Intellectual Discourse

Volume 27

Special Issue

2019

Special Issue on Disability Studies



International Islamic University Malaysia http://journals.iium.edu.my/intdiscourse/index.php/islam

Intellectual Discourse

Volume 27

Special Issue

2019

Editor Ishtiaq Hossain (Malaysia)

Guest Editor Aida Mokhtar

Associate Editors

Anke Iman Bouzenita (Oman) Khairil Izamin Ahmad (Malaysia) Saodah Wok (Malaysia)

Book Review Editor

Mohd. Helmi Bin Mohd Sobri

Editorial Board

Abdul Kabir Hussain Solihu (Nigeria) Badri Najib Zubir (Malaysia) Daniel J. Christie (USA) Habibul H. Khondker (UAE) Hazizan Md. Noon (Malaysia) Hussain Mutalib (Singapore) Ibrahim M. Zein (Qatar) James D. Frankel (China) Kenneth Christie (Canada) Nor Faridah Abdul Manaf (Malaysia) Rahmah Bt Ahmad H. Osman (Malaysia) Serdar Demirel (Turkey) Syed Farid Alatas (Singapore) Thameem Ushama (Malaysia)

International Advisory Board

Anis Malik Thoha (Indonesia) Chandra Muzaffar (Malaysia) Fahimul Quadir (Canada) Habib Zafarullah (Australia) John O. Voll (USA) Muhammad al-Ghazali (Pakistan) Muhammad K. Khalifa (Qatar) Redzuan Othman (Malaysia)

Founding Editor

Zafar Afaq Ansari (USA)

Intellectual Discourse is a highly respected, academic refereed journal of the International Islamic University Malaysia (IIUM). It is published twice a year by the IIUM Press, IIUM, and contains reflections, articles, research notes and review articles representing the disciplines, methods and viewpoints of the Muslim world.

Intellectual Discourse is abstracted in SCOPUS, ProQuest, International Political Science Abstracts, Peace Research Abstracts Journal, Muslim World Book Review, Bibliography of Asian Studies, Index Islamicus, Religious and Theological Abstracts, ATLA Religion Database, MyCite, ISC and EBSCO.

ISSN 0128-4878 (Print); ISSN 2289-5639 (Online)

http://journals.iium.edu.my/intdiscourse/index.php/islam Email: intdiscourse@iium.edu.my; intdiscourse@yahoo.com

> Published by: IIUM Press, International Islamic University Malaysia P.O. Box 10, 50728 Kuala Lumpur, Malaysia Phone (+603) 6196-5014, Fax: (+603) 6196-6298 Website:http://iiumpress.iium.edu.my/bookshop

Intellectual Discourse Vol. 27 Special Issue on Disability Studies, 2019

CONTENTS

| Note from the Guest Editor Aida Mokhtar | 825 |
|--|-----|
| Research Articles | |
| The Extra Costs of Having a Disability: The Case of IIUM Ruzita Mohd Amin and Nur Syuhada Md. Adros | 829 |
| Advertisements Shape Our Social Reality: A Study of Apple Advertisements on Promoting PWDs and Inclusion Aida Mokhtar and Souhaila Ahmed Elyass Hussain | 855 |
| The Anticipation of Malaysian Urban Cities to be Inclusive and Accessible by 2030 Nur Amirah Abd Samad and Asiah Abdul Rahim | 889 |
| Parenting Children with Hearing Impairment: The Milieu of Parents' Practices and Experiences Mastura Badzis and Rabiu Garba Idris | 899 |
| Stress in Parents of Children with Autism: A Malaysian Experience Nadzirah Ahmad Basri and Nik Nur Wahidah Nik Hashim | 923 |
| The Costs of Caregivers for Children with Disabilities that Participate in Centre-Based and Home-Based Community-Based Rehabilitation (CBR) Programmes in the East Coast of Malaysia Haliza Hasan, Syed Mohamed Aljunid and Amrizal MN | 945 |
| The Design of a Speech Delay Screening Mobile Application for Malaysian Parents <i>Siti Asma Mohammed, Nur Faizah Azahari</i> | |
| and Wan Nur Shahirah W.A. Sayuti | 965 |

INTELLECTUAL DISCOURSE, Special Issue, (2019) 923–943 Copyright © IIUM Press ISSN 0128-4878 (Print); ISSN 2289-5639 (Online)

Stress in Parents of Children with Autism: A Malaysian Experience

Nadzirah Ahmad Basri* Nik Nur Wahidah Nik Hashim**

Abstract: This study examines differences in parental stress between parents of Autism Spectrum Disorder (ASD) children (n=21) and Typically Developed (TD) children (n=41) in Malaysia. This study also compares the ages of parents of ASD children with parents of TD children with stress as a variable in these parents. Parents completed the Parental Stress Index (brief Malay version) and a socio-demographic questionnaire. Parents with ASD children were found to be significantly more stressed compared to parents of TD children (p<0.001). Significant scores were also found in the Parent-Child Dysfunctional Interaction (P-CDI) sub-scale (p<0.001) as well as Difficult Child (DC) and Parental Distress (PD) sub-scales with lower significance (p<0.05). Results also indicate that the 30-35-year-old age group among ASD parents was significantly found to be more stressed compared with parents of TD children of the same ages. Implications of the findings regarding support and intervention for families with ASD are also discussed.

Keywords: Autism Spectrum Disorder; parental stress; Parenting Stress Indexshort form; age; Malaysia

Abstrak: Kajian ini meneliti perbezaan tahap tekanan di antara ibu bapa kanak-kanak autisma (ASD) (n=21) dan ibu bapa kanak-kanak normal (TD) (n=41) di Malaysia. Kajian ini juga membandingkan umur ibu bapa kanak-kanak ASD dengan ibu bapa kanak-kanak TD dengan menggunakan tekanan

^{*} Assistant Professor, Department of Psychiatry, Kulliyyah of Medicine, International Islamic University Malaysia, Jalan Hospital, 25000 Kuantan, Pahang, Malaysia. Email: nadzirahbasri@iium.edu.my. Corresponding Author. **Assistant Professor, Department of Mechatronics, Kulliyyah of Engineering, International Islamic University Malaysia, Kuala Lumpur, Malaysia. Email: niknurwahidah@iium.edu.my

sebagai pembolehubah. Peserta diminta untuk mengisi borang soal selidik Indeks Tekanan Ibu Bapa (versi ringkas Bahasa Melayu) dan soal selidik sosio-demografik. Ibu bapa kepada kanak-kanak ASD didapati lebih tertekan berbanding ibu bapa kanak-kanak TD (p<0.001). Skor yang signifikan juga didapati dalam sub-skala Interaksi Tidak Harmoni Ibu-Bapa Dengan Anak-Anak (P-CDI; p<0.001) serta sub-skala Anak Yang Sukar Diurus (DC) dan Tekanan Ibu Bapa (PD) dengan nilai signifikan yang lebih rendah (p<0.05). Keputusan juga menunjukkan bahawa ibu bapa kanak-kanak ASD yang berada di kelompok umur 30-35 tahun didapati lebih tertekan berbanding dengan ibu bapa kanak-kanak TD pada usia yang sama. Implikasi hasil penemuan iaitu berkenaan sokongan dan intervensi untuk keluarga kanak-kanak ASD turut dibincangkan.

Kata kunci: autism; tekanan ibu bapa; Indeks Tekanan Ibu Bapa; umur; Malaysia

Introduction

Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder with impairments in communication, rigidity in behaviour and social functioning beginning in childhood. In the United States, the 2014 data indicate that the prevalence of autism in the country was as high as 1 in 59 children. This represents an increase of 15% in prevalence nationally from 1 in 68 in the previous two years to 1 in 59 (Autism Speaks, 2018). At present, there is yet any epidemiological studies that examines the prevalence of ASD in Malaysia, but a study by the Malaysian Ministry of Health in child health clinics on children between the ages of 18 to 36 months reveals a prevalence of the rate of 1.6 in 1000 children, or approximately 1 in 625 (Malaysian Ministry of Health, 2014). However, given that many cases go undetected and due to the increasing number of autism cases reported by medical and educational practitioners, there is a high chance that the prevalence of the rate of autism in Malaysia is higher (Lim, 2015).

Despite the rising number of autism cases in Malaysia, there is limited published research on the current support and intervention rendered to individuals with autism and their families in Malaysia. Indeed, the necessity of family care for children with ASD is a significant issue that has been advocated by many researchers and the government of Malaysia. Lim (2015) recommends the need to increase the number of well-trained teachers and generate more awareness to deal with the challenges of ASD for a wider audience. In addition, more comprehensive forms of care must be provided for ASD children and their families, as well as targeted and flexible financial assistance to assist families with autism. Ilias, Cornish, Kummar, Park and Golden (2018) argue that compared to Western countries, parents in South East Asia face challenges due to poorer policy and financial support for special needs and mental health. Furthermore, parents have to face the stigma towards ASD that is relatively more prevalent in Asia (Ilias et al., 2018). Some government initiatives have required the active participation of family members in the early intervention of ASD children. This includes active parental involvement which has been found to increase the number of communication acts and use of communication means along with a decrease in autistic behaviour and increased functional communication (Malaysian Ministry of Health, 2014).

Since family support for children with ASD is a significant point, this raises the question of how the family support process can be improved? Multiple studies have indicated that parents of children with ASD experience stress significantly more than parents of typically developed (TD) children (Porter & Loveland, 2019; Amireh, 2019; Siu et al., 2019; Lee, Ong, Lee & Fairuz Nazri, 2017) and children with other disabilities (De Haves & Watson, 2013; Amireh, 2019). There is the significant need to support these parents due to the stress linked with having children with a spectrum of disorders including social communication, emotional and behavioural difficulties, along with challenges of finding services to look after them (Ilias, Cornish, Park, Toran & Golden, 2019). Inadequate quality support services in South East Asia has contributed to the stress of parents with ASD children (Ilias et al., 2018). It is therefore significant to understand the causes and patterns of stress among these parents which can help clinicians identify the help they can provide to assist them with their issues.

Stressors among Parents of ASD Children

Stress among parents of ASD children has been associated with childdriven effects such as a child's sleeping problems (Martin, Papadopoulos, Chellew, Rinehart & Sciberras, 2019), internalizing and externalizing behaviour problems and ASD symptoms of the child (Rodriguez, Hartley & Bolt, 2019; Siu et al., 2019), the child's low and high functioning autism (Huang, Zhang & Chen, 2019), significant impairment in social disability and adaptive functioning (Postorino et al., 2019), and the child's need for special needs service (Schieve, Blumberg, Rice, Visser & Boyle, 2007). Stress of parents with ASD children also stems from interaction problems with their spouses (Goetz, Rodriguez & Hartley, 2019). Furthermore, studies have highlighted that many mothers of ASD children who have resigned from their jobs to become housewives in order to assist their children at home (Resurreccion, 2013). This could also be a factor that contributes to stress.

Additionally, parents experience stress upon learning about their children's diagnosis. A report by Ilias et al. (2019) indicated that Malaysian parents of ASD children were initially very stressful when they first learnt about their children's diagnosis but the stress subsided as they started to learn that the way they perceived their children's condition would affect their learning progress.

Ilias et al. (2018) reviewed articles on parenting stress among ASD parents in South East Asia and identified that sources of parenting stress comes from the severity of ASD symptoms, financial problems, parents' concerns about the future of their children; while the coping strategies found to reduce levels of parenting stress include social support, perception and understanding of parents regarding ASD, and religious beliefs.

Culture, Religious Beliefs and Parental Stress

Cultural beliefs have been found to play a significant role in aggravating the stress of parents with ASD children in South East Asia. In Malaysia, Ilias et al. (2019) reported that cultural stigma and negative perception from the society regarding ASD contributed to their stress. Some parents were accused to have made some past mistakes that caused the disorder (such as spirit possession) while others believed the child was possessed by some spirits and needed to be treated through mystical means. This mystical belief is relatively more prominent in Asia, which may contribute to the way parents of ASD children deal with challenges (Ilias et al., 2018). Even though many mothers did not believe these traditional beliefs themselves, they were still affected and felt stigmatized by these societal perspectives which consequently impacted their well-being (Ilias, Liaw, Cornish, Park & Golden, 2017). Similarly, in a study on Japanese mothers with ASD children, it was found that they experienced much higher parenting stress than mothers of typical children and children with other special needs. Their stress was reportedly related to challenges with attachment, low parenting efficacy and inadequate support which reflects the way Japanese parent and gender ideology (Porter & Loveland, 2019).

Conversely, religious beliefs have been helpful for Asian parents in painting a positive perception of their ASD children. Religious beliefs have reportedly been used as a coping mechanism for parents to help them with acceptance of their ASD child. It was reported that parents viewed their child as a present from God, in spite of his/her ASD diagnosis, finding comfort through prayers, reading holy books and involving with church activities (Ilias et al., 2018; Amireh, 2019).

Relationship Between Age and Parental Stress

Existing literature has indicated that age is significantly associated with stress in parents of developmentally disabled children. In a sample of Asian American parents with developmentally disabled children, De Lambo, Chung and Huang (2011) found that stress did not decrease even as their children grew older. It is suggested that this could be due to the culture of collectivism, whereby they tend to be more protective instead of educating their children to be independent individuals. Furthermore, parents continue to participate actively in their children's lives despite their children's growing ages.

Studies have also shown that younger parents are at higher risk of suffering from negative developmental and social effects after they find out about their child's disability. In one study, it was found that parents whose age is less than 40 experienced many adjustment problems and stress when dealing with their children with a learning disability (Konstantareas & Homatidis, 1989). This was attributed to low confidence in parenting ability among these younger parents which contributed towards a more negative perception of their children.

In another study by Oh, Rubin and Mouw (1994 cited in DeLambo, Chung and Huang, 2011) on mothers with mentally retarded (MR) children, it was found that when mothers were about 42 years old, their score on adjustment was at the highest point, indicating good adjustment. On the other hand, the findings showed that mothers of children with MR who were less than or more than 42 years old encountered lower maternal adjustment to their child. It was summarised that mothers scored lowest in parental adjustment during these four periods: (a) finding out about their child's disability, (b) confusion on the placement of their children's education, (c) making the decision of where their child would go after finishing school and (d) the awareness of their growing age and worrying about the future of their child.

Meanwhile, among mothers of male children with Duchenne Muscular Dystrophy, it was found that their stress diminished as their disabled child's behavioural problems decreased. It is concluded that the disabled child's behavioural problems were the biggest contributor to parental distress (Nereo, Fee & Hinton, 2003).

As most of the existing studies were carried out on non-Malaysian respondents, it is significant to examine if the severity of parental stress and their ages is applicable to Malaysian parents of ASD children as well. The purpose of the present study is to examine the intensity of stress, sources and pattern among parents of ASD children in Malaysia. We address the following two research questions: (a) Does the severity of stress among parents with ASD children differ from parents with TD children? And (b) Are the ages of the parents of ASD and TD children significantly correlate to parental stress?

Method

Participants

Participants were recruited from three sources: (a) a parental group skills training for ASD children at a medical centre, (b) a talk on the management of ASD children and (c) parents group on WhatsApp online application and Facebook. A total of 22 parents with ASD children participated in the survey. One questionnaire completed by an ASD parent was disqualified due to a significant score on her defence score, that would probably render it invalid.

The control group sample was mostly recruited from parents group on WhatsApp online application and Facebook and a few from a talk on management of autism. A total of 41 parents with TD children and seven parents with other disabilities completed the questionnaires. Since this study focuses only on children with ASD and TD, the seven questionnaires filled in by parents of other disabilities than ASD were disqualified. Finally, the total number of participants retained in the current study were 62; 21 parents with ASD children and 41 with TD children.

Instrument

A general questionnaire to collect socio-demographic data was used in this study along with the concise form of Parenting Stress Index (PSI), 3rd edition (Abidin, 1995) in Malay or English. Socio-demographic questions included parents' age, sex, race, occupation, education background, age of child and sex of child and clinical information (if the child has been diagnosed with a disability and the diagnosis given to the child). The Malay version of the PSI was validated by Nazurah, Dzalani, Baharudin, Mahadir and Leonard (2016) with parents of children with learning disabilities in Malaysia. The study yielded a high reliability and high internal consistency on all its sub-scales: parental distress, parent-child dysfunction interaction and difficult child with scores of 0.90, 0.82 and 0.87, respectively.

PSI is administered to parents as a screening tool used by health providers to identify the sources and stressors as a result of parenting. Parents reported their agreement or disagreement with 36 items, which are categorised into three sub-scales namely Parental Distress (PD), Parent-Child Dysfunctional Interaction (P-CDI) and Difficult Child (DC). The three sub-scales make up the total stress level (a combination of PD, P-CDI and DC). If a parent obtained a high score on PD, it may reflect his or her personal adjustment to parenthood apart from other personal stresses. Lower scores may reflect poor coping skills and indicate the need for higher participation in social support and psychological and parenting skills which could be promoted through engagement in psychotherapy and social support groups.

The sub-scale of P-CDI is defined as the extent to which parents feel satisfied with their child and whether the child meets or not the expectations of his/her parents. Parents who scored high on this subscale may indicate their feelings of discouragement or rejection by the child, or inadequate bonding with their child. Parents who scored low could find support to improve parent-child interaction helpful.

Meanwhile, the sub-scale of DC refers to parents' perception of how difficult or easy their child is. A high score could indicate that parents

are having difficulties in managing their child and in getting their child's cooperation. Parents with a low score could benefit from psychological skills to manage difficult behaviour and receive psychoeducation about age-appropriate development.

The total sum of these three sub-scales makes up the final overall score called the 'total stress'. Total stress indicates the overall stress a parent is feeling in relation to his/her role as a parent. To conclude, the PSI indicates the distress found in the following range: the parents' personal distress, distress resulting from interaction with the child and distress which are triggered from the behavioural aspects of the child (Nazurah et al., 2016).

Additionally, the PSI also measures a score of defensive responding. It is expected that some degree of parenting stress is felt by parents, which is normal. However, if parents report exceptionally low levels of stress, it raises concern that they may be answering defensively and not being completely honest in their answers. On the other hand, it could also indicate that they are actually be very competent and are able to efficiently manage responsibilities and parent-child relationship.

Procedures

Participants were recruited from three sources, i.e. parents attending skills training for ASD at a Psychiatry and Mental Health Clinic at a medical centre in East Malaysia, parents taking part in a talk on management of autism and ADHD children in Kuala Lumpur and parents with ASD children selected from online support groups and social media. Consent was asked for and given. All participants completed the assessment. Control participants were recruited from the talk on the management of autism and ADHD children and from online groups and social media. The study was approved by IIUM Research Ethics Committee (IREC).

All cases fulfilling the inclusion criteria were taken as participants of the study. The samples were parents who attended a group therapy on ASD parental skills and were on follow-up appointments at the Medical Centre; parents who attended a talk on ASD management and parents recruited from autism online support group. The typical group (TG) was regarded as the control group with the basis that they are attending normal school based on their age groups. The TG parents were recruited by distributing the link of online survey to acquaintances of researchers through online messaging system and the social media.

Data Analysis

Data were analysed using Statistical Package of Social Sciences (SPSS) programme. Socio-demographic data were summarised using descriptive statistics. Stress in parents, treated as the dependent variable and socio-demographic variables, treated as independent variables were analysed using cross-tabulation analysis. One-way ANOVA was conducted to compare differences in the parental stress level between parents of ASD and parents of TD children. Chi-square test was used to test the statistical significance of difference. Mean pairwise comparisons were carried out to examine the correlation between the age of parents of children with ASD and TD and the parental stress level and PSI sub-scale scores in each group.

Results

There were 21 participants among parents of ASD children; 16 were mothers and five were fathers. The average age was 38 (SD=6.6). Slightly more than half of the parents with ASD children were skilled workers. 43% of them had a postgraduate degree, while 48% had either a Diploma or a Bachelor's degree. These parents consisted of 20 Malays and one Indian. There were one female and 20 male children with ASD. The primary diagnosis was ASD while others had a fusion of comorbidities such as Attention Deficit Hyperactivity Disorder (ADHD) or a learning disability.

Meanwhile, a total of 41 parents of TD children took part in the current study. Thirty-eight questionnaires were completed by mothers and three were completed by fathers. The average age was 35.2 years (SD=5.9). A majority of these parents (68%) were skilled workers and 83% had a postgraduate degree. All of these parents were Malays. The TD children consisted of 23 males and 18 females. Table 1 presents the descriptive data for the participating parents in this study.

| | Children with autism (n = 21) | Typically developed children (n = 41) |
|------------------------------|----------------------------------|--|
| Demographic characteristics | | |
| Parent's gender | | |
| Female | 16 (76.19%) | 38 (92.68%) |
| Male | 5 (23.8%) | 3 (7.31%) |
| Parent's age (mean \pm SD) | 38.1 ± 6.66 | 35.2 ± 5.91 |
| Child's gender | | |
| Female | 1 (4.80%) | 23 (56.10%) |
| Male | 20 (95.24%) | 18 (43.90%) |
| Race | | |
| Malay | 20 (95.24%) | 41 (100%) |
| Indian | 1 (4.80%) | 0 |
| Child's age (mean ± SD) | | |
| 4-10 | $14(5.59 \pm 1.93)$ | 35 (3.74 ± 2.93) |
| 11-24 | 7 (13.75 ± 4.85) | 6 (15.60 ± 1.72) |
| Parent's working sector | | |
| Housewives/students | 7 (33.33%) | 8 (19.51%) |
| Low-skilled workers | 0 | 0 |
| Semi-skilled workers | 3 (14.29%) | 5 (12.20%) |
| Skilled workers | 11 (52.38%) | 28 (68.29%) |
| Parent's education level | | |
| Secondary school | 2 (9.52%) | 0 |
| Diploma/Degree | 10 (47.62%) | 34 (17.07%) |
| Master | 3 (14.29%) | 7 (82.92%) |
| PhD | 6 (28.57%) | 0 |

Table 1: Socio-demographic Data of the Participants

Parenting Stress

Results indicate that the average scores of parents of children with ASD and parents of TD children on the total stress level were 101.29 and 77.63, respectively. Abidin (1995) reported that parents who scored a total PSI score of 91 and above have clinical level of stresses and may benefit from professional help.

A one-way analysis of variance (ANOVA) was carried out to check on the significance of group (ASD or TD children) on parenting stress (total score in PSI). The results indicate a significant group difference (p<0.001), with parents of children with ASD (M=101.29, SD=15.1) whereby they were found to display higher levels of stress than parents of TD children (M=77.63, SD=20.24).

An examination on the difference between PSI total score with the sub-scale of PD indicates a significant group difference (p<0.05) between parents of ASD (M=33.43, SD=7.9) and TD (M=28.17, SD=8.75) children. This shows that parents of ASD children may have felt incompetent, restricted and depressed in their role as a parent compared to parents of TD children.

Parent-child Dysfunctional Communication

There was a statistically significant difference in the PSI total score with the P-CDI sub-scale (p<0.001) between parents of ASD (M=32.05, SD=5.18) and parents of TD (M=23.22, SD=7.02) children. The result indicates that parents of ASD children felt less satisfied in the interaction with their children compared to parents of TD children.

Relationship between Child Variables and Parenting Stress

The child variable in PSI is the sub-scale of DC. It refers to how a parent perceives his/her child to be, whether the child is easy or difficult to be taken care of or managed. In the study, results indicate a significant difference in the PSI total score with the DC sub-scale (p<0.05). This shows that parents of ASD children reported higher stress (M=32.05, SD=7.54) than parents of TD children (M=26.24, SD=7.85) due to the characteristics and behaviour of their children.

Table 2 illustrates the one-way ANOVA analysis that compares the means of the PSI between parents of ASD and TD children.

| Scale | Mean (SD) | | | Sig. |
|-----------|----------------|-------------------------|---------------------------------|------------|
| | Total (n = 62) | ASD (<i>n</i> = 21) | Control (<i>n</i> = 41) | |
| PSI total | 85.65 (21.70) | 101.29 (15.10) | 77.63 (20.24) | 0.000015** |
| PD | 29.95 (8.77) | 33.43 (7.90) | 28.17 (8.75) | 0.024* |
| P-CDI | 26.21 (7.67) | 32.05 (5.18) | 23.22 (7.02) | 0.000004** |
| DC | 28.21 (7.54) | 32.05 (7.54) | 26.24 (7.85) | 0.003* |
| DR | 18.26 (5.63) | 20.33 (4.91) | 17.20 (5.73) | 0.037* |

 Table 2: Mean Scores and Standard Deviation of PSI and its Sub-scales and

 Clinical Range Percentage

**significant at the level p<0.001

*significant at the level p<0.05

The Relationship between Ages of Parents (with ASD and TD Children) and Parental Stress

Mean scores based on age categories and mean pairwise comparisons were carried out to examine the correlation of age categories of parents with ASD and TD children with parental stress. For both categories of parents of ASD and TD children, a significant relationship (p<0.001) was found between the means for the 30-35-year-old age group with the means for the 25-30-year-old age group with the total stress score (M=94.56, SD=3.85) and the P-CDI sub-scale (M=27.95, SD=1.33). The sub-scale of DC was found to be marginally significant (p<0.05) for both total stress score (M=30.45, SD=1.44) and P-CDI (M=30.45, SD=3.75) in the same age category (30-35 years). This indicates that parents aged 30 to 35 were more stressed compared to parents aged 25 to 30, particularly in the domain of total stress score, P-CDI and DC.

A similar trend could be seen between the age group of 40 years and above when compared with parents aged 25 to 30. The mean scores of parents aged 40 and above were significant (p<0.001) for the subscale of P-CDI (M=28.41, SD=1.50) but only marginally significant for total stress (M=87.31, SD=4.35) and DC (M=28.41, SD=1.63). Again, this shows that parents aged 40 and above were significantly more stressed compared to parents aged 25-30, particularly on their child's dysfunctional interaction with them.

Tables 3 and 4 show the mean scores based on age categories and mean pairwise comparison for age categories with total stress score, P-CDI and DC, respectively. PD sub-scale was not found to be statistically significant for all categories of age.

| Parent's age | Mean (SD) | | |
|--------------|---------------|--------------|--------------|
| | Total score | P-CDI | DC |
| Less than 25 | 0 | 0 | 0 |
| 25.1 to 30 | 67.00 (7.57) | 17.67 (2.60) | 21.17 (2.84) |
| 30.1 to 35 | 94.56 (3.85) | 27.95 (1.33) | 30.45 (1.44) |
| 35.1 to 40 | 77.25 (10.02) | 26.25 (3.44) | 25.25 (3.75) |
| 40 and above | 87.31 (4.35) | 28.41 (1.50) | 28.41 (1.63) |

Table 3: Mean Scores according to Age Categories

Table 4: Mean Pairwise Comparison between Age Categories for PSI Total Scores. P-CDI and DC

| Parent's age in years | | Significance | | |
|-----------------------|--------------|-----------------|---------|--------|
| | | PSI total score | P-CDI | DC |
| 25.1 to 30 | 30.1 to 35 | 0.001** | 0.001** | 0.005* |
| | 35.1 to 40 | | 0.05* | |
| | 40 and above | 0.024* | 0.001** | 0.031* |
| 30.1 to 35 | 35.1 to 40 | | | |
| | 40 and above | | | |
| 35.1 to 40 | 40 and above | | | |

Empty spaces indicate values that are not significant **significant at the level p<0.001 *significant at the level p<0.05

Comparison of Ages between Parents of ASD Children and Parents of TD Children with Parental Stress

As indicated in Table 5 and Figure 1, parents of ASD children belonging to the age category of 30-35 years were significantly found to be more stressful (M=108.13, SD=6.56) than parents of TD children of the same

age (M=81, SD=4.05) as indicated by the total stress score. Additionally, parents of ASD children in the age group of 35-40 years (M=98.5, SD=7.57) were found to have a marginally significant total stress score when compared with parents of TD children (M=56, SD=18.55).

Table 5 also shows that that parents within the age range of 30 to 35 years scored the highest mean total stress score (in both groups of parents with ASD and TD children) which suggests that this age group contained the most stressful parents, whether or not they have an autistic child or a child with typical development.

 Table 5: Mean Pairwise Comparison between Autism Group and Control
 Group based on the Total PSI Scores

| Parent's age | Mean (SD) | | Significance |
|--------------|---------------|---------------|--------------|
| | Autism | Control | |
| 25.1 to 30 | 0 | 67.00 (7.57) | - |
| 30.1 to 35 | 108.13 (6.56) | 81.00 (4.05) | 0.001** |
| 35.1 to 40 | 98.50 (7.57) | 56.00 (18.55) | 0.038* |
| 40 and above | 95.86 (7.01) | 78.77 (5.14) | 0.054 |

**significant at the level p<0.001 *significant at the level p<0.05

Figure 1: Plot of Parents' Age Categories with respect to the Mean of the Total PSI Scores



Discussion

The present study found that parents of Autism Spectrum Disorder (ASD) children experienced a significantly greater level of parental stress than parents of Typically Developing (TD) children. The total stress score of Parental Stress Index indicates that overall, parents of ASD children had higher distress than parents of TD children. This result is consistent with previous results found worldwide such as in Japan (Porter & Loveland, 2019), Jordan (Amireh, 2019), Hong Kong (Siu et al., 2019) and Malaysia (Lee, Ong, Lee & Fairuz Nazri, 2017). In particular, parents of ASD children were found to have significantly higher stress in the dissatisfaction of their interactions with their children. This was seen in the sub-scale of P-CDI. Higher levels of P-CDI were reported in parents of children with higher number of social disability. A report on parenting stress among parents of ASD children shows parent-driven effects for child internalizing behaviour problems (Rodriguez, Hartley & Bolt, 2019). This can mostly be applied to ASD children who commonly lack skills in social interaction to express their feelings; in turn, this leads to internalising behaviour problems thus, contributing to stress in parents.

Parents of ASD children also scored marginally significant score in the sub-scale of DC. Studies indicate that higher levels of DC subscale were reported in parents of children with a higher number of disruptive behaviour. A report on parenting stress among parents of ASD children shows both parent and child factors (but in different ways for mothers versus fathers) for child externalizing behaviour problems and ASD symptoms (Rodriguez, Hartley & Bolt, 2019). This finding is also consistent with a recent study whereby disruptive behaviour, significant impairment in social disability and adaptive functioning are contributing factors to parental distress among parents of ASD children (Postorino et al., 2019).

Upon examination of the sub-scale scores, we found that only two of the three sub-scale groups - P-CDI and DC - were found to be significant for the parents of ASD and TD children, but the sub-scale of PD was not significant. This shows that parents of ASD children in the current study were feeling competent, supported and well-adjusted in their role as parents. This can be explained by the high socio-economic status (SES) that most of the parents in this study belonged to. More than half of the parents of ASD children in the present study were skilled workers (professionals) and with high academic background (48% had a diploma or degree, 14% with a Master's degree and 29% with a doctorate). Due to these reasons, the parents in the present study could have better awareness on ASD and have more opportunities and access to therapy, services and knowledge to help their child. It may also be possible that they are getting good support from family members and friends around them, thus increasing the feelings of competence and support as a parent. Furthermore, the group of ASD parents in this study were recruited while they were participating in a talk on management of ASD and a parental group skills therapy for ASD. A study found that there is a positive association between the prevalence of ASD among children in the United States with high socio-economic status. It is suggested that there may be the possibility of socio-economic disproportions in terms of services accessibility for ASD children (Durkin et al., 2010).

The current study's results indicate that specific attention needs to be directed towards the needs of parents of ASD children. Frequently, the psychosocial, interpersonal and family needs are overlooked. Lim (2015) points out that respite care is a key element that is absent in the Malaysian autism landscape. Although the findings suggest that the parents of ASD children in the study were not significantly different than parents of TD children in terms of feeling competent and supported as a parent, their stress of having to deal with difficult behavioural problems of their ASD children and low, if not absent, interactions with them are issues that need to be considered seriously. In helping patients with ASD, mental health clinicians such as clinical psychologists should spend more time in providing training for parents in behavioural modification techniques and social skills which parents can practise with their child at home. Ilias et al. (2019) insist on the inclusion of both parents in specialised parenting programmes to train them on the management of a spectrum of behavioural problems common in ASD children in addition to help with their self-efficacy. Additionally, speech therapists can also help ASD children to better interact with significant others and express themselves in a healthy manner.

Another interesting finding of this study is that parents of ASD children who were 30-35 years-old were more stressed compared to their counterparts (parents of TD children) of the same age group. One possible explanation is that their disabled child may just be in

the transition of entering the education system; therefore, they have to make a decision on whether to place their child at a special school or a mainstream school. As reported by a study (Oh, Rubin & Mouw, 1994 as cited in Delambo, Chung & Huang, 2011) on mothers of mentally retarded children, mothers experienced elevated stress when they had to make a decision on the educational placement of their child.

Additionally, parents aged 30-35 years may have other children other than their disabled child which takes a higher toll on them. According to Ilias et al. (2016), Malaysian families have further difficulties as they had to support the needs to educate multiple children in comparison to single child families in China. This is most likely true with the participants of this study who were mostly Malays.

The findings also show that older parents with ASD children tended to report a lower level of parental functioning stress than younger parents do. Results show that these parents aged 30-35 and 35-40 yearsold were the two age categories that were significantly found to be more stressful than parents of TD children of the same age categories. This finding can be related to a finding by Ilias et al. (2016) who highlight parents' anxiety in regard to the future of their ASD children to be one of their sources of stress. It is likely that parents at these ages have ASD children who have started to enter school, and thus they may be getting more worried about their children's schooling and future secondary or tertiary education. Additionally, the findings show that parents of ASD children aged 40 and above had decreased levels of stress than those younger. This could be explained by their ability to accept their children's disability after the diagnosis. A study demonstrates that Malaysian fathers had deep feelings of denial and distanced themselves in the early period after noticing symptoms in their children (Ilias et al., 2019). The "early period" could be when their children were not too young nor too old for parents to start noticing their ASD symptoms. It is likely that parents with ASD children at this stage are under 40 years of age.

The decrease of stress in parents of ASD children who are above 40 years could be explained by a finding which shows that older parents of children with ASD are able to make use of more resources to maintain social support, build meaningful network in the society and more knowledgeable of available services they could make use of (Delambo,

Chung & Huang, 2011). Additionally, Ilias et al. (2017) discovered that over time, Malaysian parents find a way to accept their child's diagnosis and find comfort through prayers and religious involvement. This could be several years after the child's diagnosis and stress would have decreased for many of the parents. Furthermore, most of the participants of this study were of a high socio-economic status, thus they may have attained a higher position in the workplace, which contributes to a more stable financial situation for the family, diminishing the stress. This is supported by a finding that financial problems contribute to the stress of Malaysian mothers with ASD children (Ilias et al., 2017).

It is imperative that in a developing country like Malaysia where the health and education system for children with ASD is still largely inadequate, medical and allied health professionals are given excessive training to support and help parents of ASD children with the diagnostic process, conduct therapies and perform treatment interventions (Ilias et al., 2019). Findings of this study highlight that parents at the midage (30-35 years) were the most stressful parents compared to other age groups; therefore, preventive measures can be taken with young parents (i.e. before age 30) so that they are better prepared to cope with future challenges in caring for their ASD children. Information on talks and services could be promoted more aggressively in the local and online media, especially targeting parents in the suburban and rural areas. Government agencies, social workers and non-profit organization workers should empower social supports for parents of ASD children. More aggressive outreach efforts could be done through schools, religious centres such as mosques and churches, and family associations to provide knowledge and information about available services to Malaysian parents with ASD children. Strong support from the community may contribute to the perception of a safe and comfortable environment for these parents to share their challenges and receive mutual support (Delambo, Chung & Huang, 2011).

Limitations and Future Research

There are some limitations in the present study that should be addressed. The techniques to recruit participants for this study were purposive and convenience sampling. Thus, the sampled parents who volunteered to complete the questionnaires of this study were likely those who have higher insights and motivation, illustrated by the fact that they were seeking treatment at the psychiatry clinic and attending a talk on ASD management held at a medical centre, which further constrained the generalisability of the findings. Therefore, future studies may want to include parents of ASD children who are of lower socio-economic background, from various races, and socio-economical and occupational backgrounds. Additionally, it is important to take into account the length of time since their children had been diagnosed, the severity of their ASD (low, medium or high functioning) and the internalising and externalising behaviours manifested by the children. Also, the larger proportion of the sample in this study were Malays; it is recommended that future research explore parental stress and associated factors in other racial groups.

Furthermore, another limitation of the study is the unbalanced range of age in the ages of the children. It is highly recommended that in the future, there would be a more balanced selection of children at different stages of the developmental process.

The study also did not take into account the number of children the parents have, which is very important considering many Malaysians tend to have many children. Furthermore, it was not stated in the questionnaire which child the parents should be thinking about when answering the questions (which refer to one specific child). Therefore, a parent who has typically developing children with different behavioural problems may think of an easy child to care for whereas another may think of a difficult child to care for in answering the questions which would make the responses invalid. Therefore, future research should take into account adding the number of children and the criteria of the child whom they should think of when answering the questions.

References

- Abidin RR, Bruner JF. (1995). Development of a parenting alliance inventory. *Journal of Clinical Child Psychology*, 24(1), 31–40.
- Amireh, M.M.H. (2019). Stress Levels and Coping Strategies among Parents of Children with Autism and Down Syndrome: The Effect of Demographic Variables on Levels of Stress, *Child Care in Practice*, 25(2), 146-156.
- Autism Speaks (2018). CDC increases estimate of autism's prevalence by 15 percent, to 1 in 59 children. Retrieved from https://www.autismspeaks.org

- De Hayes, S.A., & Watson, S.L. (2013). The Impact of Parenting Stress: A meta-analysis of studies comparing the experience of parenting stress in parents of children with and without autism spectrum disorder. *Journal of Autism and Developmental Disorders, 43*, 629-642.
- DeLambo, D., Chung, W., & Huang, W. (2011). Stress and age: A comparison of Asian American and non-Asian American parents of children with developmental disabilities. *Journal of Developmental and Physical Disabilities*, 23, 129–141.
- Durkin, M.S., Maenner, M.J., Meaney, F.J., Levy, S. E., DiGuiseppi, C., Nicholas, J.S., Kirby, R.S., Pinto-Martin, J.A., & Schieve, L.A. (2010). Socioeconomic inequality in the prevalence of autism spectrum disorder: evidence from a U.S. Cross Sectional Study. PLoS ONE, 5(7), e11551.
- Goetz, G.L., Rodriguez, G., & Hartley, S.L. (2019). Actor-partner examination of daily parenting stress and couple interactions in the context of child autism. *Journal of Family Psychology*, *33*(5), 554-564.
- Howell, D. C. & Mc Conaughy, S. H. (1982). Nonorthogonal analysis of variance: Putting the question before the answer. *Educational and Psychological Measurement*, 42, 9-24.
- Huang, X., Zhang, H. & Chen, S. (2019). Current Medical Science, 39 (2), 291-297.
- Ilias, K., Cornish, K., Kummar, A. S., Park, M. S.-A., and Golden, K. J. (2018). Parenting stress and resilience in parents of children with autism spectrum disorder (ASD) in Southeast Asia: a systematic review. *Frontiers in Psychology*, 9 (280), 1-14.
- Ilias, K., Cornish, K., Park, M.S.-A., Toran, H., & Golden, K.J. (2019). Risk and resilience among mothers and fathers of primary school age children with ASD in Malaysia: A qualitative constructive grounded theory approach. *Frontiers in Psychology*, 9 (2275), 1-20.
- Ilias, K., Liaw, J. H. H., Cornish, K., Park, M., and Golden, K. J. (2017). Wellbeing of mothers of children with "A-U-T-I-S-M" in Malaysia: an interpretative phenomenological analysis study. *Journal of Intellectual* and Developmental Disability, 42, 74–89.
- Konstantareas, M. M., & Homatidis, S. (1989). Parental perception of learningdisabled children's adjustment problems and related stress. *Journal of Abnormal Child Psychology*, 17, 177–186.
- Lee, J.X., Ong, S.I., Lee, V.Y., & Fairuz Nazri, A.R. (2017). Parenting stress among Malaysian parents of children with Autism Spectrum Disorder. *Medicine and Health*, 12(1), 42-55.

- Lim, J.M. Institute for Democracy and Economic Affairs (IDEAS) (2015). Living with Autism in Malaysia. Retrieved from http://ideas.org.my/wpcontent/uploads/2017/02/living-with-autism.pdf
- Malaysian Ministry of Health (2014). Clinical Practice Guidelines, Management of Autism Spectrum Disorder in Children and Adolescents. Retrieved from http://www.moh.gov.my/index.php/pages/view/149
- Martin, C.A., Papadopoulos, N., Chellew, T., Rinehart, N.J., Sciberras, E. (2019). Associations between parenting stress, parent mental health and child sleep problems for children with ADHD and ASD: Systematic Review. *Research in Developmental Disabilities*, 93 (103463).
- Nazurah, A., Dzalani, H., Baharudin, O., Mahadir, A., Leonard, J.H. (2016). The reliability of Malay version of parenting stress index-short form (PSI-SF) among caregivers of individuals with learning disabilities. *Polish Annals of Medicine*, 23(2),108-112.
- Nereo, N. E., Fee, R. J., & Hinton, V. J. (2003). Parental stress in mothers of boys with Duchenne Muscular Dystrophy. *Journal of Pediatric Psychology*, 28, 473–484.
- Nikmat, A. W., Ahmad, M., Oon, N., and Razali, S. (2008). Stress and psychological wellbeing among parents of children with autism spectrum disorder. ASEAN Journal of Psychiatry, *9*, 65–72.
- Noriko, P., & Katherine A. L. (2019). An Integrative Review of Parenting Stress in Mothers of Children with Autism in Japan. *International Journal* of Disability, Development and Education, 66(3), 249-272.
- Postorino, V., Gillespie, S., Lecavalier, L., Smith, T., Johnson, C., Swiezy, N., Aman, M.C., McDougle, C.J., Bearss, K., Andridge, R.R., Vitiello, B., & Scahill, L. (2019). Clinical Correlates of Parenting Stress in children with autism spectrum disorder and serious behavioral problems. *Journal of Child and Family Studies*. 28(8), 2069-2077.
- Resurreccion, R.R. (2013). Best practices of parents and interventionists of children with autism. *Philippine Journal of Counselling Psychology*, 15(1), 97–119.
- Rodriguez, G., Hartley, S.L. & Bolt, D. (2019). Journal of Autism and Developmental Disorders, 49(5), 1887-1898.
- Schieve, L.A., Blumberg, S.J., Rice, C., Visser, S.N., & Boyle, C. (2007). The relationship between autism and parenting stress., *Pediatrics*, 119.
- Siu, Q.K.Y., Yi, H., Chan, R.C.H., Chio, F.H.N, Chan, D.F.Y.& Sak, W.W.S. (2019). Journal of Autism and Developmental Disorders, 49(3), 857-870.

In This Issue

Note from the Guest Editor

Aida Mokhtar

Research Articles

- Ruzita Mohd Amin and Nur Syuhada Md. Adros The Extra Costs of Having a Disability: The Case of IIUM
- Aida Mokhtar and Souhaila Ahmed Elyass Hussain Advertisements Shape Our Social Reality: A Study of Apple Advertisements on Promoting PWDs and Inclusion

Nur Amirah Abd Samad and Asiah Abdul Rahim

The Anticipation of Malaysian Urban Cities to be Inclusive and Accessible by 2030

Mastura Badzis and Rabiu Garba Idris Parenting Children with Hearing Impairment: The Milieu of Parents' Practices and Experiences

Nadzirah Ahmad Basri and Nik Nur Wahidah Nik Hashim Stress in Parents of Children with Autism: A Malaysian Experience

Haliza Hasan, Syed Mohamed Aljunid and Amrizal MN

The Costs of Caregivers for Children with Disabilities that Participate in Centre-Based and Home-Based Community-Based Rehabilitation (CBR) Programmes in the East Coast of Malaysia

Siti Asma Mohammed, Nur Faizah Azahari and Wan Nur Shahirah W.A. Sayuti

The Design of a Speech Delay Screening Mobile Application for Malaysian Parents



ISSN 0128-4878 (Print)

ISSN 2289-5639 (Online)