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ORIGINAL ARTICLE

Unravelling the Key Influencing Factors of Economic Burden by Caregivers for Children with Autism in Malaysia

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ABSTRAK

Prevalens Gangguan Spektrum Autisme (ASD) telah meningkat dengan ketara di seluruh dunia, sekali gus meletakkan beban ekonomi yang semakin bertambah kepada para penjaga. Kajian ini bertujuan untuk mengganggarkan beban ekonomi yang ditanggung oleh penjaga kanak-kanak dengan ASD di Malaysia serta mengenal pasti faktor-faktor yang berkaitan dengannya. Kajian ini menggunakan reka bentuk keratan rentas, dengan data diperolehi daripada 297 responden antara Julai sehingga Disember 2023. Analisis kos secara restrospektif telah dijalankan menggunakan data soal selidik. Kebanyakan kanak-kanak adalah lelaki (80.1%) dan didiagnosis dengan tahap keterukan sederhana (Tahap 2) (62.6%) berdasarakan 'Diagnostic and Statistical Manual of Mental Disorders' (Edisi ke 5), dengan purata umur 7.23 tahun (SD = 3.23). Purata jumlah beban ekonomi tahunan yang ditanggung oleh penjaga bagi setiap kanak-kanak pada tahun 2022 dianggarkan sebanyak RM56,462.57, dengan kos perkembangan merupakan kos tertinggi (RM13,800.00), diikuti oleh kos tidak langsung (RM8,400.00), kos langsung bukan penjagaan kesihatan (RM3,600.00) dan kos langsung penjagaan kesihatan (RM2,420.00). Analisa regresi menunjukkan bahawa umur kanak-kanak, keadaan komorbid, status pekerjaan ibu/penjaga wanita serta purata pendapatan isi rumah tahunan ialah faktor-faktor yang signifikan dalam menentukan jumlah beban ekonomi. Pengenalpastian faktor-faktor ini dapat menumpukan kepada keperluan sokongan yang diperlukan oleh penjaga. Pembangunan dasar sosial dan intervensi oleh pihak berkepentingan berdasarkan faktor-faktor yang dikenal pasti berpotensi untuk menggalakkan kesejahteraan penjaga dan kanak-kanak yang lebih baik.

Kata kunci: *Beban ekonomi; faktor; gangguan spektrum autisme; penjaga*

ABSTRACT

The prevalence of Autism Spectrum Disorder (ASD) has increased significantly worldwide, placing a growing economic burden on caregivers. This study aimed to estimate the economic burden incurred by caregivers of children with ASD in Malaysia and identify the associated factors. A cross-sectional design was used, with data collected from 297 respondents between July and December 2023. A retrospective costing analysis was conducted using questionnaire data. Most of the children were male (80.1%), diagnosed with moderate Level 2 level of severity (62.6%) based on the Diagnostic and Statistical Manual of Mental Disorders (5th Edition) with a mean age of 7.23 (SD = 3.23). The estimated average

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annual total economic burden on the caregivers per child in 2022 was RM56,462.57, with developmental services cost being the greatest cost (RM13,800.00), followed by indirect cost (RM8400.00), direct non-healthcare cost (RM3600.00) and direct healthcare cost (RM2420.00). The regression results revealed that the children's age, co-occurring conditions, the mother/female caregiver's employment status, and the average annual household income were significant factors of the total economic burden. Identifying these factors highlighted the potential support needed by the caregivers. Development of social policies and interventions by the stakeholders based on the highlighted factors may encourage better caregivers' and children's well-being.

Keywords: Autism spectrum disorder; caregiver; economic burden; factors

INTRODUCTION

Autism spectrum disorder (ASD), commonly known as autism, is a diverse group of neurodevelopmental conditions characterised by difficulties with social interaction and communication with abnormal behavioural patterns, restricted activities, and repetitive behaviour and interest (American Psychiatric Association 2013). The prevalence of ASD varies significantly across different regions: 0.87% to 1.85% in North America, 0.42% to 3.13% in Europe, 0.11% to 1.53% in the Middle East, and 0.08% to 9.3% in Asia (Chiarotti & Venerosi 2020). A previous report indicated an increasing trend of ASD in Malaysia, where the prevalence of autism among children aged four years and below was 1.6 per 1000 in 2005 and estimated to be approximately 1.9 per 1000 in 2016 (Kassim & Mohamed 2019). However, more recent nationwide data show a notable increase. A large-scale study using data from the Ministry of Education reported that the prevalence of autism among school-age children rose significantly from 6.34 per 1,000 in 2018 to 9.29 per 1,000 in 2022 (Shair et al. 2024).

Numerous studies have reported that the estimated cost for children and adults with autism puts a financial strain on their families. For instance, Leigh and Du (2015) estimated that the annual national economic burden to care for Americans with autism is approximately $268 billion ($162-367 billion: 0.884-2.009% of GDP) in 2015 and would rise to $461 billion (range $276-1011 billion; 0.982-3.600% of GDP) in 2025. In China, the total cost of care for families with children with ASD is approximately $34,206.50, accounting for 151% of the household income. The study revealed that the expenses financially burdened 80% of the families (Zhao et al. 2023). Another study compared the estimated cost between children with ASD and the general population, and the researchers discovered that the healthcare expenses (consultations with healthcare professionals, emergency care, inpatient and outpatient services, and pharmacy) for people with ASD were twice to 10 times higher than the general population (Vohra et al. 2017). Most of the total cost born by caregivers of individuals with ASD includes non-medical expenses, such as transportation, special care assistance, special diet and special education expenses (Bieleninik & Gold 2021; Zhao et al. 2023). In addition, most caregivers have reported leaving their jobs to care for their children with ASD (Saunders et al. 2015). This circumstance might have contributed to the 28% lower earnings for families with autistic children than those with healthy children (Cidav et al. 2012).

Cost of illness (COI) studies are essential in predicting the nature and magnitude of impacts and are commonly performed with burden of disease studies. This research design was first introduced in the 1960s to estimate the direct and indirect costs of a particular illness, which is imperative to conduct future research (Rice 1967). The economic burden of ASD can be estimated as prevalence costing, the lifetime cost for new cases (incidence costing), as an annual cost for existing ASD cases, or targeted costing (cost for a specific period, condition or patient

subgroup) (Matin et al. 2022). Several studies have provided a comprehensive estimate of the ASD cost. For instance, Ganz (2007) estimated that the lifetime distribution of ASD societal costs in the United States of America (USA) is $3.2 million. Meanwhile, Leigh and Du (2015) predicted the economic burden of autism in the USA to be $268.3 billion in 2015 and will rise to $460.8 billion in 2025. Another study conducted within a large European sample population estimated that the total cost (health services and societal costs) of ASD was approximately €2834 per month (Bieleninik & Gold 2021). However, this study only estimates the cost in 2-month period thus, the cost is limited to the time being. In Ireland, Roddy and O'neill (2019) reported a €42,656.47 total estimate of childhood ASD cost. The forecasted total cost of ASD was $9,645,502 in South Korea back in 2015 (Hong et al. 2020) and $34,206.50 or 151.0% of household income in China in 2023 (Zhao et al. 2023). The COI studies on ASD may be common, but the limited cost components covered in earlier studies may have led to the underestimation of the actual costs of ASD (Cidav et al. 2012; Thomas et al. 2014).

Malaysia is a developing, middle-income country with a large population, with approximately 80% falling under low- and middle-income families. This country faces challenges in providing affordable and high-quality healthcare services to the public, including people with disabilities. Currently, the estimated actual cost far exceeds the aid offered to families of children with ASD, highlighting the urgent need for critical support and health-related resources. Several studies have utilised the COI approach to update the economic burden estimates for mental disabilities, such as cerebral palsy (Ismail et al. 2022) and dementia (Koris 2018). Despite the increasing attention to mental disability in Malaysia, cost estimates for ASD in this country remain lacking. Existing studies on this subject are either regional, focused primarily on preschool-age children (Najib & Juni 2019) or are conducted through social media groups (Kamaralzaman et al. 2018). It is essential to include children up to the age of 18 years in studies to identify at which age group families spend more on treatment and support and factors associated with the economic burden.

Previous research in high-income countries reported that parents with higher education or income levels (Lindley & Mark 2010; Zhao et al. 2023) and children with clinically severe conditions (Roddy & O'neill 2019; Zhao et al. 2023) had a higher direct cost. Nevertheless, these factors might vary in Malaysia as a developing nation. Therefore, the present study performed a nationwide survey to estimate the total costs over 12 months for caregivers to raise a child with ASD in Malaysia and to investigate the determinants of expenditure (child's and caregivers' sociodemographic, ASD severity and caregivers' socioeconomic factors). A detailed description of the distribution of ASD costs and associated factors could reveal the major costs of raising children with ASD and guide policymakers in aiding patients and their families.

MATERIALS AND METHODS

Design and Sampling Procedure

This cross-sectional study analysed quantitative data obtained from online questionnaire responses from caregivers selected based on inclusion and exclusion criteria using convenience sampling techniques. As Malaysia does not have a national autism database, the respondents were recruited from various training and rehabilitation centers for children with ASD nationwide, including the largest government and non-governmental centers. A total of eight primary training and rehabilitation centers for autism were selected for this study. The sample size calculation was performed using the single formula method for proportion by considering 5% absolute precision, a power of 80% (Kish 1965), and an estimated prevalence of ASD among children in Malaysia for 2016 (1.9 in 1000) (Kassim & Mohamed 2019), thus resulting in a sample size of 234 respondents. Upon considering a non-response rate of 20%, the required sample size for this study was 281

participants.

The inclusion criteria of this study included participants who agreed to participate in the study voluntarily and self-reported having a child aged between two to 18 years with a confirmed diagnosis of ASD by a healthcare professional (psychiatrist, pediatrician) at least one year prior to the data collection, Malaysian who was proficient in Bahasa Malaysia and had internet access to answer the online questionnaire. Meanwhile, caregivers who had >1 child with ASD or family members with disabilities or >1 child or family members with chronic illness who required long-term care were excluded from this study. In this study, main caregivers were defined as either (i) fathers or mothers who were mainly responsible for caring for and providing for the needs of their children with ASD; (ii) the main people responsible for caring for the child; or (iii) who were actively engaged in providing care and the needs of the child. At the end of the sampling phase, 297 participants were included in this study. Once the data collection was completed, a retrospective costing analysis was performed to predict the national economic burden borne by parents or caregivers of children with ASD.

Measures

The data collection tool used in this study to identify the costs related to services used by caregivers was the Parent's Financial Statement Form. The validated, self-administered questionnaire was developed in Bahasa Malaysia by public health and early childhood education development experts (Kamaralzaman et al. 2018). The questionnaire comprised five sections: Section 1: Caregivers' demographic information; Section 2: Children's demographic information; Section 3: Monthly household expenses data; Section 4: Yearly household expenses data; and Section 5: Productivity loss data. The median of the total economic burden on parents/caregivers of children with ASD was calculated based on their expenses from January to December 2022 in Ringgit Malaysia (RM). The total economic burden can be divided into four major categories: direct healthcare, direct non-healthcare, developmental and indirect costs.

Direct healthcare costs referred to the expenses imposed by the healthcare system on patients with ASD and their families/caregivers (Tonmukayakul et al. 2018), which included medical treatments such as outpatient services, inpatient expenses, diagnoses, medical treatment, surgery, medication and rehabilitation services. Based on a previous study conducted in Malaysia, the current work divided this cost into several categories: rehabilitation services, alternative treatments, medicine costs, medical aid purchasing costs, diagnostic test costs, ward entrance fees, and surgery and consultation fees (Kamaralzaman et al. 2018). Direct costs can also be extended to non-healthcare costs, including home modifications, healthcare services and education expenses (Rogge & Janssen 2019). This study employed a direct cost reporting method, where caregivers reported their total annual expenditures per item related to the care of their child with ASD. This approach was chosen due to feasibility considerations, limited access to standardised unit cost data in Malaysia, and time constraints of the study period. While this method may involve some recall bias, it allowed for efficient data collection and captured a wide range of actual out-of-pocket expenses, including informal and non-standard services. Respondents were encouraged to refer to receipts or financial records to enhance accuracy.

Direct non-healthcare costs may include transportation (appointments, therapy) and accommodation related to obtaining healthcare services. In this study, only transportation costs were included as a direct non-healthcare cost based on an existing questionnaire adopted that included transportation as the main item under direct non-healthcare costs. Other costs, such as home modifications and respite care, were not covered in the questionnaire and were not collected. To keep the data collection practical and focused, we included cost items that were commonly reported by most families. Transportation was the most frequent and measurable non-healthcare expense, especially

for trips to therapy, school and the hospital. In addition, based on local context and previous studies, services like respite care and home modifications were rarely used in Malaysia due to limited access. Transportation costs were measured by asking caregivers to report their monthly transportation expenses specifically related to their child's appointments and education, such as trips to therapy sessions, hospitals and special education centres. These monthly costs were then multiplied by 12 to estimate the annual transportation expenditure.

While the classical framework typically included the first three categories, we introduced developmental costs as a distinct category due to their particular relevance in the context of ASD. Developmental costs in this study were primarily related to congenital and childhood disabilities, which included services for childcare, special education and diet, and supplements (non-pharmaceutical healthcare products) (Kamaralzaman et al. 2018; Wang et al. 2008). These expenditures were aimed at supporting the long-term developmental outcomes of children with ASD. Although some of these items could conventionally be included under direct healthcare or non-healthcare costs, they were grouped separately in this study to provide a more precise and meaningful representation of ASD-related caregiving demands.

This decision to categorise was influenced by the specific and ongoing developmental needs found in children with ASD, which were notably different from the usual healthcare costs seen in typical children or those with chronic illnesses. By identifying developmental costs as a separate category, we aimed to emphasise their magnitude and importance in shaping both family-level economic impact and policy considerations, particularly in the Malaysian context where such cost data were limited.

The indirect costs referred to productivity loss for the caregivers and the child. In the context of COI, these costs applied to productivity losses brought on by morbidity, including visits to healthcare professionals (therapists, physicians), hospitalisation, early retirement and premature mortality. The classic human capital approach was used to measure indirect costs, which was applicable in the Malaysian context and popular in health-related studies. The cost for employed caregivers was calculated by multiplying the reduced hours or time they had to leave work to attend to their children with ASD by the median daily wage. According to the Department of Statistics Malaysia (DOSM), the median monthly salary for formal sector workers in December 2022 was RM2,764 (DOSM 2025). Assuming an average of 22 working days per month, this corresponded to a median daily wage of approximately RM125.64. Loss of income due to leaving their jobs by full-time caregivers was not considered to avoid double-counting. For caregivers who were unemployed, productivity loss was estimated in which values time spent on caregiving as an opportunity cost. The national minimum wage was used as a proxy to assign a monetary value to the hours dedicated to caregiving tasks. The total indirect costs were the sum of both employed and unemployed caregivers.

This study also collected information about the children's demographics and family socioeconomic backgrounds to predict the total costs. The children's ages were categorised based on their schooling age (0-3, 4-6, 7-12 and 13-18 years) following a study conducted locally in 2013 (Ismail et al. 2022). Children aged 0-3 years in Malaysia were often cared for by their parents or caregivers, while those who had working parents were sent to daycares. At the age of 4-6 years, children started attending preschool or kindergarten. Subsequently, children between the ages of 7-12 were mandated to enroll in primary school, followed by the secondary school from the age of 13-17. In addition, the respondents' sex was also considered in this study, which referred to their biological state of being male or female. Meanwhile, the ASD severity was obtained from the caregivers' self-report, which was determined based on the Diagnostic and Statistical Manual of Mental Health Disorders, 5th Edition (DSM V) classification by the children's healthcare providers. This classification

differentiated children with ASD based on their social communication and restricted and repetitive behaviours: Level 1: Mild autism, Level 2: Moderate autism and Level 3: Severe autism. Furthermore, the presence of an associated condition in children with ASD was categorised as no associated condition and the presence of an associated condition. The associated condition varies and can include Attention Deficit Hyperactive Disorder (ADHD), seizure, intellectual disabilities, asthma, heart disease and gastrointestinal disease.

Other sociodemographic information collected in this study were the caregiver's age, education level, residential area and employment status. The age groups used in this study were 18-25, 36-55, and >55 years, which were based on the national age classification: 18 years, young adulthood: 18-35 years, middle adulthood: 36-55 years and retirement age: >55 years. Meanwhile, the household income was categorised based on the average Malaysian household income in 2022. The Household Income and Basic Amenities Survey Report in 2022 by the DOSM (2023) stated that the average Malaysian household income was RM8,479.00 and the median national income was RM6,338.00. Therefore, an income above the national average was >RM 8,479.00, while an income below the national average was <RM 8,479.00 (DOSM 2023). DOSM conducted the Household Income and Expenditure Survey twice within any five-year period, and the 2022 cycle represented the most recent and comprehensive national data available. These figures were used as benchmarks for categorising household income levels in this study. In addition, the regional variables were classified as urban and rural. Finally, the employment status of male and female parents or caregivers was recorded as working (yes) or not working (no).

Data Collection

The data collection for this study was carried out using online Google forms from July to December 2023. The study tool was pre-tested in a pilot study to ensure its reliability and improved accordingly. The researcher shared the link for the online questionnaire in the official WhatsApp group with the participants as members. The time taken for each participant to complete the questionnaire was less than 20 minutes.

Data Analysis

The data analysis in this study was performed using the Statistical Package for Social Sciences (SPSS) version 27 (IBM, Chicago, Illinois, USA). The economic burden was analysed based on median, interquartile range (IQR), minimum and maximum values. To estimate the proportional financial burden of each cost component, the cost distribution as a percentage was calculated using median values. Specifically, for each cost item, the median annual cost reported by caregivers was divided by the total median annual economic burden across all components. This value was then multiplied by 100 to express the result as a percentage. Then, the univariate analysis was conducted to describe the participants' characteristics and to tabulate the economic burden based on the costing components. In the bivariate analysis, non-parametric tests were used to determine if there were significant differences between the categorical independent variables of economic burden. In addition, the Mann-Whitney U test was used to identify the association between economic burden and independent variables consisting of two categories (child's sex and annual household income). Meanwhile, the Kruskal-Wallis test was utilised to determine the association between economic burden and independent variables with three categories and above (age, ASD severity). Subsequently, the linear regression analysis was performed to identify factors influencing the costs (child's age, gender, co-occurring conditions, ASD severity, caregivers' age, employment status and annual household income). The level of significance was set at $p < 0.05$, and all the estimated costs were reported in RM. In 1st January 2022, $1 was equivalent to RM4.19.

Consent to Participate

All caregivers provided electronic informed consent before enrolment.

Ethics Approval

All research practices involving human subjects/ patients were approved by the Research Ethics Committee of the Univeristi Kebangsaan Malaysia (approval number JEP-2022-601).

RESULTS

Study Population

The descriptive analysis of this study population was presented in Table 1. In this study, the 297 caregivers mostly had male children with ASD (80.1%) with a mean age of 7.35 (SD = 3.23) years. A majority of the children were diagnosed with moderate or Level 2 ASD (62.6%), while the remaining children had Level 1 (30.2%) or Level 3 (7.1%) ASD. Additionally, more children with ASD had co-occurring conditions (73.7%) than those without (26.3%). Table 2 showed the distribution of co-occurring condition in the children with ASD with asthma (23%) is the most common condition presence in these children. The mean age of the caregivers was 37.8 (SD 5.96), with a majority being female (74.7%) and hadtertiary education (67.7%). More than half of mothers/female caregivers (55.9%) and a majority of fathers/male caregivers were employed (95.6%). Most respondents resided in urban areas (71.4%). The average annual household income calculated in this study was RM56,462.57, indicating that 85.9% of the families with ASD children were earning below the national average of RM8,479.00. In addition, the average monthly household income of these families was lower than the average family household income in Malaysia (RM4,240.00/month), as reported by the Department of Statistics Malaysia in 2022.

Costs

Table 3 detailed the caregivers' economic burden in 2022. This table showed a detailed breakdown of the total costs incurred by families of children with ASD in Malaysia in the previous 12 months. The median total cost was RM28,220.00 (IQR = 41,130.00) per family, reflecting the distribution of costs between families ranging from RM0.00 to RM427,600.00. Median values for most categories were null. The median total cost accounted for 49.9% of the average total household income of the families.

The developmental costs were the greatest burden, accounting for 48.9% of the total costs, with a median cost of RM13,800.00, which included domestic helper costs, nursery costs, special education costs, dietary supplements, daily necessities and insurance coverage. The highest expense within the developmental component was attributed to the purchasing of dietary supplements, totaling RM5,400.00 (19.1%). Following this, the special education component represented the second-highest cost at RM3,600.00 (12.8%), whereas the nursery incurred the third-highest expenses, with a median value of RM2,400.00.

Families of children with ASD incurred a significant burden, with indirect costs representing the second highest cost (29.8%). These indirect costs stemmed from the loss of productivity among the caregivers, totaling RM8,400.00. Following this, direct non-healthcare costs were reported at RM3,600.00 (12.8%), while direct healthcare costs amounted to RM2,420.00 (8.5%).

An analysis of the components within the direct healthcare cost category revealed the rehabilitative services incurred the highest median cost, recorded at RM2,400.00. Following this, the median cost of purchasing assistive devices emerged as the second highest, amounting to RM20.00.

TABLE 1: Study population (n = 297)

Caregiver's demographic	**Mean**	**SD**
Caregiver's age (year)	37.80	5.96
Average annual household income (RM)	56,462.57	48,473.89
	n	**Percentage (%)**
Caregiver's gender		
Male	75	25.3
Female	222	74.7
Caregiver's education level		
Primary	5	1.7
Secondary	91	30.6
Tertiary	201	67.7
Family annual household income		
Below national average	255	85.9
Above national average	42	14.1
Mother/female caregiver employment status		
Unemployed	131	44.1
Employed	166	55.9
Father/male caregiver employment status		
Unemployed	13	4.4
Employed	284	95.6
Residential area		
Urban	212	71.4
Rural	85	28.6
Children's demographic	**Mean**	**SD**
Age	7.35	3.23
	n	**Percentage (%)**
Gender		
Male	238	80.1
Female	59	19.9
Severity of ASD		
Mild	90	30.3
Moderate	186	62.6
Severe	21	7.1
Co-occurring condition in children with ASD		
No	219	73.7
Yes	78	26.3

ASD: Autism spectrum disorder; RM: Ringgit Malaysia; SD: standard deviation
$1 was equivalent to approximately RM4.19 in 1st January 2022

TABLE 2: Distribution of co-occurring condition in ASD children

Conditions	**Number of cases (%)**
Asthma	18 (23.0)
Speech delay	13 (16.7)
Allergy	13 (16.7)
Lain-lain	13 (16.7)
Epilepsy	10 (12.8)
ADHD	10 (12.8)
Hearing problem	1 (1.3)

ADHD: Attention deficit hyperactive disorder; ASD: Autism spectrum disorder

TABLE 3: Caregivers' annual economic burden in 2022 (n = 297)

Cost components	Sub-components	Range (RM)	Median (RM)	IQR (RM)	Mean (RM)	SD (RM)	Average cost (%)
Direct healthcare cost	Rehabilitative services	0.00 - 30,000.00	2,400.00	6,000.00	3,651.68	4,200.01	8.4%
	Alternative treatments	0.00 - 12,000.00	0.00	0.00	344.25	1,167.78	0%
	Medicine cost	0.00 - 18,000.00	0.00	0.00	554.13	1,587.54	0%
	Purchase of Medical Aids	0.00 - 9,000.00	20.00	500.00	512.72	1,159.10	0.1%
	Diagnostic tests	0.00 - 4,000.00	0.00	0.00	131.31	410.35	0%
	Ward entrance fee/ surgery	0.00 - 9,000.00	0.00	0.00	261.91	1,069.03	0.6%
	Total	**0.00 - 82,000.00**	**2,420.00**	**6,500.00**	**5,456.00**	**9,593.81**	**8.5%**
Direct non-healthcare costs	Transportation cost	120.00 - 30,000.00	3,600.00	3,600.00	4,747.77	4,553.79	
	Total	**120.00 - 30,000.00**	**3,600.00**	**3,600.00**	**4,747.77**	**4,553.79**	**12.8%**
Developmental cost	Domestic helper	0.00 – 48,000.00	0.00	3,000.00	2,371.31	5,465.28	0%
	Nursery	0.00 – 48,000.00	2,400.00	6,150.00	3,881.92	5,372.17	17.4%
	Special education	0.00 – 79,200.00	3,600.00	5,940.00	4,931.49	7,168.48	26.1%
	Dietary supplements	0.00 – 24,000.00	5,400.00	3,900.00	5,659.19	3,763.98	39.1%
	Insurance	0.00 – 18,000.00	0.00	1,000.00	649.58	1,417.44	0%
	Daily necessities	0.00 – 18,000.00	2,400.00	2,400.00	2,928.73	2,672.37	17.4%
	Others	0.00 – 20,000.00	0.00	50.00	631.56	1,794.85	0%
	Total	**0.00 – 237,200.00**	**13,800.00**	**20,340.00**	**21,053.78**	**24,991.83**	**48.9%**
Indirect cost	Productivity loss	530.40 – 78,400.00	8400.00	10690.00	11262.59	10,865.14	
	Total	**530.40 – 78400.00**	**8400.00**	**10690.00**	**11262.59**	**10,865.14**	**29.8%**
Overall total burden/ year		**650.40 – 427,600.00**	**28,220.00**	**41,130.00**	**42,520.14**	**50,004.57**	**100.0%**

SD: standard deviation; RM: Ringgit Malaysia
$1 was equivalent to approximately RM4.19 in 1st January 2022

Factors Associated with the Total Costs

Table 3 showed the final model of multiple linear regression (MLR) for factors affecting economic burden. The MLR was performed using the total expenditure of the caregivers as dependent variables to predict the economic burden on parents/caregivers of children with ASD based on sociodemographic factors (sex, age, education level, employment status, living area), socioeconomic factors (annual household income), ASD severity and presence of co-occurring conditions. The results demonstrated that the MLR model was statistically significant in predicting the economic burden among the caregivers (F (4,292) = 35.724, $p<0.001$) and adjusted R^2 = 0.32. Significant predictors of economic burden were ASD children's age (b = -1688.18, 95% CI -2613.50, -722.86, $p < 0.001$), mothers/female employment status (b = 12230.91, 95% CI 5827.94, 18633.89, p = < 0.001), presence of the associated condition (b = 11499.68, 95% CI 4549.52, 18449.84, p = 0.001) and household income (b = 3.641, 95% CI 2.86, 4.44, p = < 0.001) (Table 4). The participants' predicted economic burden was equal to RM3,4325.82 - (1688*children's age) + (12230.91*mother employment status) + (11499.68*presence of associated condition) + (3.64*annual household income in RM).

This analysis identified a significant linear relationship between children's age, mother/female caregivers' employment status, presence of the associated conditions and annual household income with parents/caregivers' total economic burden. The predicted economic burden decreased by RM1,688.00 as the child became a year older. An employed mother had a higher predicted economic burden of RM12,230.91 compared to a mother without employment. The presence of associated conditions among children with ASD was linked to an increase in economic burden by RM11,499.68. Families with an annual household income of >RM1,000 had a higher total economic burden of RM3,640.00. In summary, children's age, mother's employment status, presence of the associated condition and the annual household income were statistically significant predictors of the economic burden borne by families with children with ASD

TABLE 4: Multiple linear regression analysis of factors affecting economic burden

	B	Adjusted[b]	95% CI	t-statistic	p-value[c]	R^2	ΔR^2
Model						0.33	0.32
Constant	34325.82		25461.55, 43190.10	7.62			
Child's age	-1668.18	-0.17	-2613.50, -722.86	-3.47	<0.001*		
Presence of co-occurring conditions[a]	11499.68	0.16	4549.52, 18449.84	3.25	0.001*		
Mother/female caregiver's employment status[b]	12230.91	0.19	5827.94, 18633.89	3.75	<0.001*		
Annual household income	3.64	0.46	2.86, 4.44	9.17	<0.001*		

Model = "Stepwise" method in SPSS statistics; *B* = Unstandardised regression coefficient; SE *B* = Standard error of the coefficient; Adjusted b = Standardised coefficient; CI: Confidence interval; R^2: Coefficient of determination; ΔR^2: Adjusted R^2. (R^2 = 0.329; The model fitted reasonably well; model assumptions were met; no interaction between independent variables; no multicollinearity problem).
[a]Presence of associated condition = Yes if associated conditions present; [b]Mother employment status = Yes if mother's employed; [c]significant p-value < 0.05.

compared to the child's sex, caregivers age, father's employment status, education level, ASD severity and area of residence.

DISCUSSION

The significant rise in ASD prevalence in the last decades indicates an urgent need for resources for ASD care. Nevertheless, the literature and economic data related to autism in Malaysia remain lacking. This study is one of the first to examine the expenditure of families of children with ASD and its predictors using a sample population from all states in Malaysia. While it is impossible to make a direct comparison with other countries due to variations in healthcare systems and policies, assessing the distribution and drivers of costs could yield meaningful findings. The male-dominated sociodemographic among children with ASD in the present study resembled that of prior studies, reflecting the global prevalence of the male gender in ASD (Zeidan et al. 2022). Nonetheless, the current study found that the cost of care for female children with ASD was higher than their male counterparts, consistent with an earlier study that reported 16% higher costs for girls than boys (Croen et al. 2006).

Developmental costs (direct non-healthcare cost) (45.8%) and indirect costs (28.5%) constituted the majority of costs in this study, consistent with previous studies (Horlin et al. 2014; Zhao et al. 2023). Furthermore, transportation and development costs under the direct non-healthcare costs were approximately five times than medical costs, which aligned with earlier study findings where families of children with ASD spent more on annual non-medical costs than medical costs (Lavelle et al. 2014; Zhao et al. 2023). The developmental cost accounted for almost half of the total estimated economic burden of caregivers, which was consistent with previous studies (Lavelle et al. 2014; Raz et al. 2013; Zhao et al. 2023). This cost primarily involved the purchasing of dietary supplements annually (26.5%), which is up to RM24,000.00. The cost for this special diet mainly includes daily food, milk formula, vitamins and supplementary diets for children with ASD. Although special diet costs are rarely reported in the literature, Bieleninik and Gold (2021) discovered that 17% of children required a special diet, which incurred a wide range of costs for their caregivers, thus coinciding with the current study. This finding is potentially linked to the relationship between the nutritional status of children with ASD and their general health. Peretti et al. (2019) revealed that a ketogenic diet fortified with vitamin D and folic acid and gluten- and casein-free could benefit the social, cognitive, motor and communicative skills of autistic children.

Special education for children with ASD is the second highest developmental cost. The cognitive abilities of children with ASD are highly diverse, with some demonstrating average or superior intelligence while others may experience intellectual disability. Lavelle et al. (2014) revealed that school services were the biggest contributor to the costs associated with childhood ASD due to the increased use of special education services. The types of education provided differ depending on the severity of the ASD. A study in the Netherlands highlighted differences in estimated costs for three types of education tailored to children with ASD, whereby the less intensive and intensive special education costs were 70-175% higher than regular education (Peters-Scheffer et al. 2012). Some autistic children can attend regular schools, but others may require special education or special needs in addition to regular education. Private schools often offer these services at a higher cost, particularly those that cater for autistic children with multiple disabilities. Additional behaviour and communication issues among children with ASD also incur extra costs for caregivers, as reported by Knapp et al. (2009) in their study on economic costs in the United Kingdom. Behavioural intervention is generally recommended for children with ASD. Early intensive behavioural intervention, such as applied behaviour analysis, is one of the behavioural interventions commonly provided at private special education schools. For instance,

autistic children aged 2-4 years require 35 to 40 hours of teaching sessions weekly. In Malaysia, the estimated total annual average cost of this intervention is RM15,158.00 per child (Najib & Juni 2019).

The current study used regression analysis to explore factors associated with the total economic burden and identified four significantly associated predictors. Younger age of children with ASD, working mother/female caregivers, concurrent condition and higher annual income have significantly higher impact on the economic burden of caregivers. Families with younger children with ASD will bear a higher cost of care than those with older children, which is in line with earlier findings. A study conducted in the USA showed that the cost of care for children with ASD in 2014 was substantially higher in their early childhood than when they were older children (Buescher et al. 2014). In contrast, Barrett et al. (2012) reported that the service costs increased with the age of children with ASD. Likewise, Bieleninik and Gold (2021) found that age is a factor in the total economic burden for families of children with ASD and that health costs increased by €213 with every additional year of a child's age.

Dietary supplements, nursery and special education contributed to the highest cost among caregivers with younger children in the present study. Younger children require more intensive and specialised interventions, therapies and educational support, leading to a significantly higher economic burden. Studies indicate that children with ASD under the age of six often exhibit rapid and more significant improvements, indicating the importance of early intervention (Stahmer et al. 2005). This initiative involves special education or extra services in addition to regular education frequently provided by private centers, thus incurring additional costs on caregivers.

Research has shown that a substantial comorbidity burden exists among individuals with ASD, with over 70% of patients having concurrent medical, developmental or psychiatric conditions. The comorbidity associated with children with ASD were medical conditions such as asthma, gastrointestinal conditions, epilepsy, psychiatric conditions (ADHD, mood disorder, anxiety disorder, intellectual disability) and allergies (Bauman 2010; Dizitzer et al. 2020). These comorbidities require extra medical care and interventions, thus exacerbating the financial strain on families of children with ASD. In the present study, children with ASD and comorbidities were associated with an increased economic burden on their families by RM11,499.68 compared to families with solely autistic children. This finding aligned with Croen et al. (2006), who reported that the average annual cost tripled for autistic children with comorbidities than those without. Meanwhile, Bieleninik and Gold (2021) reported an increase in total health costs for children with ASD with intellectual disability, but were not significantly related to societal costs. Furthermore, a study on the USA and UK cohorts discovered that the mean annual costs for a child with intellectual disability were higher than those without (Buescher et al. 2014).

A study by Liptak et al. (2006) reported that autistic children with comorbid medical conditions, such as epilepsy, require additional medical care and have higher healthcare expenditures. The higher cost is related to the significantly higher utilisation of health services by children with ASD than those without ASD (Croen et al. 2006). Outpatient clinic visits and hospitalisations are twice as frequent for children with ASD, thus tripling their total healthcare costs. Moreover, the regular prescription for psychotropic medications and polypharmacy among children with ASD and comorbidities (seizures, attention-deficit disorders, anxiety, bipolar disorder or depression) added to their family's economic burden despite the minimal evidence of the treatment efficacy (Spencer et al. 2013). In conclusion, concurrent medical conditions in autistic children are associated with a higher economic burden on families due to increased healthcare expenditures, the need for specialised medical care and the use of psychotropic medications. Addressing the

healthcare needs of children with autism and their comorbid conditions is essential to alleviate the financial strain on families and ensure comprehensive care for these children.

The current study also identified the mother's employment status as a significant predictor of the total economic burden. Interestingly, families with working mothers have a higher economic burden than those with unemployed mothers. This finding suggests employed mothers frequently require additional childcare services due to work commitments (Dykens et al. 2014), thus adding to the family's overall expenditure. Moreover, specialised childcare for children with ASD can cost more than regular childcare. Nonetheless, working mothers often have more financial resources to invest in various therapies and interventions critical for their children with ASD, such as behavioural, speech, and occupational therapies and specialised educational programs. These services are often expensive and can significantly increase the total costs of raising a child with autism. Moreover, working mothers could have better access to high-quality or special diets their children require. Despite the advantages of maternal employment highlighted in this study, limited research has assessed the direct relationship between employment status and costs borne by families. A study has reported that employment is often disrupted due to added to the challenges posed by autism-related childcare, leading to reduced or loss of family income and significantly increased economic burden (Ou et al. 2015). In the present study, 56% of mothers of children with ASD were employed, contradicting earlier findings where maternal labour force participation outcomes are affected by having an autistic child. In Australia, Callander and Lindsay (2018) reported that a greater proportion of mothers with ASD children who have ASD were unemployed compared to those with children without ASD. These discrepancies might be attributed to cultural differences between studies. Nevertheless, mothers, regardless of their employment status, face significant challenges and financial burdens in raising autistic children, underscoring the urgency for supportive policies and programs to aid families affected by autism.

Another significant predictor of economic burden identified in this study was the families' average annual income. Families with higher incomes incurred a higher total economic burden, which coincided with the study by Zhao et al. (2023), who reported similar findings. Studies conducted in Israel (Raz et al. (2013) and the USA (Thomas et al. 2014) also reported that families of children with ASD and higher household incomes recorded higher out-of-pocket expenditures. Conversely, Roddy and O'neill (2019) found that income did not significantly influence the total economic burden when the primary caregiver has the ability to support the cost of care of a child with ASD, hence reducing dependency on extra services which the family could provide. In the current context, a higher income may allow families to spend more on supporting their children's needs, resulting in significantly higher expenditures than those with lower incomes. The specialised treatments and services for children with ASD may not be funded publicly and can be costly, thus resulting in this study outcome. Moreover, upper-middle-income households often receive less government assistance despite having the financial means to care for their special needs children. Based on the current study findings, the researchers urged local policymakers to prioritise families most impacted by autism when planning aid distribution, particularly the parents/caregivers of children with ASD facing socioeconomic challenges.

This study did not find a significant association between ASD severity and total economic burden. Likewise, Van Steensel et al. (2013) reported similar findings in a study conducted in the USA. Nonetheless, this study outcome contradicted the findings in earlier studies (Raz et al. 2013; Zhao et al. 2023). The difference in determinants identified between studies may be attributed to the methodology and cultural variations. One plausible explanation for this finding is related to the method used to assess severity. The severity level was based on a general, caregiver-reported question without

the use of any standardised diagnostic tools or clinical assessments. As such, the responses may have been influenced by individual perceptions, knowledge or experiences, leading to potential misclassification or inconsistency in severity reporting. Additionally, limited variation in severity levels across the sample may have further reduce the ability to detect statistically significant differences. It is also possible that other factors-such as household income, access to public services or the type of support received had a stronger influence on economic burden in this context.

Limitations and Recommendations

This study has several limitations. Firstly, the study population was recruited online. Families were invited to participate in this study and complete an electronic questionnaire, which does not allow for a controlled stratification sampling. Therefore, future research should use more rigorous sampling methods to determine the study outcomes. Secondly, this study relied on self-reported financial data from caregivers, which may be subject to recall bias and affect the accuracy of the cost estimates. Although self-reporting is a practical method in economic burden research, it may not capture all expenses accurately. Future studies are encouraged to validate financial estimates using additional data sources such as medical records, receipts or caregiver expenditure tracking to improve data reliability. The current sample size is small and only includes caregivers with access to mobile phones. The exclusion of caregivers who do not have mobile phone access may have introduced sampling bias, thus resulting in larger standard errors and confidence intervals. Other notable limitation of this study is the lack of cost categorisation based on the severity levels of ASD. Children with mild, moderate and severe ASD may require different types and intensities of care and intervention, which could significantly affect the financial burden experienced by caregivers. Future research is recommended to disaggregate cost estimates by ASD severity to improve the practical applicability of the findings for policy and intervention planning.

While this study provides a general overview of the economic burden faced by caregivers of children with ASD, it may not fully reflect the specific financial challenges encountered by families with different needs. The lack of detailed cost breakdowns, such as by type of service or family income level, limits the ability to draw tailored policy recommendations. Nevertheless, the findings highlight the need for financial aid programs to be more responsive to the diverse circumstances of families, particularly those caring for children with more intensive support needs. Future research should explore cost patterns in greater detail to inform targeted and need based financial support policies.

Future research is recommended to explore how the financial burden experienced by families changes as children with ASD grow older, as care requirements, therapy needs and service utilisation may vary across developmental stages. Longitudinal studies would be particularly valuable in capturing these changes over time. In addition, integrating qualitative approaches-such as in-depth interviews or focus groups with caregivers-could provide richer insights into their financial challenges, decision-making processes and coping strategies. These perspectives would complement quantitative data and contribute to a more holistic understanding of the economic impact on families.

CONCLUSION

This study is the first of its kind to focus on personal characteristics and sociodemographic factors associated with ASD costs. Based on the estimated total economic burden calculated in this study, caregivers bear a significant economic burden of approximately RM42,520.14 with a median value of RM13,800.00 in 2022 in raising a child with ASD in Malaysia. The bulk of this cost is contributed by developmental costs, primarily comprising of domestic helpers, nursery, special education, dietary supplements and insurance. This study also investigated the

determinants of the total economic burden and identified the child's age, comorbidities, mother/female caregivers' employment status and socioeconomic status as significant predictors. The study outcome indicated that a large proportion of middle-income families also struggle financially to care for children with ASD; thus, financial aid should not be restricted to low-income groups. Currently, the burden of families of children with ASD has exceeded the assistance and capacity of the existing healthcare system. Policymakers, government agencies and non-governmental organisations could utilise these findings to improve future aid distribution and support to families affected by autism. The initiative should begin with the development and implementation of integrative public policies to expedite the provision of financial support and reduce assistance barriers. Furthermore, it is imperative to enhance inter-agency and professional collaboration through efforts such as national-level inter-agency dialogue for strategic planning and policy development to relieve the burden of caregivers and ASD. Another useful strategy to support the formulation of more rational policies is to refine differentiation cost and comorbid conditions categorisation. Finally, more studies should be conducted on ASD economics involving a larger and diversified Malaysian population to provide ample and accurate data for future and continuous improvements to support autistic children and their families.

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