

PARENTAL CAREGIVING BURDEN IN RELATION TO AUTISM SPECTRUM DISORDER SEVERITY: PRELIMINARY EVIDENCE FROM BANGKOK, THAILAND

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ABSTRACT

This study investigated the association of autism symptom severity with parental caregiver burden in Bangkok, Thailand. A cross-sectional correlational study was conducted with 82 caregiver-child dyads. ASD severity was measured using the Thai Autism Treatment Evaluation Checklist (Thai-ATEC), and caregiver burden was assessed with the Thai Zarit Burden Interview (Thai-ZBI). Descriptive statistics and Spearman's rank correlations were applied. Caregivers were predominantly mothers (65.9%) with a mean age of 41.4 years. Children had a mean Thai-ATEC score of 58.8, with 26.8% classified as mild, 36.6% moderate, and 36.6% severe. The average Thai-ZBI score was 19.2, with 51.2% reporting minimal burden, 39.0% mild-to-moderate, and 9.8% moderate-to-severe. A significant positive correlation was observed between Thai-ATEC total and Thai-ZBI total scores ($\rho = 0.685$, $p < 0.01$). All ATEC subdomains were significantly correlated with ZBI dimensions, except sensory/cognitive awareness with privacy conflict. These preliminary findings suggest that greater ASD severity is linked to higher caregiver burden, highlighting the need for interventions that promote child development, self-help, and behavioral support, alongside measures to improve caregiver well-being.

Keywords: Autism Spectrum Disorder, ASD, Caregiver Burden, Severity, Thailand

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INTRODUCTION

Autism spectrum disorder (ASD) is a lifelong neurodevelopmental condition that affects communication, social interaction, and behavior (American Psychiatric Association, 2013). Global surveillance indicates that ASD prevalence has steadily increased, with recent estimates in the United States suggesting one in 36 children is affected (Maenner, 2023). In Thailand, national mental health statistics reported an incidence of 112.87 new diagnoses per 100,000 children, reflecting a sharp rise over the past decade (Jutha, 2025).

Children with ASD often experience developmental delays across multiple domains, limiting their ability to carry out daily tasks independently (Kodak & Bergmann, 2020). Higher symptom severity typically corresponds to greater functional challenges, requiring more intensive caregiver involvement (Chantratip et al., 2020). For those with severe ASD, extensive assistance in daily activities is often necessary, placing continuous demands on caregivers. Over time, these responsibilities can negatively affect caregivers' quality of life and contribute to fatigue and stress (Marsack-Topolewski et al., 2021).

Caregiver burden encompasses the cumulative physical, emotional, and psychological challenges that arise from providing sustained care to a dependent person (Zarit et al., 1980). Caregivers play a central role in ensuring children's health, development, and everyday participation (WHO, 2023). Parents and relatives commonly devote significant time, energy, and financial resources to support children with ASD, which can heighten physical strain, emotional stress, and economic difficulties (Vohra et al., 2014).

Although global research has consistently demonstrated that more severe ASD symptoms are associated with higher levels of caregiver burden, evidence from Thailand remains scarce. Most local studies have focused on children with general developmental delays or disabilities, leaving a gap in understanding the specific challenges of raising a child with ASD. Addressing this gap, the present study set out to investigate how the severity of autism symptoms, assessed using the Thai-ATEC, is related to parental caregiver burden, measured with the Thai-ZBI, among families in Bangkok. It was hypothesized that greater ASD symptom severity would be positively associated with higher levels of caregiver burden across multiple dimensions.

LITERATURE REVIEWS

Research across diverse contexts consistently demonstrates the multifaceted burden associated with caring for children with ASD. Patel et al. (Patel et al., 2022) in India and van Niekerk et al. (van Niekerk et al., 2023) in South Africa both reported that higher ASD severity was strongly linked to elevated caregiver burden and reduced quality of life, underscoring the universal challenges the families face. Similarly, Shrestha et al. (Shrestha et al., 2023) found that nearly half of caregivers in Nepal experienced a moderate-to-severe burden, particularly when children presented with greater symptom intensity.

Beyond prevalence estimates, regional studies have examined the mechanisms underlying caregiver strain. Chua et al. (Chua et al., 2023) in Singapore highlighted that behavioral difficulties and the core severity of ASD symptoms explained a significant proportion of caregiver burden variance, particularly when social support was limited. Kirby et al. (Kirby et al., 2015) further observed that sensory processing differences predicted both objective and emotional strain, though the association with privacy-related burden was weaker than with communication or behavioral difficulties. These findings emphasize that the dimensions of caregiver burden are not uniform but instead shaped by specific child symptom profiles.

Thai studies have also contributed to understanding caregiving challenges in developmental disorders. Chawasil and Thanamee (Chawasil & Thanamee, 2018) reported substantial caregiver strain among families of disabled children in rehabilitation settings, while Toonsiri et al. (Toonsiri et al., 2011) validated the Thai Zarit Burden Interview, providing a culturally appropriate tool for measuring caregiving impact. More recent work has shifted toward

identifying interventions: Sripanchat (Sripanchat, 2024) showed that promoting self-help skills in autistic children reduced caregiver burden, and Broworndat (Broworndat, 2020) emphasized that daily living skill training improved both child independence and caregiver well-being. Additionally, Singsathorn (Singsathorn, 2018) demonstrated that **behavioral intervention techniques** effectively reduced symptom severity, reflected in decreased ATEC scores. Together, these findings confirm that caregiver burden is closely tied to child functioning, especially in cases of severe ASD, and suggest that interventions targeting developmental and behavioral improvements can mitigate strain. However, despite international evidence and growing Thai research on developmental disabilities, empirical investigations directly linking ASD symptom severity to caregiver burden in Thailand remain limited. This study builds upon existing knowledge by applying validated tools, the Thai-ATEC for symptom severity and the Thai-ZBI for caregiver burden, to examine their relationship in the Bangkok context.

RESEARCH METHODOLOGY

This study employed a cross-sectional correlational design to examine the association between autism symptom severity and parental caregiver burden. Ethical approval was obtained from the Institutional Review Board of Mahidol University (COA No. MU-CIRB 2025/188.0506) and the Ethics Committee of the Queen Sirikit National Institute of Child Health (REC.043/2568). The participants were primary caregivers of children aged 4-12 years who had been diagnosed with ASD and were receiving services at the occupational therapy clinic of the Queen Sirikit National Institute of Child Health and the Physical Therapy Center, Faculty of Physical Therapy, Mahidol University, over a six-month period. Eligible participants were those aged 18 years or older who had continuously cared for their child for at least six months, were able to communicate in Thai, and provided informed consent to participate. Caregivers who were undergoing psychiatric treatment at the time of data collection were excluded.

Data were collected through paper-based self-administered questionnaires distributed at both clinical sites. The survey package included demographic questions, the Thai version of the Autism Treatment Evaluation Checklist (Thai-ATEC), and the Thai version of the Zarit Burden Interview (Thai-ZBI). The Thai-ATEC is a 77-item parent-report questionnaire composed of four subscales—Speech/Language/Communication, Sociability, Sensory/Cognitive Awareness, and Health/Physical/Behavior—where higher scores reflect greater ASD severity. The Thai version demonstrated strong psychometric properties, with overall validity of 86.9% and excellent reliability, including an intraclass correlation coefficient (ICC) of 0.97 for the total score (Sunakarach, 2018). The Thai-ZBI is a validated 22-item adaptation of the original Zarit scale, designed to assess caregiver burden across four domains: personal strain, privacy conflict, guilt, and uncertain attitude. Responses are rated on a 5-point Likert scale ranging from 0 (never) to 4 (nearly always), with higher scores indicating greater burden. Its construct validity was supported by item-total correlations ranging from 0.39 to 0.73, and it showed excellent reliability with a Cronbach's alpha of 0.92 (Toonsiri et al., 2011).

Occupational therapists not directly involved in the children's clinical care were trained to provide instructions, obtain informed consent, and support participants as needed. On average, each questionnaire required about 20 minutes to complete. Participants were informed that they could skip any question or withdraw from the study at any time without consequence, ensuring respect for privacy and autonomy. Completed questionnaires were anonymized, digitized, and securely stored, with all data retained for one year after analysis and subsequently destroyed to maintain confidentiality.

Sample size was determined using G*Power version 3.1. Based on correlation analysis parameters ($r = 0.30$, $\alpha = 0.05$, and power = 0.95), the required sample was calculated to be 138, with an additional 20% adjustment for potential attrition, resulting in a target sample size of 166. This paper, however, presents preliminary findings from 82 participants. Data analysis

was conducted using the Statistical Package for the Social Sciences (SPSS) version 29. Descriptive statistics were reported as frequencies and percentages for categorical variables and as means and standard deviations for continuous variables. Normality was tested using the Kolmogorov-Smirnov and Shapiro-Wilk tests, which indicated that the data were not normally distributed. Accordingly, Spearman's rank correlation was employed to examine associations, with statistical significance set at $p < 0.05$.

RESEARCH RESULTS

Participants' characteristics

A total of 82 caregiver-child dyads participated in this study. The demographic characteristics of children with ASD and their primary caregivers were summarized in **Table 1**. Most children were male (79.3%) with a mean age of 6.53 years ($SD = 2.03$). The majority were enrolled in primary school (40.2%) or kindergarten (36.6%). More than half of the children (53.7%) had siblings, and 61.0% were firstborn. The average duration since diagnosis was 3.11 years ($SD = 2.11$). Among caregivers, the majority were female (84.1%) with a mean age of 41.4 years ($SD = 9.17$). More than half (62.2%) had an education below a bachelor's degree, and 64.6% were employed full-time. Mothers were the most common primary caregivers (65.9%), followed by fathers (14.6%) and other relatives (19.5%).

Table 1 Demographic characteristics of children with ASD and their primary caregivers.

Children: n = 82 (100%)		Caregivers: n = 82 (100%)	
Gender		Gender	
Male	65 (79.3%)	Male	13 (15.9%)
Female	17 (20.7%)	Female	69 (84.1%)
Educational level		Age (years) (Mean \pm SD)	41.4 \pm 9.17
No formal education	9 (11.0%)	Educational level	
Pre-kindergarten & kindergarten	30 (36.6%)	No formal education	1 (1.2%)
Primary school	33 (40.2%)	Below bachelor's degree	51 (62.2%)
Special education center	10 (12.2%)	Bachelor's degree	27 (32.9%)
Siblings		Above bachelor's degree	3 (3.7%)
With siblings	44 (53.7%)	Occupation	
Without siblings	38 (46.3%)	Full-time employment	53 (64.6%)
Birth order		Unemployment	29 (35.4%)
Firstborn	50 (61.0%)	Relationship with children	
Later born	32 (39.0%)	Father	12 (14.6%)
Age (years) (Mean \pm SD)		Mother	54 (65.9%)
6.53 \pm 2.03		Others	16 (19.5%)
Duration since diagnosis (years) (Mean \pm SD)			
3.11 \pm 2.11			

ATEC Scores

Thai-ATEC scores are shown in **Table 2**. The mean total ATEC score was 58.8 ($SD = 3.29$). Among the subdomains, the Health/Physical/Behavior domain demonstrated the highest mean score ($M = 20.1$, $SD = 1.54$), followed by Sociability ($M = 14.2$, $SD = 0.88$), Sensory/Cognitive awareness ($M = 12.8$, $SD = 0.81$), and Speech/Language Communication ($M = 11.6$, $SD = 0.91$). Regarding severity categories, 26.8% of children were classified as mild, 36.6% as moderate, and 36.6% as severe, indicating a balanced distribution across severity levels.

Table 2 Thai-ATEC scores of children with ASD.

ATEC		Mean \pm SD
ATEC raw score	Speech/ Language Communication	11.6 \pm 0.91
	Sociability	14.2 \pm 0.88
	Sensory/ Cognitive awareness	12.8 \pm 0.81
	Health/ Physical/ Behavior	20.1 \pm 1.54
	Total	58.8 \pm 3.29
ASD symptom severity by ATEC, n (%)	Mild	22 (26.8%)
	Moderate	30 (36.6%)
	Severe	30 (36.6%)

ZBI Scores

Caregiver burden measured by Thai-ZBI is presented in **Table 3**. The mean total burden score was 19.2 (SD = 1.50). Among the subdomains, caregivers reported the greatest burden in Personal strain (M = 7.66, SD = 0.66), followed by Guilt (M = 7.18, SD = 0.54), Uncertain attitude (M = 2.30, SD = 0.25), and Privacy conflict (M = 2.09, SD = 0.28). Based on severity classification, 51.2% of caregivers reported no or minimal burden, 39.0% reported mild to moderate burden, and 9.8% reported moderate to severe burden.

Table 3 Thai-ZBI, 22-item scores of caregivers

Thai-ZBI		Mean \pm SD
Thai-ZBI raw score	Personal strain	7.66 \pm 0.66
	Privacy conflict	2.09 \pm 0.28
	Guilt	7.18 \pm 0.54
	Uncertain attitude	2.30 \pm 0.25
	Total	19.2 \pm 1.50
Level of burden, n (%)	No or minimal burden	42 (51.2%)
	Mild to moderate burden	32 (39.0%)
	Moderate to severe burden	8 (9.8%)

Correlation analysis

Correlation analysis between ATEC and Thai-ZBI scores is shown in **Table 4**. Significant positive correlations were observed between ATEC total scores and ZBI total scores ($\rho = 0.685$, $p < 0.01$), suggesting that higher ASD severity was associated with greater caregiver burden. Across subdomains, the Speech, Sociability, and Health domains of ATEC demonstrated moderate to strong correlations with all four ZBI domains ($\rho = 0.339$ - 0.620 , all $p < 0.01$). The Sensory/Cognitive awareness domain correlated significantly with Personal strain, Guilt, and Uncertain attitude, but not with Privacy conflict. These findings indicate that the severity of ASD symptoms, particularly in speech, sociability, and health/behavioral domains, plays a critical role in shaping caregiver burden across multiple aspects.

Table 4 Correlations between children's Thai-ATEC scores and caregivers' Thai-ZBI scores

Variables	ZBI-Personal strain	ZBI-privacy conflict	ZBI-guilt	ZBI-uncertain attitude	ZBI-total
ATEC-Speech	0.497*	0.339*	0.605*	0.456*	0.577*
ATEC-Social	0.591*	0.459*	0.586*	0.489*	0.620*
ATEC-Sensory	0.348*	0.176	0.381*	0.355*	0.396*
ATEC-Health	0.532*	0.507*	0.573*	0.537*	0.608*
ATEC-Total	0.599*	0.503*	0.686*	0.548*	0.685*

*Correlation is significant at the 0.01 level (2-tailed)

DISCUSSION & CONCLUSION

The present analysis provides early evidence that more severe ASD symptoms are linked to greater caregiver burden within the Thai context. This result supports the study objective and corresponds with global research trends. Similar to reports from India (Patel et al., 2022) and South Africa (van Niekerk et al., 2023), our results demonstrate that higher ASD severity is strongly associated with increased strain among caregivers. The Thai studies on developmental delays and disabilities also highlight high caregiver strain, consistent with the current findings. The results were further supported by a cross-sectional study in Nepal, which found that caregivers of children with higher levels of ASD reported significantly greater burden, with nearly half perceiving moderate to severe burden (Shrestha et al., 2023). Similarly, van Niekerk et al. (van Niekerk et al., 2023) highlighted that symptom severity, behavioural problems, and repetitive behaviors predicted caregiver burden. A study in Singapore by Chua et al. (Chua et al., 2023) also confirmed that behavioural problems and core ASD severity explained much of the variance in caregiver burden, especially where social support was limited. In Thailand, Lerthattasilp et al. (Lerthattasilp et al., 2015) observed that communication problems and inappropriate repetitive behaviors were strongly associated with higher caregiver burden.

Our study also noted that all ATEC subdomains were significantly correlated with ZBI burden dimensions, except for sensory/cognitive awareness with privacy conflict. This aligns with Kirby et al. (Kirby et al., 2015), who found that sensory hyperresponsiveness and hyporesponsiveness predicted objective and emotional caregiver strain, while sensory seeking behaviors showed weaker or inverse associations. These findings suggest that sensory features may influence caregiver routines and emotional well-being, but may be less likely to intrude directly on caregivers' sense of privacy compared with more visible communication or behavioral difficulties.

In contrast, some studies suggest moderating factors such as social support and caregiver education can buffer burden even when children's symptoms are severe. For example, Ilias et al. (Ilias et al., 2017) reported that greater social support was linked to reduced caregiver burden in Malaysia and Singapore, even when ASD symptoms were pronounced.

Further, interventions focusing on child development and behavioral improvement have shown promising outcomes. For example, a quasi-experimental study applying DIR/Floortime techniques demonstrated significant reductions in ATEC scores, reflecting improvements in children's ASD symptoms over 6-18 months (Singsathorn, 2018). This aligns with the idea that effective developmental interventions may reduce caregiver strain by improving children's functioning. Similarly, Broworndat (Broworndat, 2020) emphasized that supporting children to practice daily routines such as eating, bathing, and dressing enhances independence and reduces reliance on caregivers. Sripanchat (Sripanchat, 2024) further supports this, showing that when children improve self-help skills, caregiver burden is alleviated. These findings suggest that approximately 73.2% of children with moderate-to-severe ASD symptoms could benefit from such targeted interventions, which may in turn lessen caregiver burden.

In summary, Greater ASD severity imposes a higher burden across multiple caregiving dimensions. Interventions should therefore not only target ADL independence but also emphasize developmental stimulation, behaviour modification, communication skills, and self-help abilities. Such approaches can reduce caregiving demands, strengthen child autonomy, and improve caregiver quality of life. Expanding social support and resources is also essential to mitigate the negative impact of ASD severity.

Nevertheless, the findings should be interpreted with caution due to the limited sample and cross-sectional design, which restricts causal inference. Broader studies with larger, diverse samples and longitudinal follow-up are needed. Future research should also explore moderating factors such as socioeconomic status, parental education, coping strategies, and available support systems. Taken together, these preliminary findings emphasize the importance of designing interventions that not only foster child development and independence but also provide comprehensive resources to alleviate caregiver stress, thereby promoting both child well-being and caregiver quality of life.

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Data Availability Statement: The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

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