Original Article

doi:10.31674/mjn.2024.v15i04.016

MJN

# Parental Stress among Family Caregivers of Children with Autism in a Teaching Hospital

**Nur Ashida Hamidon[1,2], Nur Ily Shazwany Mohd Anuar[1,2], Siti Khuzaimah Ahmad Sharoni[1]*, Nur Azah Mohd Isa[3]**

[1]*Centre for Nursing Studies, Faculty of Health Sciences, University Technology Mara Selangor Branch, 42300 Kampus Puncak Alam, Malaysia*

[2]*University of Malaya Medical Center, Lembah Pantai, 59100 Kuala Lumpur, Malaysia*

[3]*Hospital Al-Sultan Abdullah, University Technology Mara, 42300 Bandar Puncak Alam, Selangor, Malaysia*

**Corresponding Author's Email:sitik123@uitm.edu.my*

## ABSTRACT

**Background:** Parenting is a journey that may bring joy, happiness, challenges, and frustration. However, raising children with autism with unpredictable behavior may elevate parental stress among parents and family caregivers. **Objective:** The study aims to assess parental stress among family caregivers of children with autism in a teaching hospital. **Methods:** This quantitative cross-sectional study was conducted at Hospital Al-Sultan Abdullah (HASA), University Technology MARA (UiTM), using a convenient sampling technique with a total sample size of 110 parents and family caregivers of children with autism ($n$ = 110). An online questionnaire consisting of the Parental Stress Scale (PSS) and the Childhood Autism Spectrum Test (CAST) was used in this study to assess the level of parental stress and identify the severity of probable autistic behavior. **Results:** The finding shows that 75.5% of the participants were female and 94.5% were Malay. Most autistic children were male (63.6%), and most children ($n$ = 81, 73.6%) had severe autistic behavior. However, 82.7% of participants reported low parental stress (mean = 34.41±13.06). Caregivers were found to have higher stress levels $t$ (108) = -2.16; $p$=0.033). Besides, there was no significant association between the level of parental stress and the severity of autism ($r$=0.035, $p$=0.715). **Conclusion:** Special intervention is needed for the caregiver to improve stress management strategies by involving health care professionals for counseling and assistance to address the effects of stress. A larger sample size is recommended for future research to enhance external validity.

***Keywords: Autism Spectrum Disorder; Autistic Behaviour(s); Caregiver(s); Parent(s); Stress***

## INTRODUCTION

Children are believed to bring happiness to a married couple. Most married couples feel excited and overwhelmed to change their status into parenthood. However, according to Rollè *et al*. (2017), the journey was described as a new task with a unique mandate to be carried out. Considering accountability as a parent to fulfilling children's needs in various aspects, this task might increase stress among parents and family caregivers.

Parental stress among parents and family caregivers is a diverse type of stress that results from extended and excessive parenting demands or workloads beyond their capabilities (Coulacoglou & Saklofske, 2017). Parenting itself is a complex ideology and challenging journey in managing and handling children, especially in the children's early years, and more significant among parents of children with special needs (Padden & James, 2017). Down syndrome, Asperger syndrome, autism spectrum disorder (ASD), Rett syndrome, and attention deficit hyperactivity disorder (ADHD) are examples of children with special needs.

In Malaysia, approximately 1.6 in 1,000 children in 2006 were diagnosed with ASD using the Modified

*Received: September 6, 2023 Received in revised form: December 8, 2023 Accepted: March 10, 2024*

Checklist for Autism in Toddlers (M-CHAT) among children between 18 and 36 months old (Ministry of Health Malaysia, 2018). Children with ASD mostly experience unpredictable and challenging behavioral and emotional difficulties, such as problems with socialization, self-harm, aggression, hyperactivity, anxiety, depression, and the inability to follow instructions (Lindor *et al.*, 2019). Therefore, parents and family caregivers of autistic children struggle to handle and manage their autistic children as their behavior is unpredictable, thus increasing parental stress levels.

Rahman and Jermadi (2021) reported that mental health issues in the parent population of children with ASD in Malaysia had raised the alarm, as 4 out of 5 parents reported having substantially high stress levels. Besides, the percentage of parents in Malaysia who deny the truth that their children have ASD and require professional help seems lower compared to Western countries. Mohamad *et al*. (2019) also mentioned that the primary reason for not getting medical aid and support was related to unpleasant sentiments being labelled, fear of social rejection, and difficulties in their career. However, parents and caregivers are unaware that their actions in not seeking treatment will negatively impact their mental health status, general health, and the whole family system, thus reducing parenting self-efficacy.

Nevertheless, Jx *et al*. (2017) highlighted in their study that there are minimal studies that particularly examine parenting stress in parents of children with ASD; the outcomes of existing studies are inconsistent, and not all demographic parameters were examined. Therefore, this study was conducted to identify the level of parental stress among parents and primary caregivers of autistic children. Hence, various nursing interventions can be implemented to combat parental stress at the preliminary stage to prevent the occurrence of severe mental health disorders.

## METHODOLOGY

### Study Design, Study Setting, and Target Population

The research design used was a quantitative and cross-sectional study. The study conducted at Hospital Al-Sultan Abdullah (HASA), University Technology MARA (UiTM), Puncak Alam city, Selangor, Malaysia. The target population of this study were parents and family caregivers of children with autism in the Child Development Clinic at Hospital Al-Sultan Abdullah (HASA), University Technology MARA (UiTM). The study's target population was a monthly average attendee of 125 individuals ($n$=125).

### Data Collection Process

Before beginning the process of gathering data, informed consent comprising the necessary details for the study was obtained. Confidentiality and anonymity were used to preserve the respondents' privacy while gathering, analysing, and reporting the study's data. Individuals who have taken part could not be identified in any way. Data were collected within three months, from January 2023 until March 2023. A convenience sampling technique was used, and the respondents, parents or caregivers of children with ASD in the Child Development Clinic who met all eligibility criteria, were invited to participate in this study through this online self-administered questionnaire.

### Instrumentations and Pilot Study

The instruments were divided into three sections and prepared in English and Malay. Section 1 is sociodemographic information divided into parents, caregivers, and autistic children, consisting of 10 questions. The questions include the parents or caregiver's section, age, gender, race, educational status, marital status, and relationship with the child, while the children's section includes age, gender, current diagnosis, and duration of diagnosis.

Section 2 relates to the level of parental or caregiver stress. The researcher used the Parental Stress Scale (PSS) with an 18-item questionnaire that Judy Berry and Warren Jones developed in 1995. The PSS is a measurement that focuses on how parents perceive stress rather than evaluating stressors. It was designed to be a scale that distinguishes between parental and general stress and prevents mixing up parental and marital stress. The items covered four parenting-related domains: (a) rewards, (b) stressors, (c) loss of control, or (d) satisfaction (Zelman & Ferro, 2018). Items represent the positive and negative aspects of parenting, such as emotional benefits, personal development, demands on resources, and restrictions. All statements have been

rated using a 5-point Likert scale. The range started with strongly disagree (1), disagree (2), undecided (3), agree (4), and strongly agree (5) (Berry & Jones, 1995). The scoring has been computed as the PSS; items 1, 2, 5, 6, 7, 8, 17, and 18 have been reversely scored (Berry & Jones, 1995). Meanwhile, the other scores are then summed. A low score signifies a low stress level, and a high score indicates a high stress level. The total of possible scores on the scale ranges from 18 to 90. The researcher referred to Zelman and Ferro (2018) to calculate the scores. Figure 3.3 illustrates the Parental Stress Scale's original factor structure according to 18-item questions. However, Zelman and Ferro (2018) excluded two items, items 2 and 4, without further explanation for eliminating these two items. The Malay version was translated into back-to-back translations by a professional language editor with a medical background from Institut Terjemahan & Buku Malaysia (ITBM), Malaysian Translation & Book Institute.

Section 3 is related to the severity of the possible autistic behavior of children with ASD. The researcher has used the Childhood Autism Spectrum Test (CAST), previously known as the Childhood Asperger Syndrome Test, consisting of a 39-item assessment question to screen children's possible autistic behavior in the English version by Williams *et al.* (2005) and the Malay version by Hashmi *et al.* (2021). Even though it is a screening tool, it evaluates potential autistic behavior, and the more potential autistic behavior displayed indicates higher severity and difficulties. The key for possible ASD-relevant responses was underlined and scored '1' for each item except for items 3, 4, 12, 22, 26, 33, and in the special needs section. The maximum score possible is 31, with a cut-off score of 15 for likely ASD or related social-communication difficulties. It is a "yes" or "no" questionnaire for the parent.

Besides, a pilot study was done with 30 individuals from different backgrounds, which was 31.5% of the sample size. The questionnaire reliability showed acceptable internal consistency with Cronbach's alpha value levels for PSS ($\alpha = 0.849$); meanwhile, the CAST was ($\alpha = 0.781$).

**Data Analysis**

Microsoft Excel was used to collect and organize all the data, which was then processed and analyzed using Statistical Package for Social Science (SPSS) Version 27. The statistical significance was set at *p*-value (<0.05), power 0.80, and attributes 20%. The descriptive statistical data on the level of parental stress among family caregivers of children with autism was measured on the mean and standard deviation. Meanwhile, the researcher used the parametric test, an independent t-test, one-way analysis of variance (ANOVA), and Pearson's correlation.

**Ethical Consideration**

Ethical approval was obtained from the Research Ethics Committee of UiTM, Malaysia, with reference no. FERC/FSK/MR/2022/0094 and the HASA Research Ethics Committee with reference number 500-PJI (18/4/28) on 1st December 2022.

**RESULTS**

A total of 110 set questionnaires were dispersed by Google Form, and out of these, all 110 questionnaires were done and returned by the respondents with a response rate of 100%.

**Sociodemographic Background**

As recorded, Table 1 shows the demographic background of the respondents. The findings were reported from the parents or caregivers variable; the study participants had a mean age of 33.62 years (SD = 5.32). The majority fell within the 31–40 age group, comprising 69 individuals (62.7%). According to gender, the study predominantly comprised female participants, accounting for 83 individuals (75.5%), while the remaining 27 participants (24.5%) were male. Regarding race, most participants were Malay, comprising 104 individuals (94.5%), while 6 individuals (5.5%) belonged to non-Malay racial groups. Educational status indicated that 98 participants (89.1%) had attained a tertiary level of education (college or university). Conversely, 12 individuals (10.9%) had completed primary or secondary school education's level. Marital status revealed that most participants were married, accounting for 104 individuals (94.5%), while the remaining 6(5.5%) were unmarried. Regarding the relationship with the child, most participants identified themselves as parents ($n = 96$, 87.3%), while a smaller proportion identified themselves as caregivers ($n = 14$, 12.7%).

Regarding children's variables, the children's age had a mean of 5.78 (SD = 2.26). The majority fell within the 1–5 age group, comprising 56 children (50.9%). The minimal age of the children was 2 years old. Additionally, 49 children (44.5%) were in the 6–10 age range, while a smaller proportion of 5 children (4.5%) were in the 11–15 age group. Pertain to gender, the study predominantly comprised male participants, accounting for 70 children (63.6%), while the remaining 40 participants (36.4%) were female. In terms of diagnosis, the majority of children were diagnosed with ASD, comprising 98 children (89.1%), while 12 children (10.9%) were diagnosed with ASD with other disabilities. On the duration of the diagnosis, the majority of the children were diagnosed in the range of 49–84 months, comprising 54 children (49.1%). Meanwhile, 48 children (43.6%) had ASD for less than 24 months. Lastly, 8 children (7.3%) fall within the 24- to 48-month duration of the diagnosis.

***Table 1: The Sociodemographic Background of Participants (n=110)***

| Variables | | Frequencies (*n*) | Percentage (%) |
|---|---|---|---|
| **Parents/Caregivers** | | | |
| **Age (Mean=33.62; SD=5.32)** | | | |
| | 21 years – 30 years | 35 | 31.8 |
| | 31 years – 40 years | 69 | 62.7 |
| | 41 years – 50 years | 6 | 5.2 |
| **Gender** | | | |
| | Male | 27 | 24.5 |
| | Female | 83 | 75.5 |
| **Race** | | | |
| | Malay | 104 | 94.5 |
| | Non-Malay | 6 | 5.5 |
| **Educational Status** | | | |
| | Primary/ Secondary school | 12 | 10.9 |
| | Tertiary (College/ University) | 98 | 89.1 |
| **Marital Status** | | | |
| | Married | 104 | 94.5 |
| | Unmarried | 6 | 5.5 |
| **Relationship with Children** | | | |
| | Parents | 96 | 87.3 |
| | Caregivers | 14 | 12.7 |
| **Children with ASD** | | | |
| **Age (Mean=5.78; SD=2.26)** | | | |
| | 1 year – 5 years | 56 | 50.9 |
| | 6 years – 10 years | 49 | 44.5 |
| | 11 years – 15 years | 5 | 4.5 |
| **Gender** | | | |
| | Male | 70 | 63.6 |
| | Female | 40 | 36.4 |
| **Diagnosis** | | | |
| | ASD | 98 | 89.1 |
| | ASD with other disabilities | 12 | 10.9 |
| **Duration of Diagnosis (Mean=24.55; SD=17.86)** | | | |
| | < 24 months | 48 | 43.6 |
| | 24 – 48 months | 8 | 7.3 |
| | 49 – 84 months | 54 | 49.1 |

**The Level of Parental Stress Among Family Caregivers of Children with Autism**

Table 2 below represents the results of a questionnaire measuring the parental stress scale (PSS), arranged

in descending order for each domain. The table includes data on four parenting-related domains: (a) rewards, (b) stressors, (c) loss of control, and (d) satisfaction (Zelman & Ferro, 2018). Zelman and Ferro (2018) excluded items 2 and 4 based on the Parental Stress Scale's (PSS) original factor structure.

The first domain, "Parental Rewards," focuses on the positive aspects of parenting. Parents scored an average of 9.14 (SD = 3.50) on this subscale, with $n$ = 108 and 98.2% reporting low stress levels, indicating high satisfaction in their parenting role. The "Parental Stressor" domain measures stress associated with parenting challenges, with an average score of 14.6 (SD = 5.03). Around $n$ = 66, 60.0% reported low stress levels. Meanwhile, in $n$ = 39, 35.5% of participants were found to have moderate stress levels. The third domain, "loss of control," examines feeling overwhelmed and scored an average of 5.33 (SD=2.06), with $n$ = 91 and 82.7% reporting low stress levels. Lastly, the fourth domain, "Parental Satisfaction," measures satisfaction with parenting, with an average score of 5.34 (SD=2.00) and $n$ = 101, with 91.8% reporting a low stress level, indicating a high satisfaction level.

Overall, the total PSS score ranged from 18 to 71, with a mean score of 34.41 (SD=13.06), indicating a low level of parental stress. Among 110 participants, 82.7% reported low stress levels, and no participants fell into the high stress category. These findings suggest that while some parents experience moderate to high stress in specific areas of parenting, the majority reported overall satisfaction and low stress levels in their parenting role.

***Table 2: The Parental Stress Scale (PSS), (n=110)***

| PSS Domain | Mean | SD | Level of PSS | | |
|---|---|---|---|---|---|
| | | | *n* (%) | | |
| | | | Low | Moderate | High |
| Total Parental Rewards | 9.14 | 3.50 | 108 (98.2) | 2 (1.8) | 0 (0.0) |
| Total Parental Stressor | 14.6 | 5.03 | 66 (60.0) | 39 (35.5) | 5 (4.5) |
| Total Loss of Control | 5.33 | 2.53 | 91 (82.7) | 17 (15.5) | 2 (1.8) |
| Total Parental Satisfaction | 5.34 | 2.00 | 101 (91.8) | 9 (8.2) | 0 (0.0) |
| **Total Score** | 34.41 | 13.06 | 91 (82.7) | 19 (17.3) | 0 (0.0) |

*Note: Classification of stress: 1.0-2.4 (Low stress), 2.5-3.4 (Moderate stress) and 3.5-5.0 (Perceived high stress) (Joshi et al., 2015; Zelman & Ferro, 2018)*

## The Association Between Parental Stress and their Sociodemographic Background

Table 3 presents the descriptive statistics and inferential results for the variables on each domain of the Parental Stress Scale (PSS): parental satisfaction, rewards, stressors, and loss of control associated with sociodemographic background. The independent variables in this study were the sociodemographic background of the parents or caregivers and the children with autism; meanwhile, the dependent variable was parental stress.

There was a significant association between relationships with the child and parental stressors ($t$ (108) = -2.16, $p$ = 0.033). The participants with a "caregiver" relationship with their children, with a mean of 2.73 (SD=0.70), reported higher levels of parental stressors compared to participants with a "parent" relationship with their children, with a mean of 2.39 (SD=0.52).

However, no other significant differences were identified in parental satisfaction, rewards, stressors, or loss of control. Besides, factors such as age, gender, race, educational status, marital status, children's diagnosis, and duration of the diagnosis were not found to impact parental stress significantly. These results concluded that caregivers experience higher stressors than parents, but there were no discernible variations in other parental well-being and control aspects.

## *Table 3: The Association between Parental Stress (Each Domain) and their Sociodemographic Background*

| Variables | Parental Satisfaction | | | Parental Rewards | | | Parental Stressor | | | Loss of control | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | Mean (SD) | *t (df) / F (df)* | *p*-value | Mean (SD) | *t (df) / F (df)* | *p*-value | Mean (SD) | *t (df) / F (df)* | *p*-value | Mean (SD) | *t (df) / F (df)* | *p*-value |
| **Parents/ Caregivers** | | | | | | | | | | | | |
| **Age** | | | | | | | | | | | | |
| 21 years-30 years (n=35) | 1.78 (0.46) | | | 1.46 (0.36) | | | 2.40 (0.60) | | | 1.77 (0.70) | | |
| 31 years-40 years (n=69) | 1.78 (0.51) | | | 1.55 (0.44) | | | 2.47 (0.54) | | | 1.80 (0.70) | | |
| 41 years- 50 years (n=6) | 1.78 (0.27) | *F (df)* = 0.001 (2) | 0.999[a] | 1.58 (0.42) | *F (df)* = 6.89 (2) | 0.505[a] | 2.22 (0.29) | *F (df)* = 0.68 (2) | 0.508[a] | 1.50 (0.41) | *F (df)* = 0.53 (2) | 0.590[a] |
| **Total** | **5.34 (1.24)** | | | **4.59 (1.22)** | | | **7.09 (1.43)** | | | **5.07 (1.81)** | | |
| **Gender** | | | | | | | | | | | | |
| Male (n=27) | 1.75 (0.49) | | | 1.60 (0.46) | | | 2.43 (0.48) | | | 1.74 (0.62) | | |
| Female (n=83) | 1.78 (0.49) | -0.316 (108) | 0.753[b] | 1.50 (0.40) | -1.51(108) | 0.244[b] | 2.43 (0.57) | -0.80(108) | 0.936[b] | 2.06 (0.71) | -0.30(108) | 0.762[b] |
| **Total** | **3.53 (0.98)** | | | **3.10 (0.86)** | | | **4.86 (1.05)** | | | **3.80 (1.33)** | | |
| **Race** | | | | | | | | | | | | |
| Malay (n=104) | 1.77 (0.49) | | | 1.52 (0.40) | | | 2.42 (0.55) | | | 1.76 (0.69) | | |
| Non-Malay (n=6) | 2.00 (0.42) | -1.15 (108) | 0.252[b] | 1.64 (0.64) | -0.47 (5.24) | 0.659[b] | 2.58 (0.69) | -0.68(108) | 0.496[b] | 2.00 (0.67) | -0.82(108) | 0.413[b] |
| **Total** | **3.77 (0.91)** | | | **3.16 (1.04)** | | | **5.00 (1.24)** | | | **3.76 (1.36)** | | |
| **Educational status** | | | | | | | | | | | | |
| Primary/secondary (n=12) | 1.64 (0.48) | | | 1.44 (0.36) | | | 2.30 (0.36) | | | 1.56 (0.38) | | |
| Tertiary (n=98) | 1.80 (0.49) | -1.06(108) | 0.292[b] | 1.53 (0.42) | -0.71(108) | 0.481[b] | 2.45 (0.57) | -0.85(108) | 0.397[b] | 1.80 (0.71) | -1.18(108) | 0.241[b] |
| **Total** | **3.44 (0.97)** | | | **2.97 (0.78)** | | | **4.75 (0.93)** | | | **3.36 (1.09)** | | |
| **Marital status** | | | | | | | | | | | | |
| Married (n=104) | 1.79 (0.49) | | | 1.52 (0.41) | | | 2.43 (0.53) | | | 1.77 (0.69) | | |
| Unmarried (n=6) | 1.56 (0.46) | 1.16(108) | 0.248[b] | 1.53 (0.45) | -0.02(108) | 0.983[b] | 2.42 (0.85) | 0.08(108) | 0.940[b] | 1.89 (0.83) | -0.41(108) | 0.680[b] |
| **Total** | **3.35 (0.95)** | | | **3.05 (0.86)** | | | **4.85 (1.38)** | | | **3.66 (1.52)** | | |
| **Relationship with children** | | | | | | | | | | | | |
| Parents (n=96) | 1.78 (0.48) | | | 1.51 (0.42) | | | 2.39 (0.52) | | | 1.73 (0.65) | | |
| Caregiver (n=14) | 1.74 (0.56) | 0.34(108) | 0.738[b] | 1.60 (0.41) | -0.69(108) | 0.494[b] | 2.73 (0.70) | -2.16(108) | **0.033** [b*] | 2.10 (0.86) | -1.89(108) | 0.062[b] |
| **Total** | **3.52 (1.04)** | | | **3.11 (0.83)** | | | **5.12 (1.22)** | | | **3.83 (1.51)** | | |
| **Children with Autism** | | | | | | | | | | | | |
| **Age** | | | | | | | | | | | | |
| 1-5 years (n=56) | 1.77 (0.49) | | | 1.48 (0.39) | | | 2.39 (0.58) | | | 1.70 (0.63) | | |
| 6-10 years (n=49) | 1.82 (0.48) | | | 1.59 (0.44) | | | 2.50 (0.51) | | | 1.88 (0.76) | | |
| 11-15 years (n=5) | 1.40 (0.28) | *F (df)* = 1.76 (2) | 0.177[a] | 1.37 (0.38) | *F (df)* = 1.36 (2) | 0.261[a] | 2.27 (0.68) | *F (df)* = 0.76 (2) | 0.471[a] | 1.53 (0.56) | *F (df)* = 1.25 (2) | 0.290[a] |
| **Total** | **4.99 (1.25)** | | | **4.44 (1.21)** | | | **7.16 (1.77)** | | | **5.11 (1.95)** | | |
| **Gender** | | | | | | | | | | | | |
| Male (n=70) | 1.76 (0.52) | | | 1.49 (0.40) | | | 2.45 (0.58) | | | 1.79 (0.72) | | |
| Female (n=40) | 1.81 (0.42) | -0.48(108) | 0.631[b] | 1.58 (0.43) | -1.06(108) | 0.294[b] | 2.40 (0.49) | 0.48(108) | 0.634[b] | 1.75 (0.63) | 0.30 (108) | 0.768[b] |
| **Total** | **3.57 (0.94)** | | | **3.07 (0.83)** | | | **4.85 (1.07)** | | | **3.54 (1.35)** | | |
| **Diagnosis** | | | | | | | | | | | | |
| ASD alone (n=98) | 1.78 (0.49) | | | 1.53 (0.41) | | | 2.42 (0.54) | | | 1.76 (0.68) | | |
| ASD and other (n=12) | 1.75 (0.45) | 0.22(108) | 0.829[b] | 1.50 (0.44) | 0.21(108) | 0.831[b] | 2.58 (0.67) | -0.10(108) | 0.320[b] | 1.92 (0.78) | -0.75(108) | 0.342[b] |
| **Total** | **3.53 (0.94)** | | | **3.03 (0.85)** | | | **5.00 (1.21)** | | | **3.68 (1.46)** | | |
| **Duration of diagnosis** | | | | | | | | | | | | |
| 24 months (n=54) | 1.85 (0.55) | | | 1.57 (0.39) | | | 2.43 (0.61) | | | 1.82 (0.73) | | |
| 24-48 months (n=8) | 1.63 (0.42) | | | 1.46 (0.44) | | | 2.40 (0.55) | | | 1.71 (0.77) | | |
| 49-84 months (n=62) | 1.73 (0.43) | *F (df)* = 1.21 (2) | 0.302[a] | 1.50 (0.43) | *F (df)* = 0.46 (2) | 0.632[a] | 2.44 (0.50) | *F (df)* = 0.02 (2) | 0.976[a] | 1.74 (0.64) | *F (df)* = 0.24 (2) | 0.790[a] |
| **Total** | **5.21 (1.40)** | | | **4.43 (1.26)** | | | **7.27 (1.66)** | | | **5.27 (2.14)** | | |

*Notes: One-way ANOVA a, Independent t-test b and *Statistically significant (p-value < 0.05)*

### The Association Between Parental Stress and Severity of Probable Autistic Behaviour

***Table 4: The Severity of Behaviour of Children with ASD (n=110)***

| Variable | | | | | Level of CAST, *n* (%) | |
|---|---|---|---|---|---|---|
| | Mean | SD | Min | Max | Severe | Not severe |
| Possible ASD | 13.11 | 4.07 | 3 | 26 | 81 (73.6) | 29 (26.4) |

*Note: Scores in the 15-31 range indicate possible ASD or related social-communication difficulties (Williams et al., 2005; 2006)*

Table 4 shows the severity of behavior in children diagnosed with autism spectrum disorder (ASD), as assessed by the CAST. The mean CAST score for the entire sample of children with ASD in this study is 13.11, with a standard deviation of 4.07. Scores in the sample range from 3 to 26. Most children (n = 81, 73.6%) obtained scores within the 15–31 range, suggesting a significant severity level in their behaviors and social-communication difficulties. These children can be classified as potentially having ASD or facing related developmental challenges. Conversely, n = 29, 26.4% of the children in the sample obtained scores below the 15–31 range, indicating less severe behaviors and social-communication difficulties. These children are classified as not exhibiting ASD-related behaviors to a severe extent.

***Table 5: The Pearson Correlation Analysis Between PSS and CAST (n=110)***

| | PSS |
|---|---|
| Pearson Correlation | 0.035 |
| Sig. (2-tailed) | **0.715** |

Table 5 presents the correlation coefficients between the mean Childhood Autism Spectrum Test (CAST) scores and the mean Parental Stress Scale (PSS) scores. The mean CAST score has a Pearson correlation coefficient of 0.035 with the mean PSS score. The correlation coefficient of 0.035 indicates a weak positive correlation between the two variables. However, this correlation is not statistically significant, as indicated by the *p*-value of 0.715. Thus, there was no significant association between parental stress and the severity of probable autistic behaviour.

## DISCUSSION

### The Level of Parental Stress Among Family Caregivers of Children with Autism

The finding from this study contradicted most of the previous studies, whereby parents and caregivers displayed significantly low stress levels in this study, accounting for 98.2% of the population. The research findings were parallel to the study conducted by Jx *et al*. (2017), which also found that parents and caregivers who care for children with ASD experienced less stress and expressed great satisfaction in caring for the children.

The fact that they have a high level of confidence and optimism toward their child is one factor that contributes to a low level of stress among parents and caregivers. They are positively taking care of their children and making a reasonable effort to raise them. According to Zulkipli, Mansor, and Ismail (2020), positive feelings can refill resources exhausted by stress, offer psychological support, and help with ongoing coping efforts.

In addition, this study shows that the items highlighting children as the primary sources of parental and caregiver stress had the lowest score in the central domain of parental stressors. Thus, it proves that children are not the only primary source of stress in parents' and caregivers' lives. The financial burden, economic impact, and family breakdown also contribute to parents' and caregivers' stress. The finding was consistent with previous studies (Prata, Lawson & Coelho, 2019). Most parents reported experiencing direct and indirect financial stress due to raising a child.

Additionally, this study shows low stress levels in the domain of "Loss of Control" in the PSS on the item having children will be limited and control parents and caregiver lives. It proves that parents and caregivers in this study did not feel their children burdened them, which can affect their bonding with the children. Besides, most of them feel overwhelmed by their parenthood journey in caring for their child. However, the study's findings differed from the previous study by Rahman and Jermadi (2021), which showed the stress brought on by their disappointment, rejection, or alienation from the children and a lack of adequate bonding with the child.

Another factor contributing to low stress among parents and caregivers is parental satisfaction with their children. Most parents and caregivers enjoyed managing their children and were well-informed and aware of their children's problems. In addition, due to high acceptance and awareness of ASD, most parents and caregivers managed to avoid stigmatization, fear of shame, and exclusion from normal social activities. This statement was supported by Alibekova *et al*. (2022), who found that the leading cause of the parents' psychological misery was their lack of social acceptance and support.

**The Association Between Parental Stress and their Sociodemographic Background**

The study showed a significant association between parental stress and sociodemographic background. The findings were similar to the study conducted by Jx *et al*. (2017), where their study found a significant correlation between parental stress and the children's gender.

However, the variable "Relationship with child" showed a significant association between the parental stressor and the total Parental Stress Scale (PSS) score in this study. Caregivers were found to have higher stress levels than parents, even though the total number of caregivers who participated in this study was low. It has to do with the fact that autistic children have unpredictable behavior, and sometimes they are hyperactive; caregivers need to devote more time and effort to caring for them. Autistic children also need to attend additional regular therapy sessions and rehabilitation programs; thus, caregivers need to spend more time on this rather than having their leisure time. The results of this study are consistent with previous research by Fithriyah and Carrasco (2021), which reported that undergoing treatments requires more time, patience, and effort than necessary, which results in anxiety, depression, and psychological anguish.

Parents' sociodemographic background showed no significant association with parental stress. Most parents express their satisfaction and happiness with their respective roles as parents of children with autism. Even though they were grieving about their child's condition, at the same time, they were relieved, grateful, and accepting of their child's condition. It was similar to the study by Wang (2022); most parents undergo a psychological process of denial, self-blame and guilt, uncertainty, frustration, and acceptance before fully accepting their child's condition.

Additionally, children's sociodemographic background showed no significant correlation with parental stress, contradicting previous studies by Jx *et al*. (2017). Parents and caregivers do not guide stress in caring for children who have been diagnosed with autism for a long time or are newly diagnosed. When children with autism enter puberty or adolescence, social development and communication disorders become more apparent. Their experiences caring for the child allow them to overcome these additional difficulties as their child grows.

**The Association Between Parental Stress and Severity of Probable Autistic Behaviour**

The study's findings contradicted the present study, which revealed no correlation between parental and caregiver stress and the severity of autistic behavior, even though most children had severe autistic behavior. The results of this study revealed that parents of children with autism who showed positive parental attitudes or positive adapted feelings about their children's condition scored a low level of stress. These findings correlated with previous studies by Zulkipli, Mansor, and Ismail (2020), which showed the significance and potency of parental personality traits in determining stress levels. Parents and caregivers get much affection for their children, and they will always love their children to raise them.

Based on the parent's and caregivers' interactions with professionals who aid in enhancing the family environment and assist them in meeting the requirements of their children, parents, or caregivers in this research, they expressed their satisfaction feelings with the support services, social support, and social network. The results are consistent with a previous study by Alvarez (2021), which showed that it is essential to involve extended family members, such as grandparents who have received ASD education, and that this can be a great source of support.

Besides positive parental attitudes and having good social support, parental self-efficacy is a central component of parenting that can simultaneously affect parents' actions and children's growth. This statement was consistent with previous research findings that children's cognitive, emotional, and behavioral development would be favorably impacted if parents could increase their self-efficacy (Kishimoto *et al.*, 2023). Hence, the parents will feel more confident, engage with their kids more frequently, and adopt better educational behavior.

## CONCLUSION

This study aimed to determine parental stress among family caregivers of children with autism, the association between parental stress and the sociodemographic background, and the association between parental stress and the severity of probable autistic behavior. The finding of this study was that there is no significant relationship between the level of parental stress and the severity of ASD in children.

Based on the study, most parents and caregivers express their gratitude, acceptance, and relief for their child's problems and try to provide for their children as best as possible. To maintain this kind of attitude, close attention should be paid to parents to develop better coping strategies for stress and child-specific autism symptoms. Nurses have a crucial role in identifying any early signs of parental stress during assessment sessions and determining appropriate nursing interventions to combat extensive complications related to parental stress. Nurses and other healthcare professionals must address the effects of stress and unmet needs in families of children with autism. There must be more public awareness of ASD, and supporting policy and service improvements are essential for effective change for children and families affected by the disorder.

### Conflict of Interest

The authors declare that they have no competing interests.

## ACKNOWLEDGEMENT

The authors are thankful to the Center for Nursing Studies, Faculty of Health Sciences, UiTM Puncak Alam city, the UiTM Research Ethics Committee, and the HASA Research Ethics Committee for their ethical approval. The authors are also, thankful to the respondents who participated in this research. Special thanks to the FRGS grant (Ref: FRGS/1/2023/SS10/UITM/02/6) UiTM Ref: 600-RMC/FRGS 5/3 (042/2023) for sponsoring this publication.

## REFERENCES

Alibekova, R., Chan, C. K., Crape, B., Kadyrzhanuly, K., Gusmanov, A., An, S., ... & Rakhimova, M. (2022). Stress, anxiety and depression in parents of children with autism spectrum disorders in Kazakhstan: prevalence and associated factors. *Global Mental Health, 9*, 472-482. https://doi.org/10.1017/gmh.2022.51

Alvarez, E. (2021). Stress and Coping among Parents or Caregivers Raising a Child with an Autism Spectrum Disorder (ASD). California State University, Fresno. https://search.proquest.com/openview/92957c3a08e0d091be5ee9a2b9bc3d4b/1?pq-origsite=gscholar&cbl=18750&diss=y. Accessed on 26th April, 2022

Berry, J. O., & Jones, W. H. (1995). The parental stress scale: Initial psychometric evidence. *Journal of Social and Personal Relationships, 12*(3), 463-472. https://doi.org/10.1177/0265407595123009

Coulacoglou, C., & Saklofske, D. H. (2017). *Psychometrics and Psychological Assessment: Principles and applications*. Academic Press. https://scirp.org/reference/referencespapers?referenceid=2394794. Accessed on

28th April, 2022

Fithriyah, I., & Carrasco, M. E. (2021). Caregiver burden and psychosocial factors in mothers with autism spectrum disorder children. *Biomolecular and Health Science Journal, 4*(2), 103. https://doi.org/10.20473/ bhsj.v4i2.28875

Hashmi, S. I., Gang, G. C. A., Sombuling, A., Nawi, N. H. M., & Ahmad, P. H. M. (2021). Psychometric Properties and Factor Structure of the Malay Autism Spectrum Quotient: Children's Version. *The Malaysian Journal of Medical Sciences: MJMS, 28*(6), 108. https://doi.org/10.21315/mjms2021.28.6.11

Joshi, A., Kale, S., Chandel, S., & Pal, D. K. (2015). Likert scale: Explored and explained. *British Journal of Applied Science & Technology, 7*(4), 396-403. https://doi.org/10.9734/bjast/2015/14975

Jx, L., Si, O., Vy, L., & Ar, F. N. (2017). Parenting stress among Malaysian parents of children with Autism Spectrum Disorder (ASD). *Journal of Medicine and Health Care, 12*(1), 42-55. https://doi.org/ 10.17576/mh.2017. 1201.06

Kishimoto, T., Liu, S., Zhang, L., & Li, S. (2023). How do autistic severity and family functioning influence parental stress in caregivers of children with autism spectrum disorder in China? The important role of parental self-efficacy. *Frontiers in Psychology, 14*, 956637. https://doi.org/10.3389/fpsyg.2023.956637

Lindor, E., Sivaratnam, C., May, T., Stefanac, N., Howells, K., & Rinehart, N. (2019). Problem behavior in autism spectrum disorder: considering core symptom severity and accompanying sleep disturbance. *Frontiers in Psychiatry, 10*, 487. https://doi.org/10.3389/fpsyt.2019.00487

Ministry of Health Malaysia. (2018). *Clinical Practive Guidelines Management of Autism Spectrum Disorder in Children and Adolescents*. Malaysian Health Technology Assessment Section (MaHTAS). https://efaidnbmnnnibpcajpcglclefindmkaj/https://www.moh.gov.my/moh/attachments/CPG%202014/CPG%20Management%20of%20Autism%20Spectrum%20Disofer%20in%20Children%20and%20Adolescents.pdf

Mohamad, S. P., Yusoff, M. Y., Mohd, Z., Adli, D. S. H., & Golden, K. J. (2019). Mental Health Studies on The Coping Strategies of Muslim Parents of Children with Autism Spectrum Disorder in Malaysia (A Narrative Review). *Malaysian Journal of Medicine & Health Sciences, 15*. https://medic.upm.edu.my/upload/dokumen/2019042916043625_0351(Final)25.pdf

Padden, C., & James, J. E. (2017). Stress among parents of children with and without autism spectrum disorder: a comparison involving physiological indicators and parent self-reports. *Journal of Developmental and Physical Disabilities, 29*(4), 567-586. https://doi.org/10.1007/s10882-017-9547-z

Prata, J., Lawson, W., & Coelho, R. (2019). Stress factors in parents of children on the autism spectrum: An integrative model approach. *International Journal of Clinical Neurosciences and Mental Health, 6*(2), 1-9. https://doi.org/10.21035/ijcnmh.2019.6.2

Rahman, P. A., & Jermadi, S. H. (2021). Parental Stress and Parenting Styles in Managing Autistic Children With Behaviour Problems. *Malaysian Journal of Medicine & Health Sciences, 17*(3). https://efaidnbmnnnibpcajpcglclefindmkaj/https://medic.upm.edu.my/upload/dokumen/2021060913532012_2020_1168.pdf

Rollè, L., Prino, L. E., Sechi, C., Vismara, L., Neri, E., Polizzi, C., ... & Brustia, P. (2017). Parenting stress, mental health, dyadic adjustment: A structural equation model. *Frontiers in Psychology, 8*, 256995. https://doi.org/10.3389/fpsyg.2017.00839

Wang, L. (2022, December). Social Dilemmas Faced by Parents of Children Diagnosed with Autism in China. In *2022 6th International Seminar on Education, Management and Social Sciences (ISEMSS 2022)* (pp. 1377-1382). Atlantis Press. https://doi.org/10.2991/978-2-494069-31-2_163

Williams, J., Allison, C., Scott, F., Stott, C., Bolton, P., Baron-Cohen, S., & Brayne, C. (2006). The Childhood Asperger Syndrome Test (CAST) Test–retest reliability. *Autism, 10*(4), 415-427. https://doi.org/10.1177/ 1362361306066612

Williams, J., Scott, F., Stott, C., Allison, C., Bolton, P., Baron-Cohen, S., & Brayne, C. (2005). The CAST (childhood

asperger syndrome test) test accuracy. *Autism, 9*(1), 45-68. https://doi.org/10.1177/1362361305049029

Zelman, J. J., & Ferro, M. A. (2018). The parental stress scale: psychometric properties in families of children with chronic health conditions. *Family Relations, 67*(2), 240-252. https://doi.org/10.1111/fare.12306

Zulkipli, A. E., Mansor, M., & Ismail, Z. (2020). Parental Attitude, Social Support, and Parental Stress Among Parents of Children With Autism in Selangor, Malaysia. *International Journal of Education, Psychology and Counseling, 5*(34), 160–175. https://doi.org/10.35631/ijepc.5340013