

# **UNIVERSITI PUTRA MALAYSIA**

# FACTORS ASSOCIATED WITH AUTISM SEVERITY IN CHILDREN WITH AUTISM SPECTRUM DISORDER AT AN AUTISM INTERVENTION CENTER IN KUALA LUMPUR, MALAYSIA

**EOW SHIANG YEN** 

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## FACTORS ASSOCIATED WITH AUTISM SEVERITY IN CHILDREN WITH AUTISM SPECTRUM DISORDER AT AN AUTISM INTERVENTION CENTER IN KUALA LUMPUR, MALAYSIA

By

EOW SHIANG YEN

Thesis Submitted to the School of Graduate Studies, Universiti Putra Malaysia, in Fulfilment of the Requirements for the Degree of Master of Science

November 2019

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Abstract of thesis presented to the Senate of Universiti Putra Malaysia in fulfilment of the requirement for the degree of Master of Science

## FACTORS ASSOCIATED WITH AUTISM SEVERITY IN CHILDREN WITH AUTISM SPECTRUM DISORDER AT AN AUTISM INTERVENTION CENTER IN KUALA LUMPUR, MALAYSIA

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## EOW SHIANG YEN

#### November 2019

Chair : Gan Wan Ying, PhD Faculty : Medicine and Health Sciences

Autism is a life-long neurodevelopmental condition that affects the ability of a person to communicate and relate to others. Its symptoms can be conceptualized along a continuum ranging from mild to severe expression. Children with Autism Spectrum Disorder (ASD) of higher symptom severity exhibit different behaviors and characteristics compared to their counterparts of lower symptom severity. To date, there is limited nutrition-related study in children with ASD of different autism severity in Malaysia. Most of the previous local studies on ASD in Malaysia focused on education, engineering, information technology, medical, and psychology. Therefore, this cross-sectional study aimed to determine the associations between sociodemographic factors, parental factors, and lifestyle factors with autism severity in children with ASD at a selected autism intervention center in Kuala Lumpur.

A total of 224 children with ASD (82.6% boys and 17.4% girls) with a mean age of  $5.19 \pm 0.87$  years and their mothers participated in this study. Mothers completed a self-administered questionnaire on sociodemographic background, autism severity, parenting style, parental feeding practices, parenting stress, child sleep habits, and child eating behaviors. A 3-day food diary was recorded by the mothers at home to determine dietary adequacy of their children. Body weight and height of the children were measured by the researcher in the center.

The Social Communication Questionnaire (SCQ) was used to measure autism severity. Results showed that the mean score of the SCQ was  $20.12 \pm 6.93$ , ranging from 3 to 38. Majority of the children with ASD in this study (78.1%) were in the high level of autism severity. In term of nutritional status, the prevalence rates of underweight, stunting, wasting/thinness, and overweight/obesity were 9.3%, 8.0%, 4.0%, and 21.5%, respectively. More than half of the children with ASD did not meet the recommended nutrient intake (RNI) requirement for fiber

(99.6%), thiamin (67.4%), and calcium (90.2%). Most of the mothers (94.6%) practiced authoritative parenting style, which is characterized by reasonable demands and high responsiveness.

Multiple linear regression results showed that mother's educational level (*B*=6.185, 95% CI=2.389, 9.982, *p*=0.002), father's employment status (*B*=2.912, 95% CI=0.917, 4.906, *p*=0.004), perceived child weight (*B*=2.912, 95% CI=0.917, 4.906, *p*=0.004), concern about child weight (*B*=1.111, 95% CI=0.139, 2.083, *p*=0.025), total fiber intake (*B*=-0.297, 95% CI=-0.569, -0.026, *p*=0.032), and sodium intake (*B*=0.001, 95% CI= 0.0001, 0.002, *p*=0.044) predicted autism severity among children with ASD in this study. These six variables accounted for a significant 19.6% of the variability in autism severity (*F*=8.773, *p*<0.001;  $R^2$ =0.196, Adjusted  $R^2$ =0.174).

In conclusion, children with ASD in this study reported high level of autism severity. More parental involvement and time spent with children with ASD should be encouraged to promote better parent-child interactions. Nutrition education programs for parents should emphasize healthy child weight management, healthy eating and parenting practices in order to improve ASD symptomatology and to ensure optimal growth of children with ASD. Abstrak tesis yang dikemukakan kepada Senat Universiti Putra Malaysia sebagai memenuhi keperluan untuk ijazah Master Sains

## FAKTOR BERKAITAN DENGAN KESERIUSAN AUTISME DALAM KALANGAN KANAK-KANAK YANG MEMPUNYAI GANGGUAN SPEKTRUM AUTISME DI PUSAT INTERVENSI AUTISME DI KUALA LUMPUR, MALAYSIA

Oleh

#### EOW SHIANG YEN

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Autisme merupakan keadaan perkembangan neuro sepanjang hayat yang mempengaruhi keupayaan seseorang untuk berkomunikasi dan berhubung dengan orang lain. Simptomnya berada pada siri tahap keterukan dari ringan ke teruk. Kanak-kanak yang mempunyai Gangguan Spektrum Autisme (ASD) dengan keseriusan autisme yang lebih teruk mempamerkan tingkah laku dan ciriciri yang berlainan berbanding dengan kanak-kanak yang mempunyai tahap keseriusan autisme yang ringan. Penilaian dan pengkategorian keseriusan autisme memberi maklumat penting mengenai simptom dan prognosis ASD. Kini, kajian berkaitan dengan pemakanan dalam kalangan kanak-kanak dengan ASD yang mempunyai tahap keseriusan autisme yang berbeza di Malaysia adalah terhad. Kebanyakan kajian tempatan mengenai ASD memberi tumpuan kepada pendidikan, kejuruteraan, teknologi maklumat, perubatan, dan psikologi. Oleh itu, kajian keratan rentas ini bertujuan untuk menentukan hubungkait antara faktor sosiodemografi, keibubapaan dan gaya hidup dengan keseriusan autisme dalam kalangan kanak-kanak dengan ASD di pusat intervensi autisme yang terpilih di Kuala Lumpur.

Seramai 224 kanak-kanak dengan ASD (82.6% lelaki dan 17.4% perempuan) dengan purata umur 5.19  $\pm$  0.87 tahun dan ibu mereka terlibat dalam kajian ini. Ibu melengkapkan satu borang soal selidik mengenai latar belakang sosiodemografi, keseriusan autisme, gaya keibubapaan, amalan pemberian makanan, tekanan keibubapaan, tabiat tidur kanak-kanak, dan tingkah laku makan kanak-kanak. Diari makanan selama tiga hari direkod oleh ibu di rumah untuk menentukan kecukupan diet kanak-kanak. Berat badan dan ketinggian kanak-kanak diukur oleh penyelidik di pusat intervensi autisme.

Borang Soal Selidik Komunikasi Sosial (SCQ) digunakan untuk menilai keseriusan autisme. Hasil kajian menunjukkan bahawa nilai purata bagi SCQ adalah  $20.12 \pm 6.93$ , skor antara 3 hingga 38. Majoriti kanak-kanak dengan ASD dalam kajian ini (78.1%) berada pada tahap keseriusan autisme yang teruk. Kadar prevalens kurang berat badan, terbantut, susut berat badan, dan berat badan berlebihan/obes adalah masing-masing 9.3%, 8.0%, 4.0%, dan 21.5%. Lebih separuh daripada kanak-kanak dengan ASD tidak memenuhi saranan pengambilan nutrien untuk serat (99.6%), thiamin 67.4%), dan kalsium (90.2%). Kebanyakan ibu (94.6%) mengamalkan gaya keibubapaan authoritatif yang berciri tuntutan yang munasabah dan responsif yang tinggi.

Hasil analisis regrasi pelbagai linear menunjukkan bahawa tahap pendidikan ibu (*B*=6.185, 95% Cl=2.389, 9.982, *p*=0.002), status pekerjaan bapa (*B*=2.912, 95% Cl=0.917, 4.906, *p*=0.004), persepsi berat badan kanak-kanak (*B*=2.912, 95% Cl=0.917, 4.906, *p*=0.004), kebimbangan berat badan kanak-kanak (*B*=1.111, 95% Cl=0.139, 2.083, *p*=0.025), pengambilan fiber (*B*=-0.297, 95% Cl=-0.569, 0.026, *p*=0.032), dan pengambilan natrium (*B*=0.001, 95% Cl= 0.0001, 0.002, *p*=0.044) meramalkan keseriusan autisme dalam kalangan kanak-kanak dengan ASD. Keenam-enam pembolehubah ini menyumbang secara signifikan 19.6% varians dalam keseriusan autisme (*F*=8.773, *p*<0.001; *R*<sup>2</sup>=0.196; Adjusted *R*<sup>2</sup>=0.174).

Kesimpulannya, kanak-kanak dengan ASD dalam kajian ini melaporkan keseriusan autisme yang teruk. Penglibatan ibu bapa dan masa yang diluangkan untuk kanak-kanak dengan ASD yang lebih harus digalakkan untuk mempromosi interaksi yang lebih baik antara ibu bapa dan kanak-kanak. Program pendidikan pemakanan untuk ibu bapa harus menekankan pengurusan berat badan yang sihat, pemakanan sihat dan amalan keibubapaan untuk meringankan gejala ASD dan untuk memastikan pertumbuhan yang optimum pada kanak-kanak dengan ASD.

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I certify that a Thesis Examination Committee has met on 18 November 2019 to conduct the final examination of Eow Shiang Yen on his thesis entitled "Factors Associated with Autism Severity in Children with Autism Spectrum Disorder at an Autism Intervention Center in Kuala Lumpur, Malaysia" in accordance with the Universities and University Colleges Act 1971 and the Constitution of the Universiti Putra Malaysia [P.U.(A) 106] 15 March 1998. The Committee recommends that the student be awarded the (insert the name of relevant degree).

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## LIST OF ABBREVIATIONS

| 5-HT   | 5-hydroxytryptamine  |
|--------|--|
| AbBC   | Aberrant Behavior Checklist                                    |
| ABC    | Autism Behavior Checklist                                      |
| ADDM   | Autism and Developmental Disabilities Monitoring               |
| ADHD   | Attention-deficit/hyperactivity disorder                       |
| ADI-R  | Autism Diagnostic Interview-Revised                            |
| ADOS   | Autism Diagnostic Observation Schedule                         |
| ADOS-G | Autism Diagnostic Observation Schedule-Generic                 |
| AMDR   | Acceptable micronutrient distribution ranges                   |
| APA    | American Psychiatric Association                               |
| ASD    | Autism Spectrum Disorder                                       |
| ASQ    | Autism Screening Questionnaire                                 |
| ASSQ   | Autism Spectrum Screening Questionnaire                        |
| ATN    | Autism Treatment Network                                       |
| AuBC   | Autism Behavior Checklist                                      |
| BAZ    | BMI-for-age z score  |
| BMI    | Body mass index  |
| BMR    | Basal metabolic rate   |
| CARS   | Childhood Autism Rating Scale                                  |
| CAST   | Childhood Autism Spectrum Test                                 |
| CDC    | Centers for Disease Control and Prevention                     |
| CEBQ   | Child Eating Behavior Questionnaire                            |
| CFQ    | Child Feeding Questionnaire                                    |
| CHAT   | Checklist for Autism in Toddlers                               |
| CSHQ   | Children Sleep Habit Questionnaire                             |
| DRI    | Dietary Reference Intake                                       |
| DSM-IV | Diagnostic Statistical Manual of Mental Disorders, 4th edition |
| DSM-V  | Diagnostic Statistical Manual of Mental Disorders, 5th edition |
| EAR    | Estimated Average Requirement                                  |
| EI     | Energy intake  |
| FFQ    | Food frequency questionnaire                                   |
| HAZ    | Height-for-age z score   |
| IQ     | Intellectual quotient  |
| M-CHAT | Modified Checklist for Autism in Toddlers                      |
| MCH    | Mother and child health  |
| MCV    | Mean corpuscular volume  |
| MREC   | Medical Research and Ethics Committee                          |
| NASOM  | National Autism Society of Malaysia                            |
| NHMS   | National Health and Morbidity Survey                           |

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| NII       | National Insurance Institute                             |
|-----------|--|
| NSCH      | National Survey of Children's Health                     |
| PAQ       | Parental Authority Questionnaire                         |
| PDD       | Pervasive developmental disorder                         |
| PDD-NOS   | Pervasive Developmental Disorder-Not Otherwise Specified |
| PECS      | Picture Exchange Communication System                    |
| PHGG      | partially hydrolyzed guar gum                            |
| PSDQ      | Parenting Styles Dimensions Questionnaire                |
| PSI™-4-SF | Parenting Stress Index Short Form, 4th edition           |
| PSI™-3-SF | Parenting Stress Index Short Form, 3rd edition           |
| RNI       | Recommended Nutrient Intake                              |
| SEANUTS   | South East Asian Nutrition Survey                        |
| SES       | Socio-economic status                                    |
| SCQ       | Social Communication Questionnaire                       |
| SNAP      | Special Needs and Autism Project                         |
| SRS       | Social Responsive Scale                                  |
| TD        | Typical development                                      |
| WAZ       | Weight-for-age z score                                   |
| WHO       | World Health Organization                                |

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## CHAPTER 1

## INTRODUCTION

#### 1.1 Background

Autism Spectrum Disorder (ASD) is a summary term for a combination of social communication deficits and repetitive, restricted behaviors based on the Diagnostic Statistical Manual of Mental Disorders, 5th edition (DSM-V) (American Psychiatric Association [APA], 2013). The previous subcategories in the Diagnostic Statistical Manual of Mental Disorders, 4th edition (DSM-IV) including Asperger's disorder, autistic disorders, childhood disintegrative disorder, and Pervasive Developmental Disorder-Not Otherwise Specified (PDDNOS) have been replaced by the diagnosis of ASD based on the latest definition in the DSM-V (American Psychiatric Association [APA], 2013).

The symptoms of ASD can be conceptualized along a continuum ranging from mild to severe expression, in which it is present from infancy or early childhood although its deficits may be detected later in life due to minimal social demands and compensations by parents or caregivers earlier in life (APA, 2013). Some symptoms of ASD include highly obsessive interest and/or repetitive activities; unusual reactions to the ways things sound, smell, look, taste, or feel; extreme distress at small changes in daily routine, including diet; and difficulties with social interaction and communication, including limited language development, marked impairment of eye-to-eye gaze, limited joint attention, and lack of social reciprocity (APA, 2013). Signs of atypical development in these areas must be apparent at an early age for a diagnosis of ASD (APA, 2013).

Worldwide prevalence of autism was 6.2 per 1000 people (Elsabbagh et al., 2012). In developed countries such as United Kingdom, the prevalence of ASD showed an increase of 222.6% from 3.1 per 1000 people in 2000 (Baron-Cohen, Wheelwright, Skinner, Martin, & Clubley, 2001) to approximately 10 per 1000 people in 2009 (Baron-Cohen et al., 2009). Another study in the United Kingdom reported that the prevalence rates of ASD in children aged 2-8 years were 3.8 per 1000 boys and 0.8 per 1000 girls (Taylor, Jick, & MacLaughlin, 2013). In the United States, the overall prevalence of ASD was 16.8 per 1000 children aged 8 years old (Baio et al., 2018). In other developed countries such as Canada, the prevalence of ASD in children aged 4-8 years was 9.4 per 1000 children (Ghali et al., 2014), while in Ireland, its prevalence was 12.0 per 1000 children aged 0-8 years (Saemundsen, Magnússon, Georgsdóttir, Egilsson, & Rafnsson, 2013).

In Asia, the prevalence of autism was 26.4 per 1000 in children aged 7-12 years in South Korea (Kim et al., 2011), 11.9 per 1000 in children aged 6-10 years in China (Sun et al., 2015), 5.0 per 1000 in children aged 8-18 years in Israel (Raz, Weisskopf, Davidovitch, Pinto, & Levine, 2015), and 0.7 per 1000 in children

aged 5 years in Iran (Samadi, Mahmoodizadeh, & McConkey, 2012). To date, the data on the prevalence of ASD in Malaysia remain scarce. However, a previous study on the Modified Checklist for Autism in Toddlers (M-CHAT) among children 18 to 36 months of age in the child health clinics in Ministry of Health Malaysia showed that the prevalence of ASD in Malaysia was approximately 1.6 in 1000, or approximately 1 in 625 children (Family Health Division, 2006). According to the National Autism Society of Malaysia (NASOM), a 30% increase in the organizational intake of individuals with autism was observed from year 2006 to year 2008, indicating an increase in the prevalence of ASD in Malaysia (Cheong, 2009).

In the DSM-V, the severity of autism is classified into three different levels, which are Level 1, Level 2, and Level 3 (APA, 2013). The level in which individuals with ASD belong to depends on their degree of impairment in the domains of social communication and restricted and repetitive behaviors (APA, 2013). Individuals with the severity level of Level 1 (requiring support) possess deficits in social communication which result in clear impairments in the absence of support. They have problems with inflexibility, planning, poor organization, and switching between activities, which impair independence. Poor social skills, poor attempts to make friends, difficulty in initiating interactions, and odd and unsuccessful social reciprocity can also be observed among them. For individuals with the severity level of Level 2 (requiring substantial support), they have marked deficits in both verbal and non-verbal social communication skills. They also exhibit markedly odd, restricted repetitive behaviors, and noticeable difficulties changing activities or focus. For individuals with the severity level of Level 3 (requiring very substantial support), they have severe difficulties in verbal and non-verbal communication, in which they have only limited speech and exhibit many odd, repetitive behaviors. Many individuals in this Level 3 are capable of expressing only their basic needs. The level of autism severity is not fixed and may vary by context and over time in individuals with ASD (APA, 2013).

Children with ASD are different from children with typical development (TD) in terms of social interaction, communication, food selectivity, and feeding patterns (Sharp et al., 2013). In recent years, the severity of core ASD symptomatology became a subject of interest (Mehling & Tassé, 2016). The reason for the high interest in autism severity was that the assessment and categorization of autism severity provided valuable information on the symptom course and prognosis of ASD (Gotham, Pickles, & Lord, 2012). Children with ASD of different autism severity showed differences in parenting style, parental feeding practices, parenting stress, sleep habits, child eating behaviors, dietary intake, and body weight status (Allen et al., 2014; Boyd, 2002; Brei, Schwarz, & Klein-Tasman, 2015; Chan & Lam, 2016; Gabriels, Cuccaro, Hill, Ivers, & Goldson, 2005; Lukens & Linscheid, 2008; Sharp, Jaquess, & Lukens, 2013; Xiong et al., 2009).

Most of the local studies on children with ASD did not classify them into different autism severity. Children with ASD of higher symptom severity exhibit different behaviors and characteristics compared to their counterparts of lower symptom severity (De Pauw, Mervielde, Van Leeuwen, & De Clercq, 2011). Different treatments are required for children with ASD of different autism severity. Therefore, there is an urgency to determine different factors associated with autism severity in children with ASD. This is important for the development of effective public health interventions for children with ASD with different autism severity in order to assist them to have a healthy social life.

## 1.2 Problem Statement

Autism is a life-long neurodevelopmental condition that affects the ability of a person to communicate and relate to others (Elsabbagh et al., 2012). Well-being of children with ASD is an emerging area of concern which requires urgent attention due to its increasing prevalence (Adak & Halder, 2017; Brett, Warnell, McConachie, & Parr, 2016; Sharda, Subbalakshmi, Narayana, & Samal, 2012). Higher autism severity in children with ASD predicted a higher number of comorbid symptoms such as tantrums, repetitive behaviors, and avoidant behavior, which affect the children's ability to learn (Jang & Matson, 2015). Besides, children with ASD of higher symptom severity in social responsiveness, repetitive behavior, internalizing behaviors, and externalizing behaviors were reported to have lower health-related quality of life (Kuhlthau et al., 2010), lower daily living skills (Green & Carter, 2014), and less satisfactory parent-child interactions due to their impaired ability in interpersonal relatedness (Beurkens, Hobson, & Hobson, 2013) compared to their counterparts of lower autism severity. Furthermore, the increased severity of child autistic symptoms resulted in more family problems and high pessimism in a family (Lyons, Leon, Phelps, & Dunleavy, 2010). Overall, children with ASD of higher autism severity suffered physically and mentally at both intrapersonal and interpersonal levels.

Children with ASD required autism-related services in different sectors including medical, therapeutic, behavioral, and educational (Thomas, Ellis, McLaurin, Daniels, & Morrissey, 2007). The economic burden experienced by families with children with ASD is substantial and not only limited to the healthcare expenses (Lavelle et al., 2014). Children with ASD had higher frequency of healthcare service visits, special educational services, prescription drug use, higher healthcare costs, and higher school costs compared with children with TD (Lavelle et al., 2014). The frequent needs for autism-related services of children with ASD also affected parents' work and family routines (Becerra, 2017; Montes & Halterman, 2008). Apart from financial and time burden, the diagnosis of ASD on their children subjects their parents to stigma processes from their surroundings in the form of peer rejection, stereotyping, and exclusion, all of which contribute to difficulty of parents in raising the children with ASD (Kinnear, Link, Ballan, & Fischbach, 2016). The affiliate stigma as a result of internalizing the external criticism towards the uncontrolled behavior of their children caused the development of psychological distress among parents (Feng et al., 2013).

The risk factors responsible for autism severity of children with ASD included sociodemographic (Adak & Halder, 2017; Emerson, Morrell, & Neece, 2016; King & Bearman, 2009; Osborne, McHugh, Saunders, & Reed, 2008), nutritional (Adams et al., 2011; Bandini et al., 2010; Gunes, Ekinci, & Celik, 2017; Guo, Li,

et al., 2018; Lane, Geraghty, Young, & Rostorfer, 2014; Liu et al., 2016), and lifestyle factors (Adams, Matson, Cervantes, & Goldin, 2014; Cohen et al., 2017; Hollway, Aman, & Butter, 2013; Thenhausen, Kuss, Wiater, & Schlarb, 2017). For example, a growing body of evidence has indicated that children with ASD were at higher risk of feeding problems than children with TD and displayed more feeding problems (Lukens & Linscheid, 2008; Schreck, Williams, & Smith, 2004). Parental feeding practices (Allen et al., 2014; Johnson et al., 2014) and different parenting styles (Tripathi, 2016) were found to be correlated with autism severity. Schieve, Blumberg, Rice, Visser, and Boyle (2007) found that parents whose children had ASD and required special health care needs due to emotional, developmental, and behavioral problems possessed higher aggravation in their parenting compared to their counterparts without special health care needs. However, the associations between parental feeding practices and parenting style with autism severity have not been studied in Malaysia. Furthermore, controversial findings were reported in the associations between parenting stress (Brei et al., 2015; Ingersoll, Meyer, & Becker, 2011; Pastor-Cerezuela, Fernández-Andrés, Tárraga-Mínguez, & Navarro-Peña, 2016; Tomeny, 2016), child's sleep habits (Adams, Matson, Cervantes, & Goldin, 2014; Cohen et al., 2017; Hollway, Aman, & Butter, 2013; Thenhausen, Kuss, Wiater, & Schlarb, 2017), and eating behaviors (Lukens & Linscheid, 2008; Schreck & Williams, 2006, Sharp et al., 2013) with autism severity in children with ASD. It is important to clarify these associations with autism severity.

The selective eating and sensory sensitivity possessed by children with ASD predisposed them to the risks of poor nutritional status (Bandini et al., 2010; Bicer & Alsaffar, 2013; Lockner, Crowe, & Skipper, 2008; Schmitt, Heiss, & Campbell, 2008; Schreck & Williams, 2006). Although there has been an increase in research on body weight status of children with ASD, evidence on the association between body weight status and autism severity is scarce. On the other hand, children of higher autism severity were reported to be more prone to nutrient deficiencies such as vitamin A, biotin, vitamin K, iodine, linolenic acid, omega-3 fatty acids, and choline than their counterparts of lower autism severity (Lane, Geraghty, Young, & Rostorfer, 2014; Liu et al., 2016). However, there is no published local study examining dietary intake of children with ASD. Most of the local studies focused on dietary intake of general healthy children (Chong, Lee, Ng, Khouw, & Poh, 2017; Koo et al., 2016; Poh, Tham, Wong, Chee, & Tee, 2012). Furthermore, little is known about the association between dietary intake and autism severity in children with ASD. Nutritional status of children between the age of 2 and 11 is important for optimal physical and cognitive development and reduction of the risk of chronic diseases in the future (Ogata & Hayes, 2014). Therefore, it is crucial to determine the association between nutritional status and autism severity in children with ASD.

Autism severity can be influenced by a number of both external factors and internal factors including genetic vulnerability, neurobiological factors, and environmental factors (Ministry of Health, 2014). Given the limited number of studies available in Malaysia regarding the nutritional problems of children with ASD and the mixed results reported to date, more studies should be conducted. To the best of our knowledge, there is no study examining the associations between parental factors and lifestyle factors with autism severity in Malaysian children with ASD. Hence, this study aimed to determine these factors associated with autism severity in children with ASD. This study attempted to address the following research questions:

- (1) What is the level of autism severity in children with ASD?
- (2) Are there associations between sociodemographic factors, parental factors, and lifestyle factors with autism severity in children with ASD?

## 1.3 Significance of the Study

The increasing number of ASD cases resulted in higher healthcare expenses for treatment and facilities, with many public and private autism centers being established to accommodate the assessment, intervention, and consultation needs of the children with ASD and their parents. In recent years, the association between nutrition and severity of ASD symptoms has attracted research interest in the western countries. However, there is little information on nutritional aspects of the children with ASD in Malaysia. Most of the previous local studies on ASD in Malaysia focused on education, engineering, information technology, medical, and psychology. Therefore, this study seeks to fill the dearth of knowledge by examining nutritional aspects such as parenting style, parental feeding practices, child eating behaviors, dietary intake, and body weight status of children with ASD. Useful baseline data on children with ASD in Malaysia would be generated. Early attention on the nutritional status, eating behaviors, and feeding practices is important to ensure timely interventions for the children with ASD.

In addition, findings of this study could provide useful information to Ministry of Health, NASOM, GENIUS Kurnia (formerly known as PERMATA Kurnia), and other autism intervention centers. Appropriate parenting intervention programmes and nutritional guidelines for children with ASD could be developed in order to alleviate nutritional deficiencies or parenting issues that worsen the autism severity. Good nutritional and parenting practices could be established and healthcare burden of the family as well as the country could be reduced. These could help to improve the overall functioning, social communication, and adaptive behaviors in children with ASD.

## 1.4 Objectives

#### 1.4.1 General objective

To determine the factors associated with autism severity in children with ASD at a selected autism intervention center in Kuala Lumpur.

#### 1.4.2 Specific objectives

a) To examine the sociodemographic factors (parents' educational level, parents' occupation, parents' monthly income, monthly household income, parents' marital status, child's age, sex, ethnicity, gestational

age, birth weight, number of siblings, birth order, number of siblings with ASD, and duration in the center), parental factors (parenting style, parenting feeding practices, and parenting stress), and lifestyle factors (sleep habits, child eating behaviors, dietary intake, and body weight status) of children with ASD.

- b) To identify the level of autism severity among children with ASD.
- c) To determine the associations between sociodemographic factors, parental factors, and lifestyle factors with autism severity of children with ASD.

## 1.5 Research Hypothesis

There are significant associations between sociodemographic factors, parental factors, and lifestyle factors with autism severity of children with ASD.

## 1.6 Research Framework

As shown in Figure 1.1, autism severity is the dependent variable while sociodemographic factors, parental factors, and lifestyle factors are the independent variables of this study. Several studies reported associations between sociodemographic factors such as sex (Adak & Halder, 2017), parents' socio-economic status (SES) (King & Bearman, 2009), birth order (Emerson et al., 2016), and number of siblings with ASD (Osborne et al., 2008) with autism severity in children with ASD.

A number of previous studies showed that children whose parents adopting aggressive parenting style had higher autism severity (Boyd, 2002; Duan et al., 2015; White & Hastings, 2004). Conflicting findings were reported on the association between parental feeding practices and autism severity (Allen et al., 2014; Schreck & Williams, 2006). Majority of the studies reported positive correlations between parenting stress and autism severity (Brei et al., 2015; Ingersoll & Hambrick, 2011; Konstantareas & Papageorgiou, 2006; Pastor-Cerezuela et al., 2016; Tomeny, 2016).

Children with ASD of poor sleep habits were correlated with higher autism severity (Adams et al., 2014; Cohen et al., 2017; Hollway et al., 2013; Thenhausen et al., 2017). There were inconsistent findings on the association between eating behavior and autism severity in children with ASD (Lukens & Linscheid, 2008; Schreck & Williams, 2006; Sharp et al., 2013). Furthermore, children with ASD of higher symptom severity were at higher risk for micronutrient deficiencies (Guo et al., 2018; Moore, Crook, James, Gonzales, & Hakkak, 2012). There were inconclusive findings between body weight status of children with ASD and their autism severity (McCoy, Jakicic, & Gibbs, 2016; Memari, Kordi, Ziaee, Mirfazeli, & Setoodeh, 2012; Must et al., 2014; Xiong et al., 2009).

## Sociodemographic factors

- Age of children
- Sex of children
- Ethnicity of children
- Parents' marital status
- Parents' educational level
- Parents' age
- Parents' occupation
- Monthly household
  - Gestational age
  - Birth weight
- Number of siblings
  - Birth order
- Duration in the center

## Parental factors

- Parenting style
  Parental feeding
- practices
- Parenting stress

Autism severity of children with Autism Spectrum Disorder

## Lifestyle factors

- Sleep habits
  - Child eating behaviors
  - Dietary intake
- Body weight status



## 1.7 Operational Definitions

Autism severity: The level of severity of ASD symptoms is dependent on the level of support needed by individuals with ASD in terms of social communication and restricted, repetitive behaviors (APA, 2013). The Social Communication Questionnaire (SCQ) Lifetime Form (Rutter, Bailey, & Lord, 2003) was used to measure autism severity in this study. It is a 40-item parent-report questionnaire that provides a total SCQ score and assesses three domains: reciprocal social interaction, communication, and restricted, repetitive, and stereotyped patterns of behavior. The higher the total score, the higher the level of autism severity. The total score is further categorized into two different levels: low symptom (<15) and high symptom (≥15) (Rutter et al., 2003).

**Parenting style:** The classification of attitudes and behaviors that characterizes the way of interaction between mothers with their children across domains of parenting (Darling & Steinberg, 1993). It was assessed by using the 30-item Parental Authority Questionnaire (PAQ) (Buri, 1991) in this study. One of the three parenting styles (permissive, authoritarian, and authoritative) with the highest score is the parenting style adopted by the mothers. Permissive parenting style refers to parents with only few demands on their children and allow freedom in their children's life choice (Buri, 1991). Authoritarian parenting style refers to parents who are highly directive and demand respect towards their authority (Buri, 1991). Authoritative parenting style refers to parents with high responsiveness and high demands and who treat their children with disciplinary clarity but moderated by warmth and flexibility (Buri, 1991). Children exposed to authoritative parenting style exhibit the highest levels of emotional maturity, self-discipline, and self- efficacy (Gahagan, 2012).

**Parental feeding practices:** Different feeding strategies are used by parents to control the timing, frequency, and content of food consumption of their children (Russell, Haszard, Taylor, Heath, Taylor, & Campbell, 2018). It was assessed by using the 31-item Child Feeding Questionnaire (CFQ; Birch et al., 2001), a self-reported measure of parental beliefs, attitudes, and practices regarding child feeding. The CFQ has seven subscales, four of which measure parental control in child feeding (perceived responsibility, parent perceived weight, perceived child weight, and parent's concerns about child weight), and three of which measure parents' behavior (monitoring, restriction, and pressure to eat). The total score for each subscale is obtained by adding the scores for each item in the subscale. The higher the mean score, the higher the feeding practices.

**Parenting stress:** The distress or discomfort that is experienced by mothers as a result of excessive demands associated with the role of parenting (Deater-Deckard, 1998). The 36-item 4th edition of Parenting Stress Index Short Form (PSI<sup>™</sup>-4-SF; Abidin, 1990) with three subscales: parental distress, parent-child dysfunctional interaction, and difficult child was used in this study. These three subscales are summed up to form a total stress scale, which is an indication of the overall stress level a person is feeling in their role as a parent. The higher the total stress score, the higher the parenting stress of mothers.

**Sleep habits:** They are characterized by behaviorally-based aspects and medical sleep disorders before, during, and after sleeping (Owens, Spirito, & McGuinn, 2000). The Children Sleep Habit Questionnaire (CSHQ) with eight subscales: bedtime resistance, sleep duration, sleep onset delay, sleep anxiety, parasomnias, night waking, sleep disordered breathing, and day time sleepiness (Owens et al., 2000), was used in this study. The scores of these eight subscales are summed up. A higher total score indicates a higher sleep disturbance.

**Child eating behavior**: It refers to broad aspects of eating-related problems and motives when making food choices, and eating practices displayed by children (LaCaille, 2013). It was assessed by using the 35-item Child's Eating Behavior Questionnaire (CEBQ; Wardle, Guthrie, Sanderson, & Rapoport, 2001) in this study. There are eight subscales of eating behaviors that assess food approach behaviors (food responsiveness, enjoyment of food, emotional overeating, and desire to drink) and food avoidance behaviors (satiety responsiveness, slowness in eating, emotional undereating, and food fussiness). The higher the score of each subscale, the higher the preference for that specific eating behavior.

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## LIST OF PUBLICATIONS

- Eow, S. Y., Gan, W. Y., Lim, P. Y., Hamidin, A., & Zalilah, M. S. (2020). Factors associated with autism severity among Malaysian children with Autism Spectrum Disorder. *Research in Developmental Disabilities*, 100, 103632.
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