with better occupational balance, the differences are not definitive.

Family income, analyzed using one-way ANOVA, did not significantly affect caregiver burden or OB (Table 2 and 3). Parents in the T20 group (n = 25, 28.1%) reported slightly lower caregiver burden (mean = 29.20, SD = 9.35) and marginally higher OB (mean = 30.24, SD = 4.18) compared to the B40 (n = 26, 29.2%; burden mean = 30.35, SD = 13.53; OB mean = 28.15, SD = 4.18) and M40 groups (n = 38, 42.7%; burden mean = 32.68, SD = 13.87; OB mean = 28.55, SD = 4.18), with differences failing to reach significance (burden: $F(2, 86) = 0.63, p = 0.536, \eta^2 = 0.014$; OB: $F(2, 86) = 1.72, p = 0.186, \eta^2 = 0.038$).

Finally, a Pearson correlation analysis between caregiver burden and OB revealed a slight negative correlation ($r = -0.305$), indicating that as caregiver burden increases, the occupational balance might decrease. However, this relationship was not statistically significant ($p = 0.205$), suggesting that the observed association may be attributable to random variation rather than a true underlying link.

Table 2. Caregiver burden among parents of children with ASD (n=89)

Category	Subgroups	Mean (SD)	Statistical Test	p-value
Age Group	21-30 years old (n=9)	30.67 (11.50)	$F(2,86) = 1.56$	0.217

	31-40 years old (n=56)	29.45 (13.66)		
	41-50 years old (n=24)	34.83 (9.75)		
Relationship Status	Mother (n = 18)	30.39 (10.44)	t(87) = -0.237	0.813
	Father (n = 71)	31.81 (13.17)		
Racial Status	Malay (n = 72)	32.50 (11.92)	t(87) = 2.33	0.022*
	Non-Malay (n = 17)	24.76 (13.90)		
Marital Status	Married (n=81)	30.98 (12.68)	t(87) = -0.11	0.911
	Separated (n=8)	31.50 (12.74)		
Education Level	Secondary Level (n=12)	28.67 (15.05)	t(87) = -0.70	0.490
	Tertiary Level (n=77)	31.39 (12.26)		
Family Income	B40 (n=26)	30.35 (13.53)	F(2,86) = 0.63	0.536
	M40 (n=38)	32.68 (13.87)		
	T20 (n=25)	29.20 (9.35)		

Note: * indicate significant figures

Table 3. Occupational balance among parents of children with ASD (n=89)

Category	Subgroups	Mean (SD)	Statistical Test	p-value
Age Group	21-30 years old (n=9)	28.22 (5.63)	F(2,86) = 0.65	0.527
	31-40 years old (n=56)	28.66 (4.38)		
	41-50 years old (n=24)	29.75 (3.81)		
Relationship Status	Mother (n = 18)	27.50 (3.87)	t(87) = -1.551	0.125
	Father (n = 71)	29.27 (4.42)		
Racial Status	Malay (n = 72)	28.93 (4.13)	t(87) = 0.09	0.928
	Non-Malay (n = 17)	28.82 (5.34)		
Marital Status	Married (n=81)	28.86 (4.46)	t(87) = -0.32	0.753
	Separated (n=8)	29.38 (3.29)		
Education Level	Secondary Level (n=12)	26.92 (5.66)	t(87) = -1.73	0.088
	Tertiary Level (n=77)	29.22 (4.07)		
Family Income	B40 (n=26)	28.15 (4.81)	F(2,86) = 1.72	0.186
	M40 (n=38)	28.55 (4.18)		
	T20 (n=25)	30.24 (3.96)		

5.0 Discussion

This study found that parents aged 41–50 reported the highest caregiver burden, which may be due to the cumulative effects of prolonged caregiving. However, despite experiencing increased strain, this group also demonstrated slightly higher OB scores than younger parents. This suggests that older caregivers might have developed better strategies for managing daily responsibilities, allowing them to maintain some level of balance despite their challenges. Azubuike et al. (2024) similarly reported that caregivers aged 36 years and above experienced a high caregiver burden, but the difference in OB levels across age groups was not significant. Declining energy and resilience in older parents make caregiving tasks, such as managing difficult behaviors and providing physical support, more demanding over time. Meanwhile, Musa (2022) highlighted that younger parents, though more physically capable, often sacrifice their occupational balance by reducing social interactions to accommodate their children's needs.

Mothers of children with ASD reported slightly higher caregiver burden than fathers, yet they also demonstrated slightly better OB scores. This finding suggests that, although caregiving responsibilities significantly impact both parents, mothers might develop adaptive strategies to manage daily routines effectively. Women experience higher levels of stress from caregiving, which negatively impacts their mental well-being. However, while burdened by caregiving, fathers struggle more with maintaining OB, as they must balance employment, financial obligations, and caregiving responsibilities. Van Niekerk et al. (2023) further emphasized that caregiver burden is prevalent among both parents. However, mothers, due to their primary caregiving role, tend to develop structured routines that support occupational balance better than fathers.

Malay parents reported a higher caregiver burden compared to non-Malay parents, which also correlated with lower OB scores. This disparity may be attributed to cultural expectations surrounding caregiving roles in Malay society, where strong familial obligations increase emotional and psychological stress. Subramaniam and Mehta (2024) emphasized that cultural and religious values shape caregiving experiences, influencing both burden levels and the ability to maintain occupational balance. Contrarily, Chan et al. (2022) found that Indian caregivers reported the highest caregiver burden, likely due to differing family support structures. Across ethnic groups, OB is affected by intergenerational expectations, with some cultures placing heavier demands on caregivers, reducing opportunities for self-care and work-life balance.

Single parents of children with ASD reported a higher caregiver burden and lower OB scores than married parents, primarily due to a lack of shared responsibilities. Sit and Erkan (2024) noted that single caregivers are more likely to experience burnout as they navigate parenting challenges alone. Meanwhile, married parents often receive spousal support, allowing them to maintain occupational balance and reduce stress (Dey & Amponsah, 2020). However, Cook (2021) highlighted that modern single mothers have become more financially independent and self-sufficient, leading to improved OB in some cases. In addition, single mothers of children with ASD were at risk for clinical depression, directly linked to their high caregiver burden and diminished occupational balance.

Parents with tertiary education reported slightly higher caregiver burden, yet they also had higher OB scores than those with lower education levels. This suggests that while well-educated parents face increased stress due to greater awareness of their child's needs, they are also better equipped to access resources and strategies that promote occupational balance (van Niekerk et al., 2023). Conversely, caregivers with lower education levels experienced a greater burden, particularly in financial and lifestyle domains, which

significantly impacted their OB. Given the mixed findings, further research is needed to clarify the relationship between education, caregiver burden, and occupational balance (Musa, 2022).

Families in the T20 (high-income) group reported a lower caregiver burden and higher OB scores compared to the B40 (low-income) and M40 (middle-income) groups. Financial resources play a crucial role in mitigating caregiver burden, as parents with higher incomes can afford specialized education, therapies, and additional support services (Chua et al., 2023). However, Azubuike et al. (2024) found that even high-income families experience financial strain due to the cumulative costs of ASD-related care. Moreover, financial challenges disproportionately affect low-income caregivers, leading to higher caregiver burden and reduced OB, as these parents often sacrifice personal and professional opportunities to manage expenses.

This study found a negative correlation between caregiver burden and OB, suggesting that as caregiver burden increases, occupational balance decreases. However, this relationship was not statistically significant, likely due to sample size limitations. No prior research has specifically examined this association, making these findings valuable for future studies exploring how caregivers can balance responsibilities while reducing stress. Despite experiencing higher caregiver burden, older parents demonstrated slightly better OB scores, indicating that experience and established routines contribute to better time management. Subramaniam and Mehta (2024) observed that, over time, caregivers develop resilience, which helps them manage their duties more effectively. However, despite this, all caregivers require continuous support to maintain occupational balance and alleviate stress.

Mothers reported higher OB scores than fathers, despite experiencing slightly higher caregiver burden. This suggests that while caregiving responsibilities are overwhelming, mothers may develop coping strategies that allow them to balance multiple roles (Uthede et al., 2023). Fathers, on the other hand, struggle with OB as they juggle caregiving with professional responsibilities. Mousavi (2020) emphasized that increasing paternal involvement in caregiving can improve OB for both parents, reducing maternal exhaustion and fostering a more balanced family dynamic.

Parents across different racial backgrounds demonstrated similar OB scores, likely due to shared coping strategies such as problem-solving, religion, and social support. Caregivers with strong spiritual beliefs often perceive their child's condition as a form of divine fate, fostering a sense of acceptance and improving occupational balance. Schoenmakers (2024) also noted that social support networks play a crucial role in helping caregivers maintain OB, even when their burden levels are high.

6.0 Conclusion & Recommendation

6.1 Conclusion

This study highlights the intertwined nature of caregiver burden and occupational balance among parents of children with ASD. Older parents, mothers, and those in lower-income groups experience higher caregiver burden, while factors such as education, financial resources, and coping strategies contribute to occupational balance. Cultural and societal expectations further influence stress levels and OB, shaping how caregivers manage their roles. Although no statistically significant correlation was found, the negative trend suggests that interventions aimed at improving occupational balance could help reduce caregiver burden. A key limitation of this study is the relatively small sample size ($n = 89$), which may affect the generalizability of the findings and limit the statistical power to detect significant relationships between variables. Future research should explore targeted strategies, particularly through occupational therapy, to support caregivers in achieving a healthier balance while alleviating stress.

6.2 Recommendation

Future studies should adopt a longitudinal approach, incorporate qualitative insights, include a control group of parents with typically developing children, and examine the impact of ASD severity, coping mechanisms, and workplace support on caregiver burden and occupational balance across diverse socioeconomic and cultural backgrounds.

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Paper Contribution to Related Field of Study

This study contributes to both Occupational Therapy and Psychology & Mental Health by examining how caregiver burden impacts occupational balance, providing insights into the emotional, psychological, and functional challenges faced by parents of children with ASD, which can help design targeted therapeutic interventions and coping strategies.

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