

Associated Factors of Parental Stress: Child Repetitive Behaviour and Cognitive Emotional Regulation in Parents of Children with Autism Spectrum Disorder in Kelantan

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ABSTRACT

INTRODUCTION: Restricted and Repetitive behaviour (RRB) is one of the main features in autism spectrum disorder (ASD). This behaviour may disrupt children's routines and adaptability, contributing to significant parental stress. Good coping strategies are important for parents in handling this stress. This study aims to study the parents' stress levels, children's restricted and repetitive behaviour, and cognitive-emotional regulation among parents of ASD children in Kelantan and its associations. **MATERIALS & METHODS:** A cross-sectional study was conducted from December 2023 to May 2024, involving 177 parents, selected through purposive sampling. Data were collected using the Malay versions of the Perceived Stress Scale, Repetitive Behaviour Scale-Revised, and Cognitive Emotional Regulation Questionnaire. Descriptive statistics and linear regression analyses were performed using SPSS to identify significant predictors. **RESULTS:** Among the respondents, 80.2% were mothers. The mean perceived stress score was slightly high at 16.86 (6.26). Positive Reappraisal had the highest cognitive strategy score with a mean 15.30 (3.89). The most common RRB was *Sameness* with a mean 7.95 (6.38). Factors significantly associated with parental stress included being a mother, having mental illness, *Rumination*, *Positive Refocusing*, *Positive Reappraisal*, *Stereotyped*, and *Sameness* behaviour (all $p < 0.05$). **CONCLUSION:** Parental stress was moderately high among those with ASD children in Kelantan. Major stressors included being a mother, having mental illness, *rumination*, and children's *stereotyped* and *sameness* behaviours, while *positive refocusing* and *reappraisal* acted as protective factors. These findings highlight the need to promote effective cognitive emotional regulation strategies to alleviate stress in parents of children with ASD.

Keywords

Autism Spectrum Disorder, Repetitive Behaviour, Stress, Parents, Emotional Regulation.

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INTRODUCTION

Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder characterised by impairments in communication, behaviour and social functioning beginning in childhood¹. ASD affects approximately 0.6% of children worldwide.² Ministry of

Health Malaysia recorded that the prevalence of ASD was 1.6 in 1000 population. One of the key domains in diagnosing ASD in children is restricted and repetitive patterns of behaviour, interests, or activities.³

Caring for a child with ASD presents unique challenges that significantly impact the mental health and well-being of caregivers.⁴ The stress associated with these demands can be substantial and often leading to multiple mental health issues compared to caregivers with typically developed children.^{5,6} Xin Lee compared stress levels among Malaysian parents of typically developed children to parents of ASD children and found significant higher level of parenting stress among the latter group ($U=15.0$, $p<0.001$).⁷ A study by Adib et al found that 81.6% of parents with ASD children in Kelantan experienced moderate to high level of stress with mean perceived stress score of 16.96 ($SD=4.66$).⁸

Parental stress in families with children diagnosed with ASD significantly impacts the well-being of both parents and children, influenced by environmental, child-related, and parent-related factors.⁹ These include residing far from healthcare facilities, lack of personal transportation to treatment centres, children of younger age, children with comorbid intellectual disability and social impairment and parents poor coping strategies.^{8,9,10,11}

Restricted and repetitive behaviour (RRB) is thought to be a hallmark of ASD.¹² According to Esbensen et al., RRBs encompass a wide range of behaviours, from repetitive movements to more cognitively mediated symptoms like excessive interests or preoccupations.¹³ Restricted and repetitive behaviours can be particularly challenging for parents as they may interfere with daily routines and make transitions or unexpected changes more difficult for children. Managing these behaviours often requires additional time, attention, and flexibility from caregivers, which may contribute to increased parental stress. A study in Italy found that among the RRB subtype, Stereotype and Ritualistic/Sameness behaviour was the most frequent behaviour among ASD children.¹⁴ While a local study by Chua et al., found positive correlation between behavioural problems and caregiver burden.¹⁵

Often, parents of children with ASD employ maladaptive coping strategies, and this too increase their

susceptibility to stress exhibiting higher levels of anxiety and depression compared to parents with typically developed children.^{16,17} Cognitive emotional regulation (CER) is a process of integrating emotional and behavioural responses, allowing individuals to adapt their strategies in response to changing emotional contexts.¹⁸ Parents of children with ASD who had difficulty in managing emotions are linked to an increase perception of stress in their parenting roles.¹⁹

Existing research on ASD has focused on parental stress related to meeting children's needs, social factors, and general behaviours. Although studies such as Harrop et al. have reported associations between restricted and repetitive behaviours (RRB) and caregiver stress, evidence from Malaysia remains limited. Research examining the combined influence of children's RRB and parental cognitive emotional regulation (CER) strategies on parental stress is also scarce. Therefore, this study investigates the relationship between RRB, CER strategies, and parental stress, among parents of children with ASD in Kelantan.

MATERIALS AND METHODS

Design and Participants

This cross-sectional study was conducted from December 2023 to May 2024, employing purposive sampling to select participants from two populations: children attending the psychiatric clinic at Hospital Pakar Universiti Sains Malaysia (HPUSM), Kubang Kerian, Kelantan and those at the Kelantan Autism Care Centre (KACC), Kota Bharu, Kelantan. HPUSM offers multidisciplinary services, including Child and Adolescent Psychiatry, while KACC provides education and rehabilitation for children with ASD throughout Kelantan. This approach facilitated access to a larger and more diverse cohort of children with ASD by incorporating children from various districts in Kelantan.

All parents attending psychiatry clinic and KACC and met the inclusion and exclusion criteria were invited to

participate in this research. The inclusion criteria were parents with ASD children aged 2-12 years, who were diagnosed by psychiatrists or paediatricians. The exclusion criteria were parents who do not understand Malay or illiterate. Only one parent from each family was invited to participate. The participating parent was the one who met the inclusion criteria of spending more time with the child. Both parents or a parent-child dyad were not included to avoid duplication of data and to ensure consistency in reporting the child's experiences. The sample size was calculated using the single mean formula, and the total number of respondents required, after accounting for a 10% attrition rate (based on prior similar online surveys among parents in our setting, which showed minimal dropout when the questionnaire was concise and recruitment was via targeted networks; additionally, the questionnaire was designed to be completed in one sitting of approximately 10-15 minutes, reducing incomplete responses), was 195.

Four sets of questionnaires were distributed online to parents, with guidance from the researcher. In cases where both parents were present, the parent who spent more time with the child completed the questionnaires (defined as the parent who, on average, spent most the child's waking hours during a typical week, more than 50% of waking hours). The questionnaires used were i) sociodemographic data ii) Perceived Stress Scale-10 (PSS-10), iii) Repetitive Behaviour Scale-Revised RBS-R) and iv) Cognitive Emotional Regulation Questionnaire (CERQ). All the questionnaires used were the validated Malay versions. The sociodemographic section contained 19 questions, divided into parent and child data. It included information on sex and age of both parents and children, educational level, employment, monthly income, which were then categorized according to the Department of Statistics Malaysia in 2020, distance to the therapy centre, medical and psychiatric conditions in parents, number of children and number of children requiring special needs, participation in therapy, and whether the children had a disability card.²⁰

The Malay version of the PSS-10 consists of 10 items rated on a 5-point Likert scale (0-4), with higher total scores indicating greater perceived stress. Stress levels are categorized as: much lower (0-7), slightly lower (8-11), average (12-15), slightly higher (16-20), and much higher (>20).²¹ The Malay version of PSS-10 was validated by Sandhu et al., and had a Cronbach's alpha of 0.63 and an ICC of 0.8. Significant correlations were found with the DASS-21 stress component ($r=0.61$, $p<0.001$; $r=0.56$, $p<0.004$).²²

The RBS-R Malay version consisted of 43 items with 6 subdomains: i) stereotyped Behaviour; ii) Self-injurious Behaviour; iii) Compulsive Behaviour; iv) Ritualistic Behaviour; v) Sameness Behaviour; and vi) Restricted Behaviour. Items on the RBS-R were rated on a 4-point Likert scale ranging from 0 to 3. The higher the RBS-R scores, the more severe the behaviours. The Malay-validated RBS-R questionnaire has a good internal consistency with Cronbach's alpha ranging from 0.758 to 0.914. The internal consistency for the overall questionnaire scale gave Cronbach's alpha coefficient of 0.940, while the overall scale-level FVI was above 0.²³

The CERQ, a 36-item self-report questionnaire, measures nine cognitive emotional regulation strategies, both i) adaptive (i.e. *positive refocusing*, *positive reappraisal*, *putting into perspective*, *refocus on planning* and *acceptance*) and ii) the less-adaptive (i.e. *rumination*, *self-blame*, *blaming others* and *catastrophizing*). The Malay version, CERQ-M, demonstrated strong reliability ($\alpha = .891$) and satisfactory fit (CFI=0.80).²⁴

STATISTICAL ANALYSIS

Data were entered, cleaned, and analysed using statistical software Statistical Package for Social Study (SPSS) version 29. Descriptive statistics were used to analyse demographic data, with categorical data presented as frequencies and percentages, and numerical data as mean and standard deviation (SD). Simple and multiple linear regression were used to identify factors associated with perceived stress. Demographic, CERQ, and RBS-R scores were analysed as independent variables, while

PSS-10 scores were the dependent variable. Variables with a p-value <0.25 and clinically relevant variables were included in the multiple regression model. Significant variables (p<0.05) were checked for interactions and multicollinearity to determine the final model.

RESULT

Characteristics of the parents and children

A total of 177 caregivers participated in this study, with a mean age of 37.29 (5.16) years old. The majority were mothers 142 (80.2%), predominantly Muslims and Malay 169 (95.5%). Educational attainment indicated 72.3% with tertiary education, while only 68.9% were employed. The majority of the participants reside less than 25km away from the therapy centre. Only 27 (15.3%) of the parents reported having underlying chronic diseases, and 14 (7.9%) had underlying mental illness. On average, the participants had one disabled child.

Meanwhile, the children with ASD had a mean age of 6.45 (2.10) years old. The majority of the children were male, 140 (79.1%). The mean age at diagnosis was 4 (1.38) years old, with 169 (95.5%) receiving therapy and 150 (84.7%) own the disability card. Their sociodemographic characteristics are shown in **Table I**.

Table I Sociodemographic profile (n=177)

Variables	n(%)	Mean (SD)
<i>Parents' Information</i>		
Age		37.29 (5.16)
Sex		
Male	35 (19.8)	
Female	142 (80.2)	
Religion		
Islam	169 (95.5)	
Buddha	4 (2.3)	
Christian	4 (2.3)	
Race		
Malay	169 (95.5)	
Non-Malay	8 (4.5)	
Marital Status		
Married	167 (94.4)	
Divorced	10 (5.6)	
Education		
Tertiary level	128 (72.3)	
Secondary level	49 (27.7)	
Employment		
Employed	122 (68.9)	
Unemployed	54 (30.5)	
Retired	1 (0.6)	

Income (n=173)		
B40 (< RM 3030)	69 (39.9)	
M40 (RM 3030 – 6619)	53 (30.6)	
T20 (> RM 6620)	51 (29.5)	
Distance (n=170)		
< 25km	147 (86.5)	
> 25km	23 (13.5)	
Chronic disease		
Yes	27 (15.3)	
No	150 (84.7)	
Mental illness		
Yes	14 (7.9)	
No	163 (92.1)	
*Disabled children		1 (0)
Children's Information		
Child age		
2-4 years old	31 (17.5)	
5-6 years old	69 (39)	6.45 (2.1)
7-9 years old	62 (35)	
10-12 years old	15 (8.5)	
Child sex		
Male	140 (79.1)	
Female	37 (20.9)	
Age of diagnosis		
Therapy		4.00 (1.38)
Yes	169 (95.5)	
No	8 (4.5)	
Disability card		
Yes	150 (84.7)	
No	27 (15.3)	
*No of siblings		2 (1)

*Median (IQR) used for number of siblings

Level of Stress Among Parents with ASD Children in Kelantan

The mean total score on the PSS for the 177 caregivers of children with ASD was 16.86 (6.26), with item 5, “*felt that things were going your way*,” scoring the highest with a mean of 2.14 (1.11).

Types of Cognitive Emotional Regulation Among Parents with ASD Children in Kelantan

Positive reappraisal (attaching a positive meaning to a negative situation for personal growth) scored the highest among parents, with a mean score of 15.30 (3.89). On the other hand, *blaming others* (attributing the responsibility for one's experiences to others) scored the lowest with a mean score of 5.62 (2.54). The result is shown in Table II.

Table II Types of cognitive emotional regulation among parents with ASD children (n=177)

Cognitive Emotional Regulation	Mean	SD
Positive Reappraisal	15.30	3.89
Refocus on Planning	14.85	3.89
Rumination	12.70	4.63
Positive Refocusing	12.53	3.57
Putting into Perspective	12.25	3.48
Acceptance	10.95	3.19
Self-Blame	9.47	4.10
Catastrophizing	8.59	3.69
Blaming others	5.62	2.54

Types of RRB Among Children with ASD in Kelantan

Sameness behaviour (resistance to change, insisting that things stay the same) scored the highest with a mean score of 7.95 (6.38), followed by *compulsive behaviour* (behaviour that is repeated and performed according to a rule or involves things being done “just so”) with mean score of 6.73 (4.57). Self-injurious behaviour scored the lowest with a mean score of 2.59 (2.06). The result is shown in Table III.

Table III Level of RRB among children with ASD in Kelantan (n=177)

RBS-R Subscales	Mean (SD)
Sameness Behaviour	7.95 (6.38)
Compulsive Behaviour	6.73 (4.57)
Stereotype Behaviour	6.29 (3.58)
Ritualistic Behaviour	5.42 (3.84)
Restricted Behaviour	4.33 (3.00)
Self-injurious Behaviour	2.59 (2.06)

Factors associated with perceived stress among caregivers with ASD children

Variables with a p-value <0.25 from simple linear regression (Self-blame, Rumination, Catastrophizing, Blaming Others, Positive Refocusing, Refocus on Planning, Positive Reappraisal, Stereotyped Behaviour, Self-injurious, Compulsive, Ritualistic, Sameness, Restricted Behaviour, Parents' Sex, Religion, Mental Illness, and Number of Children) and clinically relevant variables (distance to therapy centre, household income, and Putting into Perspective) were further analysed using multiple linear regression. The results are shown in Table IV.

The result demonstrated that mothers exhibited higher perceived stress levels than fathers, increasing the PSS score by 2.13 (p=0.037, 95%CI 0.35 to 4.00). Caregivers with underlying mental illness experienced elevated perceived stress, illustrating an increment in the PSS score by 3.36 (p=0.019, 95% CI 0.55 to 6.16).

For cognitive emotional regulation, employing strategies such as *Rumination* led to an elevation in the PSS score by 0.61 (p<0.012, 95% CI 0.44 to 0.78), while *Positive Refocusing* and *Positive Reappraisal* demonstrated reductions in the PSS score by 0.40 (p=0.01, 95% CI -

0.71 to -0.09 and 0.36 (p=0.011, 95% CI -0.64 to -0.09) respectively.

Children's behaviour *Stereotypes* and *Sameness* affects parents' perceived stress by increment in PSS score of 0.40 (p=0.001, 95% CI 0.16 to 0.64) and 0.20 (p=0.012, 95% CI 0.04 to 0.35), respectively.

Table IV Associated factors of perceived stress among caregivers with ASD children

Variables	Simple Linear Regression			r	Multiple linear regression		
	b	95% CI	P-Value		b	95% CI	P-value
Mother vs Father	2.75	(0.45, 5.05)	0.019	0.03	2.127	(0.12, 3.76)	0.037
Experiencing Mental illness	7.75	(4.50,11.00)	<0.001	0.11	3.36	(0.55,6.16)	0.019
Rumination	0.56	(0.37, 0.74)	<0.001	0.17	0.61	(0.44, 0.78)	<0.001
Positive Refocusing	-0.3	(-0.56, -0.04)	0.024	0.03	-0.40	(-0.71, -0.09)	0.012
Positive Reappraisal	0.43	(-0.70, -0.20)	<0.001	0.07	-0.36	(-0.64, -0.09)	0.011
Stereotype	0.51	(0.26, 0.76)	<0.001	0.09	0.40	(0.16, 0.64)	0.001
Sameness	0.30	(0.16, 0.44)	<0.001	0.10	0.20	(0.04, 0.35)	0.012

DISCUSSION

Consistent with previous studies, the majority of the participants were mothers, as mothers spent more time caring for the children.^{25,26} The distribution in this study reflected the Kelantanese population, where 95% of them were Muslims. The majority of the participants were Malay and Muslims.²⁷

The level of perceived stress among parents of children with ASD in Kelantan was found to be slightly high. This is aligned with previous literature whereby parents caring for ASD children were experiencing more stress compared to those with typically developing children and those with Down Syndrome.^{4,5,6,10} This heightened stress is often attributed to the children's behaviours and community stigmatization, stemming from a lack of public awareness, and understanding about ASD.^{4,7,28}

Our study found that the most commonly used cognitive emotional regulation strategies among parents in our sample were positive reappraisal, refocus on planning, and rumination. These findings align with Isa et al., where cognitive reframing, which is conceptually similar to positive reappraisal, was among the most common coping strategies, alongside religion and acceptance.¹⁰

This suggests that adaptive strategies such as reframing and planning are commonly used by caregivers, while cultural and religious contexts may also influence coping behaviours. The predominance of Malay Muslim participants in the present study may partly explain the high use of positive reappraisal. Within the local context, concepts such as *redha* (acceptance of God's will) and gratitude may encourage parents to reinterpret caregiving challenges in a more positive and meaningful manner. Such religious coping mechanisms may complement positive reappraisal and help reduce the psychological impact of caregiving stress.

Sameness behaviour emerged with the highest mean score among RRBs, confirming a trend seen in other studies where it consistently appears as one of the top three most prevalent behaviours, alongside stereotypy, restricted, and ritualistic behaviours.^{14,29,30}

Our study found that mothers experienced higher stress levels than fathers, likely due to their greater involvement in parenting and social activities with their children, as supported by previous studies^{31,32}. In contrast, Adib et al. and Azamin Anuar et al. reported no significant gender differences in stress.^{8,26} This discrepancy may stem from differences in statistical models (logistic vs. linear regression), lower PSS cut-off points in previous studies, and differences in sample populations, as earlier studies focused on broader caregiver groups rather than parents specifically.

In our study, the heightened stress levels observed, particularly among parents with underlying mental illnesses, could be indicative of the role that mental well-being plays as a contributing factor. According to Teh et al., compromised mental well-being may exacerbate the perceived stress levels in parents of children with ASD, suggesting that mental health status significantly influences stress perception.³³ This underscores the importance of supporting mental health to mitigate stress among parents of children with ASD, highlighting a crucial area for intervention.

Our findings are consistent with previous research, showing that adaptive coping strategies, such as positive reappraisal and positive refocusing, are negatively associated with stress, reinforcing their role as protective buffers against parental stress.³⁴ These strategies help parents manage stress more effectively by promoting optimism and cognitive control. In contrast, maladaptive coping strategies such as rumination are positively associated with perceived stress, as rumination is believed to perpetuate the cycle of negative thoughts and emotions in parents. This aligns with previous studies which found that emotional dysregulation and maladaptive coping strategies increase parents' vulnerability to stress, highlighting the importance of adaptive emotional regulation.^{16,17,19}

Our study found that *stereotype* and *sameness* behaviours in children with ASD cause significant stress for parents. Stereotype behaviours in children with ASD are often inappropriate and unpredictable, causing disruptions in everyday routines and adding to parental stress.^{34,35} On the other hand, sameness behaviours make it difficult for children to adapt to changes, making transitions and unexpected events particularly challenging for parents to manage. A lack of awareness about ASD makes it harder for parents and others to understand these behaviours, adding to the stress.²⁵

While previous studies have not directly associated *sameness* behaviour with increased parental stress, our findings reveal a significant connection, suggesting that such behaviours can substantially stress parents. This new insight underscores the necessity for further detailed research to understand how sameness and other RRBs specifically affect parental stress in families with ASD, potentially informing targeted interventions to better support these families.

LIMITATION AND RECOMMENDATION

One major limitation of this study is its cross-sectional design, which limits the ability to determine causal relationships between mental health issues and perceived stress. While a strong association was found,

it's unclear whether pre-existing mental health conditions increase stress or if high stress leads to mental health disorders. Longitudinal studies are needed to clarify these dynamics over time, identifying key intervention points to reduce stress and prevent mental health problems in caregivers.

The use of purposive sampling and self-reported measures may limit the generalizability of the findings, as self-reporting can introduce biases like social desirability or recall errors. Future research should adopt more rigorous sampling methods and include objective measures to improve reliability and applicability across different populations, thus confirming and expanding upon these preliminary results.

We acknowledge the potential bias due to the predominance of mothers (80%) in our sample, which reflects their more active role in caregiving. While this provides valuable insights, we recognize the importance of capturing both parents' perspectives, as fathers may experience and manage stress differently. Fathers may experience stress differently from mothers, often focusing on financial responsibilities, future planning, and concerns regarding long-term care, whereas mothers are typically more involved in daily caregiving activities and behavioural management. These differing roles may influence both the nature and intensity of stress experienced by each parent. Therefore, we recommend future studies aim for a more balanced representation of both parents to gain a fuller understanding of parental stress. Despite the bias, our findings remain relevant, as mothers are often the primary caregivers in families with children with ASD.

The findings also underscore the importance of parental mental well-being and its impact on stress levels. Therefore, screening for mental health and coping strategies in parents is crucial and should be implemented in clinical settings to better support families. Proper interventions could improve family dynamics and enhance overall quality of life.

CONCLUSION

This study examined a range of environmental, parental, and child-related factors associated with parental stress among parents of children with ASD in Kelantan. The findings highlight the significant role of cognitive emotional regulation in shaping parental stress and underscore the influence of children's stereotyped and sameness behaviours on caregiver well-being.

INSTITUTIONAL REVIEW BOARD (ETHICAL COMMITTEE)

This study was approved by the Human Ethical Committee of the School of Medical Sciences (JEPeM), Universiti Sains Malaysia, with JEPeM ethical code of USM/JEPeM/KK/23050388.

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