ORIGINAL ARTICLE

Parental Stress and Coping Attitudes in Autism Spectrum Disorder Children: A Survey during Movement Control Order period amid COVID-19 Pandemic

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ABSTRACT

Introduction: Parents with autistic children are more susceptible of developing stress due to genuine challenges in treasuring them. During the world pandemic disaster of COVID-19 emergency, the challenge is far greater than expected as movement control order restricted them to seek for help and resources as the country adopting strict isolation measurement to restrain COVID-19 virus infection. This survey was conducted online to determine the prevalence of stress, independent predictor and assessing coping style that help to overcome them. **Methods:** This was a cross-sectional study using Facebook platform. The survey was posted into *Autisme Malaysia* group for 2 weeks duration from 17th June until 30th June 2020. Stress was measured using Malay version of Perceived Stress Scale (PSS-10) and coping style using Brief COPE questionnaire. Independent t-test was used to determine coping style associated with stress and multiple logistic regression for independent stress predictor. **Results:** The mean age of respondents was 38.9 years old with mean child's age was 8.6 years old. Majority of respondents were female, Malay, and married couples with 83.1% of the caregivers were having stress. The independent predictor for stress were age of the caregivers and the level of education. The approach style of coping was significantly associated with stress. **Conclusion:** The pandemic has directly and indirectly contributed to stress prevalence among caregivers of children with autism. Hence, the right coping style should be embraced and empowered to parents for healthier stress therapy. Our findings recommended that coping style of informational support, behavioural disengagement, religion and acceptance as dynamic model of coping style.

Keywords: Autism Spectrum Disorder, Parental Stress, Coping Style, COVID-19

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INTRODUCTION

Autistic Spectrum Disorder (ASD) is a neurodevelopmental disorder characterised by deficits in social interactions and communication skills, both verbal and non-verbal, restricted interests, and stereotypical behaviours, impairments in communication, behaviour and social functioning beginning in childhood (1). Due to this, there are mega challenges in raising children with ASD. Parents or caregivers are at higher risk for stress where they may develop enervation, resentment, anger, or guilt that results from unrelenting caring for

a chronically ill dependent or even more alarming "caregiver burnout" where they become negative and unconcerned towards ASD children. This is a genuinely real situation where abuse cases are commonly being reported in the news despite the statistics being under reported. This was highlighted by Hoover (2015), in his review paper, looking at the effects of psychological trauma among children with autism spectrum disorders (2). Out of 17 studies in his review, the rate of exposure to potentially traumatisation event in ASD children was 20% higher compared to children in general population (2). He concluded that children with ASD may be more sensitive to the effects of traumatising situation than other groups (2).

Several studies argued that having ASD children amplifies challenging issues, limits family opportunities

(3), and increases the incidence of clinically significant anxiety and depression for these parents to be more than three times the rate of the normal adult population (4). Furthermore, another challenge involves differences in parenting including differences in accepting the ASD diagnosis, discipline, managing the child's behaviour and caring for the child (5). In fact, marital difficulty experience was little to report despite high divorce rate and strategies to manage the relationship (6). Fathers tend to use avoidance approach to avoid dealing with stressors brought in by ASD children and mothers typically use emotional approach and struggle with feelings of incompetency and low self-efficacy thus scoring higher than fathers for stress and depression (4,6,7).

Ever since the world had been struck by COVID-19 towards the end of 2019, it had caused a global chaos and declared pandemic by the World Health Organization. Thus, in order to contain the COVID-19 pandemic in the country, Malaysia has implemented the Movement Control Order (MCO) starting on 18th March and lasted for over 3 months. The lockdown or partial lockdown period resulted in restrictive rules in which all social activities and mass gatherings were banned, schools and offices were closed, restrictions of entry, both citizens and non-citizens, were implemented (8). Only essential services were allowed to resume, with restrictions in the number of working staff. Apparently, this unprecedented event has caused a great impact not only financially but also emotionally.

In this situation, parents or caregivers and autistic children require to stay at home as per the MCO and handling them could be challenging. This measure resulted in no outside activities or therapeutic interventions being delivered and no advice nor consultation being conducted. To a certain extent, it could instigate parental stress and exacerbate children's behavioural problems. The aim of this study is to measure the stress prevalence, the associated factors and identify predictor for the stress. The study also aim to describe the associated patterns of coping styles with stress among the caregivers.

MATERIALS AND METHODS

Study design and participants
A cross sectional study was conducted using an online survey during the MCO period from 17th June until 30th June 2020. Participants were approached through the Malaysia Autisme group on Facebook platform. The group consisted over 90000 users and a google form link was posted into the platform wall for dissemination among the group users. Any parent of children with ASD in the Facebook group are invited to participate in the study on a voluntary basis. Those who meet the inclusion and exclusion criteria will be given the online participant information sheet and will be explained regarding the study before giving the informed consent. We include all adult primary caregivers of children with ASD, and we exclude those with underlying psychiatric illness or chronic illness. Sample size was calculated for the primary outcome based on single proportion estimation using Gpower software (9). Based on systematic review by Ilias et al (2018) show that more than 90% of parents with autistic children experience some form of stress in Malaysia (10). We are estimating the stress level of 90% with 5% precision, alpha level of 0.05 and 80% of power. The minimal required sample size is 231. Due to online survey, we estimate 50% response rate, the final estimated sample size to be 460. Online questionnaires were distributed to the respondents in the group. The questionnaires used in this study are validated and consist of three sections which are sociodemographic data, 10-item Malay version Perceived Stress Scale (PSS-10) and the 28- item of Brief COPE questionnaire to measure coping skills of respondents. Reminders were given in the Facebook group every 48 hours to increase the rate of response.

Study instruments
The main outcome variable is the stress level and the factors considered are the characteristics of caregivers and the coping style. The first section was the sociodemographic characteristics include age, gender, race, marital status, place of stay, occupational status, educational level, family structure and physical illness and history of mental illness of caregivers. Child's current age, child's gender, and period of child diagnosed with ASD will also be asked. The second part of the questionnaire was Perceived Stress Scale (PSS-10). This psychological instrument for measuring the perception of stress had been developed by Cohen et al in 1983 (11). It has been widely used since then. There was 10 items covered about emotional state and beliefs during the last month. Each item was rated on 5-point Likert scale based on the frequency of the stressful event experienced by the participant (0 = never, 1= almost never, 2 = sometimes, 3 = fairly often, 4 = very often) (11). The higher the PSS-10 score indicates the higher the stress perceived by the participant (11). The total score are 40 and then re-categorized into having stress if more than 13. The previous study reported that the Malay version of PSS-10 had good internal consistency reliability with Cronbach's alpha coefficient was 0.78 for the total scale (12). Test-retest reliability analysis showed that the Malay version of the PSS-10 by Al-Dubai et al. 2012 had an intra-class correlation coefficient (ICC) of 0.82 (95% CI: 0.70, 0.89) (12). Its good factor loading values for all items which ranging from 0.67 to 0.84 (12). Al-Dubai et al. also showed good internal consistency reliability of the Malay version of PSS 10 with Cronbach's alpha coefficient of 0.77 (12). The Cronbach's alpha measured in this study was consistent with value of 0.73 (95% CI 0.68, 0.78).

The third section measure the coping mechanism using BRIEF COPE questionnaire that were translated in

Malay by Yusof et al (2010) (13). 14 Subscale of coping category were measured and described. The coping styles are re-categorized into avoidance or approach. Reliable and valid instrument which could be applied for the Malaysian population. It was validated on cancer patients with internal consistency ranging 0.51–0.99 (13). The Cronbach's alpha measured in this study was consistent with value of 0.85 (95% CI 0.82, 0.88).

Data analysis
Data was analysed using RStudio software. The characteristics of respondent and outcome were described using frequency and percentage as well as mean and standard deviation for continuous variables. The outcome of stress was re-categorized into binary outcome. The normality of the data was tested using statistical significance and histogram. All assumptions were checked prior to analysis. The significant level was set at 0.05 conducted using a two-tailed test. We then conducted simple logistic regression to determine the predictor for stress among the caregivers. We selected variables that were significant at <0.25 in simple logistic regression to be included in the multivariate logistic regression. For the coping style, we compare the coping score between the stress and non-stress using independent t-test.

Ethics
Ethical approval was obtained from the Research Ethics Committee of International Islamic University of Malaysia IREC 2020-068.

RESULTS

A total of 230 caregivers responded. The respondent characteristics are in Table I. The mean age was 38.9 years old with mean age of child was 8.6 years old. Majority of the respondents are female (84.8%), Malay (87%) and married (91.7%). Only a quarter of the caregivers have medical illness and psychiatric illness. Although most have university education level, the socio-economic status is reflecting the tier. Majority of the children have autism less than 5 years and they received intervention, special education, and social support.

The PSS-10 and Brief COPE results are in Table II and the predictor for stress are in Table III. The prevalence of stress among caregivers was 83.1%. The factors that are associated with stress among caregivers were their age, socio-economic status, and education level. Those with stress are younger caregivers and having younger ASD child. The prevalence of stress is lower among the T20 and those with higher education.

The independent predictors for stress among caregivers were age and education of the caregivers after control for other variables. As the age increases the odds of having stress are reduced probably due to increased

Table I: Respondent characteristics (N=230)

		Mean (SD)
Age		38.9 (6.5)
Child age		8.6 (4.2)
		n (%)
Gender		
	Female	195 (84.8)
	Male	35 (15.2)
Ethnicity		
	Malay	200 (87.0)
	Chinese	15 (6.5)
	Indian	4 (1.7)
	Others	11 (4.8)
Marital status		
	Single	6 (2.6)
	Married	211 (91.7)
	Divorced	13 (5.7)
Socio-economic Status		
	B40	87 (37.8)
	M40	107 (46.5)
	T20	36 (15.7)
Education		
	No formal education	1 (0.4)
	Up to primary school	3 (1.3)
	Up to secondary school	54 (23.5)
	College or universities	172 (74.8)
Medical illness		
	No	176 (76.5)
	Yes	54 (23.5)
Mental illness		
	No	219 (95.2)
	Yes	11 (4.8)
Relationship		
	Father	33 (14.3)
	Mother	194 (84.3)
	Others	3 (1.3)
Relationship		
	Father/mother	227 (98.7)
	Others	3 (1.3)
Autism duration		
	5 years	185 (80.4)
	>5 years	45 (19.6)
Other syndromes		
	No	78 (33.9)
	Present	152 (66.1)
Intervention		
	Yes	176 (76.5)
	No	54 (23.5)
Special education		
	Yes	162 (70.4)
	No	68 (29.6)
Social support		
	Yes	202 (87.8)
	No	29 (12.2)

experience. Those with higher education have 0.30 lower odds and might be a proxy for income level.

The type of copings that are significantly associated with stress level are in Table IV. The mean score of stress were compared between those stress and not stress. Self-distraction, access of informational support, substance use, positive reframing, behavioural disengagement, and acceptance are types of coping style associated with

Table II: COPE and PSS-10 Outcome (N=230)

	Mean (SD)
Cope Self Distraction	5.6 (1.2)
Cope active	3.7 (1.1)
Cope denial	4.0 (0.9)
Cope substance use	5.6 (1.2)
Cope emotional support	3.8 (1.4)
Cope use of informational support	5.5 (1.3)
Cope Behavioral disengagement	3.7 (1.4)
Cope venting	4.5 (1.4)
Cope Positive reframing	5.6 (1.3)
Cope planning	4.9 (1.0)
Cope humor	4.9 (1.2)
Cope acceptance	6.2 (1.3)
Cope religion	3.3 (1.4)
Cope self-blame	4.9 (0.9)
Cope avoidant	28.3 (4.5)
Cope approach	29.7 (4.7)
PSS Stress score	18.2 (5.3)

	n (%)
PSS Stress Category	
No	39 (17.0)
Yes	191 (83.1)

stress. When re-categorized all the type of coping into either approach or avoidant. Majority of the approach mechanism is significantly associated with stress.

DISCUSSION

The study was conducted in the midst of the MCO, implemented in Malaysia by the government in order to minimize the potential to spread COVID-19 in the community (8). It is therefore decided that the best way to capture the respondents during this period was to target online social media platform users which has been utilised by many to gain positive support during this pandemic situation. A local qualitative study conducted by Azizan et al (2020) for example, highlighted the utilisation of Facebook platform as a source of positive social influence during the pandemic among Malaysians (14). The use of social media as a peer support platform for parents with autistic child has been widely appraised and among common reason was the lack of negative

Table III. Predictors for stress level (N=230)

		Stress level		Crude OR	Adjusted OR
		No	Yes		
Age		42.0 (6.3)	38.2 (6.4)	0.92 (0.87, 0.97)*	0.92 (0.86, 0.99) *
Child age		10.5 (4.5)	8.3 (4.0)	0.89 (0.83, 0.96)*	0.97 (0.87, 1.08)
Gender					
	Female	33 (16.9)	162 (83.1)	Ref	-
	Male	6 (17.1)	29 (82.9)	0.98 (0.40, 2.79)	
Ethnicity					
	Malay	35 (17.5)	165 (82.5)	Ref	-
	Non-malay	4 (13.3)	26 (86.7)	1.38 (0.49, 4.90)	
Marital status					
	Single/divorced	3 (15.8)	16 (84.2)	Ref	-
	Married	36 (17.1)	175 (82.9)	0.91 (0.20,2.92)	
SES					
	B40	9 (10.3)	78 (89.7)	Ref	Ref
	M40	19 (17.8)	88 (82.2)	0.53 (0.22, 1.22)	0.94 (0.34, 2.47)
	T20	11 (30.6)	25 (69.4)	0.26 (0.10, 0.70)*	0.51 (0.16, 1.57)
Education					
	Up to secondary school	5 (8.6)	53 (91.4)	Ref	Ref
	College or universities	34 (19.8)	138 (80.2)	0.38 (0.13, 0.95)*	0.30 (0.07, 0.98) *
Medical illness of caregiver					
	No	28 (15.9)	148 (84.1)	Ref	-
	Yes	11 (20.4)	43 (79.6)	0.74 (0.35, 1.66)	
Mental illness of caregiver					
	No	37 (16.9)	182 (83.1)	Ref	-
	Yes	2 (19.2)	9 (81.8)	0.91 (0.22, 6.16)	
Relationship					
	Father	6 (18.2)	27 (81.8)	Ref	-
	Mother	33 (17.0)	161 (83.0)	1.08 (0.38, 2.68)	
	Others	0 (0)	3 (100.0)	0.01 (0.01, 9.99)	
Autism duration					
	5 years	27 (14.6)	158 (85.4)	Ref	Ref
	> 5 years	12 (26.7)	33 (73.3)	0.47 (0.22, 1.04)*	0.65 (0.27, 1.65)
Other syndromes					
	No	12 (15.4)	66 (84.6)	Ref	-
	Present	27 (17.8)	125 (82.2)	0.84 (0.39, 1.74)	
Intervention					
	Yes	30 (17.1)	146 (82.9)	Ref	-
	No	9 (16.7)	45 (83.3)	1.03 (0.47, 2.44)	
Special education					
	Yes	29 (17.9)	133 (82.1)	Ref	-
	No	10 (14.7)	58 (85.3)	1.26 (0.59, 2.88)	
Social support					
	Yes	37 (18.3)	165 (81.7)	Ref	-
	No	2 (7.1)	26 (92.9)	2.92 (0.82, 18.60)	

Model R^2 Nagelkerke 0.019

Table IV: Association between type of coping and stress level (N=230)

	Stress level		t-statistic	p value
	No	Yes		
Cope - Self Distraction	6.1 (1.4)	5.6 (1.1)	2.158	0.036*
Cope - Active	3.7 (1.2)	3.7 (1.1)	-0.017	0.986
Cope - Denial	4.2 (1.0)	3.9 (0.9)	1.635	0.108
Cope - Substance use	6.0 (1.2)	5.5 (1.2)	2.470	0.016*
Cope - Emotional support	3.6 (1.4)	3.9 (1.4)	-0.956	0.344
Cope -Use of informational support	6.1 (1.2)*	5.4 (1.3)	2.980	0.004*
Cope - Behavioral disengagement	3.2 (1.3)*	3.8 (1.3)	-2.850	0.006*
Cope - Venting	4.8 (1.5)	4.4 (1.3)	1.586	0.119
Cope - Positive reframing	6.2 (1.1)	5.5 (1.3)	3.094	0.003*
Cope - Planning	5.0 (0.9)	4.8 (1.1)	0.965	0.339
Cope - Humor	4.8 (0.8)	4.9 (1.2)	-0.079	0.937
Cope - Acceptance	6.9 (1.1)*	6.1 (1.3)	4.322	<0.001*
Cope - Religion	3.0 (1.3)*	3.4 (1.4)	-1.474	0.146
Cope – Self-blame	5.1 (0.7)	4.8 (0.9)	1.869	0.065
Cope - Avoidant	29.3 (4.6)	28.0 (4.5)	1.630	0.109
Cope - Approach	31.4 (4.1)	29.4 (4.8)	2.732	0.008*

judgement they get through this online community (15). Autisme Malaysia Facebook group, the site chosen for recruitment of subjects in this study has also been recognised as among main sources of support in understanding autism among parents. A study by Roffeei in 2015 found that the highest percentage of messages offered in this group dealt with informational support (30.7%) followed by emotional support (27.8%) (16). Network and esteem support messages were responsible for 20.97% and 20.2%, respectively (16).

From table I, majority of the respondents were mothers of children with autism (84%), which is consistent with many studies that stressed the primary involvement of mothers in the care of special needs children (17). However, it was noted that racial distribution of the respondents were not consistent with the local population demography as a high proportion of the respondents were Malay (87%). This was postulated due to the nature of the source of study sampling, Autisme Malaysia, which is an online platform using Malay language as primary medium of communication. Therefore, it is possible that parents of different racial groups with limited Malay language capacity would have minimal involvement in this platform.

The distribution of socioeconomic status of the respondents was normally distributed with the majority of them were categorised as middle income earners. Socioeconomic status was taken as one of the parameters given the recognised role of financial assistance as one of the main determinants of care status among children with autism. A more recent local study by Yakub et al (2020) also revealed income as a predictors for depression among parents in the general population.

There were also reported medical and psychiatric morbidity among respondents with percentages of 23.5 and 4.8 respectively (18). Although the proportion was low, it is important to highlight as psychiatric disorder among parents of children with autism has been reported as higher compared to parents of typically-growing children (19). However the finding from this study could not differentiate whether these factors occur as cause or consequence as it is beyond the objective of the study. The findings from this study also revealed that the majority of the children of the respondents were already under some form of intervention with 76.5 percent of them under specific intervention and 70.4 percent already under special education. Even though this is a promising fact, we also postulated that this could also mean that most of the children in the study are directly affected by the closure of school and intervention centres during the MCO implemented locally during the time of study. This could have contributed as the source of stress among parents of the children with autism. Manning et al. (2020) reported that disruption in school closure and intervention centres gave indication of stress to caregivers (20). Caregivers sometimes see school and intervention centres as respite care and opportunity for relieve (21).

The stress level of the respondents was assessed using PSS-10 given its good reliability and consistency with the Cronbach alpha derived from this study (22). It was reported (table II), from this study that the prevalence of parents' experience stress is high (83.1%). This is consistent with other studies which also highlighted high levels of stress among local parents of children with autism was 90.4% (23). However, due to design of the study, it is difficult to postulate if there is any

change with regards to the level prior and during the pandemic season. The high level of stress among parents in this study is consistent with global finding as other highlighted from studies in other countries such as Italy and Saudi Arabia, which also experience similar restriction in the movement during this pandemic period (24, 25). Similarly, the changes in the lifestyle prompted our population to stay indoors for over 20-24 hours per day (26). This prevented vitamin D and sunlight exposure simultaneously breaking down social activities. Low in vitamin D level in our body has been associated with an increased risk of mental health problems as well as individual responses to stress (27).

There have been many factors postulated to be responsible for this trend, namely the nature of this pandemic which restrict many activities, including access to education and intervention (28). Narzisi (2020) also suggested how change in routine during this pandemic also causes difficulties in adaptation among children and parents affected. Since children with autism require on-going support, any disruption in their intervention would potentially result in challenging behaviour (20). As parents are their sole support during this critical period, it is not surprising to find that parental stress is increasing during this period.

This study also attempted to see any predictors to this stress (table III), through the association between stress and sociodemographic factors. Simple logistic regression analysis revealed that older parents, those with older age children, upper end of financial status, higher education level and duration of diagnosis (more than 5 years) are among identified protective factors from experiencing stress. However further analysis, by controlling these variables, reported that only age and education level were found to be statistically significant parameters to predict lower levels of stress.

These findings were supported by a similar outcome of study by Falk et al (2014), which also identified age as a predictor for parental stress in similar groups (29). However the economic factor that was identified as significant in Falk study was not supported in this study. The role of education in protecting parents from stress was also supported by Rivard et al. (2014) who identified specifically that maternal education is associated with lower levels of stress (30). This may be related indirectly to the financial assistance provided with the better education among these parents. Shahabadi et al (2018) studied using integration of sectional and time-series data in selected Islamic countries showed that a significant positive relationship between education and income inequality (31). This means the effect of the enrolment rate into higher education will lead to increasing income share of middle class group by 20-30 percent (31). Better education also serves as a potential proxy to better understanding of the challenging situation and better access to support and assistance.

Interestingly, our study found no association between parental medical and psychiatric morbidity as the contributing factors for stress despite some other study highlighted the relationship between parental mental illness and caregiver stress in the context of caring for children with autism (32). Our study also did not show any significant differences between mothers and fathers' levels of stress as opposed to some previous findings reported a higher level of stress among mothers. This may be contributed by the small sample size of male respondents in the study.

This study also looked into specific types of coping applied by these participants in dealing with their current situation. Based on Brief-COPE questionnaire used, different methods of coping were then subdivided into two major types - avoidant and approach. Based on the analysis (table IV), the types of coping styles that are associated with stress are self-distraction, substance use, and observance to informational support, behavioural disengagement, positive reframing and acceptance. However given the nature of cross-section study, we could not make direct inference if the coping styles were contributing to the stress or there were chosen as coping styles in response to their current level of stress.

Previous study on coping styles among parents of children with autism also reported various inconsistent findings. For example, some coping styles identified in this study, such as acceptance, was consistent with another study in Southeast Asian subjects (33). However, some specific coping styles, for example positive reframing, were suggested to be associated with good emotional well-being among parents in this population (34). Clifford and Minnes (2013), suggested that, parents are quite accommodative to adopt adaptive coping approach where they participate in parental support groups (35). By exchanging thoughts and opinions among them, coping strategies including seeking emotional and instrumental support, active coping, and planning making the pattern of coping styles become more inconsistent. Therefore it is important to highlight the need to gather an understanding into parents' coping styles and encourage them to use healthy coping styles to cope with the situation.

The limitations of this study includes its convenience sampling approach which may introduce selection and affect generalisability of this study. There were some other parameters that could have been included in this study such as the clinical characteristics of the children, sociodemographic of families, access to internet and online group support and timing of the study, which could have added better understanding of the stress phenomenon among parents of children with autism.

CONCLUSION

This pandemic is a new experience for most of us

globally. Parents of children with autism are also not excluded from the challenge to adapt and cope with the stress associated with it. Therefore this study helps us to shed some light to understand how much the pandemic and current public approach have impacted parents of children with autism. The high level stress should be addressed properly to assist them with the situation better. Understanding that some coping strategies are helpful for parents, these coping strategies should be educated among these parents in order to empower them during this critical period. Our study recommended that coping style of informational support, behavioural disengagement, religion and acceptance are associated with lower stress incidence. This should be advocated among parents of ASD children. Parenting method should be dynamic and interchangeable to alleviate the challenge in the family during the pandemic crisis.

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