

PARENTAL STRESS AND ITS ASSOCIATED FACTORS AMONG  
PARENTS OF AUTISM SPECTRUM DISORDER CHILDREN IN KOTA  
KINABALU SABAH

By  
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## **DECLARATION**

I hereby declare that the work of this dissertation is of my own except for quotations and summaries that have been duly acknowledged.

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## **CERTIFICATION**

I hereby certify that to the best of my knowledge, this research project is the original work of the candidate, Dr. AHMAD ABDUL JALIL BIN MOHD RAZALI (PUM 0166/12).

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## LIST OF ABBREVIATION

<	: Less than
$\geq$	: Equal to and more than
=	: Equal to
%	: Percentage
$\alpha$	: Alpha
n	: Sample size
N	: Population size
Z	: Z statistic
P	: Expected proportion
d	: Precision
PSI-SF	: Parental Stress Index-Short Form
ASD	: Autism Spectrum Disorder
CARS	: Childhood Autism Rating Scale
DSM	: Diagnostic and Statistical Manual for Mental Illness
WHO	: World Health Organization
NASOM	: National Autism Society of Malaysia
CIEC	: Child Intervention and Enrichment Centre
NMRR	: National Medical Research Registry
CPG	: Clinical Practice Guidelines

## ABSTRAK

### **Tekanan Keibu-bapaan dan Faktor-faktor Berkaitan Dengannya Di Kalangan Ibu Bapa Kanak-kanak *Autism Spectrum Disorder* Di Kota Kinabalu Sabah**

**Latar Belakang:** Membesarkan kanak-kanak *Autism Spectrum Disorder* (ASD) telah dibuktikan boleh menyebabkan tekanan yang ketara. Menentukan kelaziman dalam suasana tempatan dan mengenal pasti faktor penyebab untuk tekanan ibu bapa boleh menjadi satu langkah awal dalam merumuskan perawatan yang praktikal untuk mengelakkan kesan gangguan psikologi yang memudaratkan.

**Objektif:** Objektif kajian ini adalah untuk menentukan kelaziman tekanan ibu bapa di kalangan ibu bapa kanak-kanak ASD, mengkaji faktor-faktor yang mempunyai hubungkait dengan tekanan ibu bapa, dan memeriksa hubungan antara ciri tertentu ASD dan tekanan ibu bapa .

**Metodologi:** Ini adalah satu kajian keratan rentas yang melibatkan 103 ibu bapa dan anak-anak ASD mereka yang menghadiri Pusat Intervensi dan Pengayaan Kanak-kanak (CIEC), Hospital Mesra Bukit Padang, Kota Kinabalu Sabah dari Ogos 2016 hingga Oktober 2016. Ibu Bapa yang kanak-kanak didiagnosa dengan ASD menurut *Diagnostic and Statistical Manual for Mental Disorder* edisi kelima (DSM-5) dan memenuhi kriteria pemilihan telah dimasukkan dalam kajian itu. Tekanan ibu bapa telah dinilai melalui *Parental Stress Indeks-Short Form* (PSI-SF). Keterukan ASD kanak-kanak telah dikadarkan menggunakan *Childhood Autism Rating Scale* (CARS). Ciri sosiodemografi untuk ibu bapa dan anak-anak mereka telah direkodkan di dalam Risalah Data Pesakit. Kelaziman tekanan ibu bapa telah ditentukan menggunakan takat skor yang penting secara klinikal untuk PSI-SF ( $>$  persentil ke-90) manakala hubungan antara ciri

sosiodemografi, keterukan ASD, dan ciri tertentu ASD dengan tekanan ibu bapa telah dianalisis menggunakan *Multiple Linear Regression*.

***Keputusan:*** Kelaziman tekanan di kalangan ibu bapa kanak-kanak ASD di CIEC, Kota Kinabalu adalah 39.8%. Faktor-faktor yang berkaitan dengan tekanan ibu bapa adalah ibu ( $B = 16.82$ ,  $p < 0.001$ ) dan keterukan ASD ( $B = 1.62$ ,  $p < 0.001$ ). Peramal ciri-ciri tertentu ASD untuk tekanan ibu bapa dalam kajian ini adalah '*object use*' dan '*intellectual response*'.

***Kesimpulan:*** Kelaziman tekanan di kalangan ibu bapa kanak-kanak ASD di CIEC, Kota Kinabalu adalah agak rendah. Ibu-ibu mengalami tekanan yang ketara berbanding dengan bapa dan keterukan gejala ASD mempunyai hubungkait yang jelas dengan tekanan ibu bapa. Kanak-kanak ASD dengan defisit dalam '*object use*' dan '*intellectual response*' akan meramalkan tekanan ketara dalam ibu bapa mereka. Rawatan dengan menasaskan pembolehubah tersebut boleh mengurangkan tekanan ibu bapa.

***Kata Kunci:*** *Autism Spectrum Disorder, Tekanan ibubapa, Parental Stress Index-Short Form*

## **ABSTRACT**

### **Parental stress and Its Associated Factors Among Parents of Autism Spectrum Disorder Children in Kota Kinabalu Sabah.**

**Background:** Parenting an Autism Spectrum Disorder (ASD) children had been established to cause significant stress. Ascertaining its prevalence in local setting and identifying the predictors for parental stress could be an important step in formulating a practical intervention to avert a more disruptive psychological outcome.

**Objectives:** The objective of this study was to establish the prevalence of parental stress among parents of ASD children, examine the factors associated with parental stress, and examine the association between ASD specific characteristic and parental stress.

**Methods:** This was a cross-sectional study involving 103 parents with their ASD children attending the Child Intervention and Enrichment Centre (CIEC), Hospital Mesra Bukit Padang, Kota Kinabalu Sabah from August 2016 to October 2016. Parent's whose child was diagnosed with ASD according to Diagnostic and Statistical Manual for Mental Disorder, fifth edition (DSM-5) and fulfilled the selection criteria were included in to the study. Parental stress was evaluated by means of Parental Stress Index-Short Form (PSI-SF). ASD children's severity was rated using Childhood Autism Rating Scale (CARS). Sociodemographic characteristic for parents and their children were recorded in Participant's Data Sheet. The prevalence of parental stress was established using the clinically significant cutoff score of PSI-SF (>90<sup>th</sup> percentile) while the association between sociodemographic characteristic, ASD severity, and ASD specific characteristic with parental stress were analysed using Multiple Linear Regression.

**Results:** The prevalence of parental stress among parents of ASD children in CIEC, Kota Kinabalu was 39.8%. Factors associated with parental stress were mothers (B=16.82,  $p<0.001$ ) and ASD severity (B=1.62,  $p<0.001$ ). The ASD specific characteristic predictors for parental stress in the study were ‘object use’ and ‘intellectual response’.

**Conclusion:** The prevalence of parental stress among ASD children’s parents in Kota Kinabalu were relatively low. Mothers experience significant parental stress as compared to fathers and ASD severity had a significant association with parental stress. ASD children with deficit in ‘object use’ and ‘intellectual response’ would predict significant stress in their parents. Intervention targeting at modifying these variables could improve parental stress.

**Keywords:** *Autism Spectrum Disorder, Parental stress, Parental Stress Index-Short Form*



## **CHAPTER ONE**

### **INTRODUCTION**

Autism Spectrum Disorder (ASD) being a chronic, lifelong disorder, had been lately witnessed to have rocketed in prevalence worldwide. Even though no single determinant had been concluded, factor that are in consideration are broadening of diagnostic classification, improvement in recording practice, implementation of comprehensive screening program, and finally the true increase of the ASD cases. The latest reiteration of Diagnostic and Statistical Manual for Mental Illness, 5<sup>th</sup> edition (DSM 5) managed to address this issue and improve the sensitivity and specificity of the diagnosis. As a neurodevelopmental disorder, nothing much can be done to halt the development of ASD. However, what can be done are ensuring diagnosis can be made early through routine screening in high risk children and intervention services is started timely.

Raising a child with Autistic Spectrum Disorder (ASD) had been documented by many experts to have negative effect on parent's psychological wellbeing. The spectrum of psychological disturbance could range from stress to depression. Stress, being an adaptive response to negative experience can sometimes be considered normal in parents of children with disability. However, when the experience is persistent and no measures taken to address the issue, the stress could proliferate and ensued into anxiety or depressive disorder (Hastings and Brown, 2009). Emotional resilience and coping strategies employed could be a protective element averting detrimental outcome it this group of parents.

The prevalence of parental stress had been highlighted in various studies with extreme disparity between different population. This could be influenced by variation in cultures, socioeconomic status, availability of specialized care services, and the method of research used to obtain the result. A good healthcare policies especially in high income countries, where the implementation of latest evidence-based practice and the amount of resources allocated in dealing with the ASD children could also mediate better outcome in the parents.

Various factors that can potentially mediate the development of parental stress among parents with ASD children had also been identified in past literature. Parent's sociodemographic characteristics, child characteristics, child's ASD severity, and parent's coping strategy among others are the factor examined by researchers across the globe.

Recognizing parent's psychological distress is another crucial in managing ASD children in a comprehensive manner. The association between ASD child's behavioural characteristic and parental stress has a bidirectional relationship. This is based on understanding that parents with high negative emotion will increased child's maladaptive behaviour and affect child's treatment engagement and this relationship can go both way in a reciprocal manner.

This study was conducted in Kota Kinabalu Sabah. Being one of the less fortunate state in Malaysia in term of economic growth, Sabah has always been left behind as compared to its counterparts in peninsular in term of infrastructure development and socioeconomic growth (Department of Statistics Malaysia, 2016). This caused the people of Sabah to be in a disadvantageous position, in term of feasible assess to education,

welfare service, and health care system. Despite things are progressively changing for the better, there's a great majority of Sabahan still live an arduous life in this beautiful and resourceful state of East Malaysia. It is interesting to see how parents in Sabah cope with ASD children and determines any specific characteristics that may be associated with development of psychological stress in them.

Despite many studies conducted to examine the prevalence of stress among parents of ASD children and the effect of ASD severity on parental stress in local setting, none to the investigator's knowledge, was done in Sabah. Apart from that, there was no known local studies examine the specific ASD characteristics that have any association with parental stress. Therefore, the intention of the study is to fill in the gap and establish the prevalence of parental stress among parents of ASD children in CIEC, Kota Kinabalu Sabah and identify the factors associated with parental stress.

## CHAPTER TWO

### LITERATURE REVIEW

#### 2.1 *Overview of Autism Spectrum Disorder (ASD)*

Autism Spectrum Disorder (ASD) is a chronic neurodevelopment disorder characterized by functional deficits in the areas of social interaction, communication, and stereotypic behaviour (American Psychiatric Association, 2013). ASD characteristic can be detected as early as 18 months of age and has a significant reliability if an assessment done by healthcare professionals at the age of two (Lord *et al.*, 2006). Up until now, ASD is considered incurable and the characteristics will persist to adulthood.

Generally, the prevalence of ASD ranged between 1% to 2% of the population (American Psychiatric Association, 2013). The ratio between male and female sufferer is 4.5 to 1 (Christensen *et al.*, 2016). A large-scale population study performed in South Korea reported a 2.6% prevalence of ASD in the target population with male to female ratio of 2.5 to 1 (Kim *et al.*, 2011). According to the World Health Organization (WHO) records, 1 in 160 children suffer from ASD worldwide (World Health Organization, 2016). A systematic review assessing the worldwide prevalence of ASD estimated every 62 out of 10,000 population have ASD (Elsabbagh *et al.*, 2012). The prevalence among children aged 8 years in the United States (US) reported by Centre for Disease Control and Prevention (CDC) was considerably higher with 1 in 68 children had been identified as having ASD (Christensen *et al.*, 2016). This discrepancy is probably due to the advancement of US's population surveillance system and the high level of awareness regarding ASD among the general population.

Meanwhile, in our local setting, there is no recent epidemiological report on the prevalence of ASD among Malaysian population. However, in a study to assess the practicability of employing an instrument for ASD screening in the government's health clinic involving children between the age of 18 to 36 months old, the prevalence of ASD was estimated at 1.6 in 1000 population (Ministry of Health Malaysia, 2006). This observation is considered relatively low and do not represent the real situation of the disability in Malaysia. Whatever the circumstances, new ASD cases referral to the Ministry of Health facilities are indisputably on the rise by year (Ministry of Health Malaysia, 2006). Similar situation was also experienced by National Autism Society of Malaysia (NASOM), a local non-profit organization that provide support services to ASD children and their family, where they reported an increase in ASD children intake by 30% in three years (Cheong, 2009). At global level, the trend of increasing prevalence of ASD cases were evident in various epidemiological studies done in different countries (Baird *et al.*, 2006; Ting, Neik and Lee, 2014).

The main concern of the researchers and authorities of the field are the perturbing rate of the prevalence increase. Among factors that might possibly be attributable to the increase in ASD prevalence are improved awareness and understanding of ASD among parents, improvement in reporting of new cases by related authorities, broadening of diagnostic criteria, and the availability of practical screening tools (Dillenburger *et al.*, 2013).

The knowledge and awareness regarding ASD had been steadily increasing for the past decade (Weintraub, 2011). In the era of unlimited boundaries to open source information through the internet, people can assess the relevant materials regarding ASD freely. In a huge population-based surveillance study conducted in Northern Ireland, up

to 80% of the respondent reported adequate knowledge and awareness regarding ASD (Dillenburg *et al.*, 2013). However, the respondent's perception on the availability of intervention services were not satisfactory. A web-based survey conducted among college students in the US, 76% of the respondent were reported to have an acceptable knowledge regarding ASD (Tipton and Blacher, 2014). As opposed to the findings in the higher income nations, ASD awareness and knowledge in our local population are still disappointing (Dolah *et al.*, 2012).

*Diagnostic and Statistical Manual* for mental illness (DSM) and *International Classification of Disease* (ICD) are the two widely used operational classification to diagnosed ASD (World Health Organization, 1992; American Psychiatric Association, 2013). Throughout the years, these two documents had undergone several changes to improve their sensitivity and specificity to detect ASD. It includes the broadening and narrowing of the diagnostic criteria based on contemporary evidence available through continuous research in the field (Nassar *et al.*, 2009). Taking an example on how the broadening of diagnostic criteria could cause a rise in ASD prevalence, the implementation of revised version of DSM in Western Australia (DSM III to DSM III-TR) had cause increased in the reported prevalence of ASD by 11.9 % annually (Nassar *et al.*, 2009). This was the consequence of broadening the criteria for age of onset in the revised edition of DSM. Being the latest reiteration of the widely used diagnostic manual, DSM-5 has made an effort to narrow down the classification for ASD and other neurodevelopmental disorder (American Psychiatric Association, 2013). This among others, was an attempt to reduce the rate of false positives diagnosis and unnecessary ASD diagnosis in other neurodevelopmental disorder (Barker and Galardi, 2015).

The operational criteria that a country employs to report the prevalence of ASD in their national health registry could have effect on how a national prevalence of ASD is presented. In Denmark, a change to the latest diagnostic criteria in reporting ASD prevalence, together with the inclusion of outpatient record into their registry had resulted in 60% increase in the ASD prevalence (Hansen, Schendel and Parner, 2015). Similar observation was also evident in Western Australia where there was 22% increase in ASD diagnosis among children less than 5 years old annually since 1992 after the implementation of new diagnostic criteria (Nassar *et al.*, 2009).

Another possible reason for the alarming rise in the ASD prevalence was the availability of reliable screening tool and its wide implementation in community setup. In the US, *American Academy of Pediatric (AAP)* made a recommendation for routine ASD screening in children aged between 18 to 24 months during their regular health review (Zwaigenbaum *et al.*, 2009). The widely used screening tool to detect early signs of ASD is *Modified Checklist for Autism in Toddlers (M-CHAT)*. M-CHAT is a 23-items parent rated questionnaire with 98% specificity to detect ASD (Mawle and Griffiths, 2006). In our local setup, the Ministry of Health of Malaysia through the Clinical Practice Guidelines (CPG) for ASD recommended the screening of high risk children as early as 18 months old using M-CHAT (Ministry of Health Malaysia, 2006).

In term of management of ASD children, recommendation by Autism and Developmental Disabilities Monitoring (ADDM) network is early evaluation should be done by the age of 36 month and community based treatment should be started at least at 48 month (Christensen *et al.*, 2016). Since emotional and behavioural problems in ASD children often persisted into adulthood, early intervention is crucial to ensure reduction in impairment and encourage acceptable outcome in the future. McConachie & Diggle

(2007) in their systematic review had highlighted that parent implemented early intervention has potential to reduce parent's psychological disturbance and improved child's problematic behaviours related to ASD.

## **2.2 *Autism Spectrum Disorder and Parenting Stress***

Generally, being a parent could be a considerably stressful task in vulnerable individuals. This is evident even in parents with typically developing (TD) children (Hoffman *et al.*, 2009). Beyond that, parenting children with disability posed a far more detrimental effect towards the parent's emotion (Gupta, 2007).

Stress related to parenting children with ASD is a fathomable phenomenon. It is observed across various cultures, socioeconomic status, and geographical boundaries. In a local study done to investigate the prevalence of parental stress among parents of ASD children, 90.4% respondents reported significant parenting stress (Nikmat & Ahmad, 2008). A Jordanian study established an almost identical prevalence with 89% parents reported significant stress (Ali Dardas, 2014). Lecavalier *et al.* (2006) in their study executed in the United States of America (USA) described a moderate prevalence of 57.7%. A group of researchers in Tokyo concluded an almost identical prevalence of 57% parents with ASD children reported significant parental stress (Mori *et al.*, 2009). Davis & Carter (2008) on the other hand had their respondents with significant degree of parental stress at a lower percentage with a prevalence of 39%.

The relationship between child's ASD severity and parental stress had been established in multiple studies. A local study conducted in Johor Bharu managed to observed a significant association between ASD severity and parental stress (Yeo and Lu, 2012). Similarly, Huang *et al.* (2014) in their study conducted in Taipei concluded an



identical association. Meanwhile, researcher from higher income countries such as in the Japan and US were also able to find linear association between ASD severity and parental stress (Mori *et al.*, 2009; Lyons *et al.*, 2010; Ingersoll and Hambrick, 2011).

Parental stress associated with having an ASD children had been recognised to be significantly greater compared to TD children and other type of developmental disabilities. A meta-analysis study examining the difference in parental stress among parents of ASD children and TD children concluded that the former group of parents experienced more stress with a large effect size (Hayes and Watson, 2013). Similarly, whilst comparing parenting stress experienced by parents of TD children, Hoffman et al. (2009) observed parents of ASD children who underwent a special intervention program scored higher level of stress.

Schieve et al. (2007) in a large-scale *National Survey of Children Health* in the US had concluded that parents of ASD children experienced significantly higher degree of stress compared to other developmental disabilities. Researchers in Poland supported the finding by proving that parenting children with ASD had more negative psychological impact compared to other developmental disabilities such as Down's Syndrome (Dabrowska and Pisula, 2010). However, when the parental stress among parents with ASD children was compared with Attention Deficit and Hyperactivity Disorder (ADHD) children, the latter group had higher percentage of clinically significant stress based on Parental Stress Index (PSI) scoring (Miranda *et al.*, 2015).

Recognizing parental stress early on its course could benefit both the parent and their ASD children. The mutual relationship between parental stress and ASD severity, as been observed by Lecavalier et al. (2006) justifies the need of addressing both

components and not just focusing on child's ASD behaviour. Early measures to alleviate parental stress could in return warrant child's engagement to treatment plan and subsequently result in favourable change in ASD child's maladaptive behaviours (Hayes and Watson, 2013). A parent-focused intervention, which is a type of parenting intervention program had been proven to reduced parental stress related to parenting ASD children and at the same time also improved ASD child's adaptive behaviour (Keen *et al.*, 2010).

### ***2.3 Association between Characteristics of Parent with ASD Children and Parental Stress***

Parent's sociodemographic characteristics have potential to predict their vulnerability to parental stress related to parenting children with ASD. Variation in age, sex, ethnicity, level of education, employment status, monthly income and coping styles among others could mediate parental stress.

Yamada *et al.* (2007) in a study based in Japan had established mothers as the predictor of parental stress. An Irish study looking at stress among parents with ASD children reported that mothers experienced significantly more stress as compared to fathers (Tehee, Honan and Hevey, 2009). Hastings & Brown (2009) expanded the scope of their observation beyond parental stress and concluded that vulnerability toward depression are evident among mothers. A Kuala Lumpur based study by Nikmat *et al.* (2008) find no significant different in parental stress between mothers and fathers. Herring *et al.* (2006) in their study conducted in Australia concluded that fathers experienced significantly less stress compared to mothers. However, contrary observation was made by Rivard *et al.* (2014) in Canada setting where they found out that fathers

were the one experiencing significantly higher degree of stress compared to mothers. This had a comparable conclusion in a study conducted in Iran where they found that stress among fathers of ASD children had a significant association with ASD severity (Soltanifar *et al.*, 2015).

Parent's age could be one of the factor predicting parental stress. Ha et al. (2008) in their study highlighted that advanced age of the parents had significantly reduced risk to experience negative affect related to taking care of disabled child. Comparably, Smith et al. (2012) in a study among US population concluded that increasing parent's age was linked with better positive affect and lower negative affect. Those observation were consistent with adaptation model describe by Lazarus and Folkman (1984) where according to the theory, the longer an individual is exposed to a stressful situation, the better he will adapt to the hurdle, which in this context is parenting a child with ASD.

Variation in ethnicity had been proven by various study to predict parental stress and psychological disturbances among parents of ASD children. Bishop et al. (2007), based on US's population, had observed higher psychological resilience among African-American respondent compared to Caucasians in regards to caregiving ASD children. The local study by Nikmat *et al.* ( 2008) on the other hand, even though had classified the ethnicity of the group into *bumiputera* and *non-bumiputera*, did not find any significant difference in term of parental stress between the two.

Living a married life can be a challenge by itself, and having an ASD child might complicate the matter. It was reported that the rate of divorce among parents with ASD children were higher than normal population (Hartley *et al.*, 2010). Marital satisfaction was identified as a mediator to parental stress among parents with ASD children (Hartley

*et al.*, 2011). Respite care service for ASD children on the other hand had been proven to improve marital quality of the parents (Harper *et al.*, 2013). The magnitude of burden carried in raising a child with ASD should be shared by both parents together to ensure that they will be able to cope with the stress generated during the caregiving process. Marital discord and dissatisfaction will hinder the synergistic partnership between both parents, and the outcome would not only be damaging to them, but also detrimental to their ASD children development.

An individual's education level, employment status, and income are the direct indicator for Socioeconomic status (SES) in a population. SES has been linked with ASD in the way that parents of lower socioeconomic status are at increased odds to have an ASD child (Rai *et al.*, 2012). Sun *et al.* (2014) in their population based study in Cambridgeshire UK had concluded that higher SES parents expressed greater level of concern regarding their children's ASD symptoms. Similarly, Moh & Magiati (2012) highlighted in their study that parents from upper SES group would express concern about their children's problem earlier. According to Thomas *et al.* (2012), ASD children from higher SES group had better access to professionals and their ASD diagnosis were made earlier. Indirectly, this might reduce negative affect in their parents.

Parents with lower education level are more likely to have ASD children with severe symptoms compared to the one with higher education (Kogan *et al.*, 2009). Lower education level had also been observed by Phetrasuwan & Miles (2008) as a predictor for heightened parental stress. Parents with higher education level expressed more concern regarding their children's progress and experienced higher level of stress (Moh and Magiati, 2012).

Employment status and household Income determine the financial capabilities of a family. Both variables are imperative in the context of managing an ASD child, especially when considering the amount of fund needed to enrol the children into specific intervention program. Earning low income, coupled with high expenses for intervention, resulted in financial burden to parents with ASD children (Sharpe and Baker, 2007). The financial burden in the long run could ensue into psychological distress in the parents. According to Shimabukuro et al. (2008) in their analysis report, the medical expenditure for children with ASD are 4.1 to 6.2 times greater than children without ASD with value range from USD 4110 – USD 6200 annually.

Effective coping strategies is vital in ensuring parents with ASD children could tolerate the affective outcomes of caretaking their child (Smith *et al.*, 2008). The type of coping strategy employed by parents with ASD children can act as a protective factors towards parental stress. Smith et al. (2008) had examined the coping strategies employed by mothers in their sample and concluded that lower level of emotion-focused coping and higher level of problem focused coping predicted a positive outcome linked to parenting ASD children. Tway et al. (2006) in a study conducted in California reported that fathers had better coping scores as compared to mothers in relation to parenting ASD children. A contradicting finding was reported in another study where a better coping were observed among mothers of ASD children (Montes and Halterman, 2007).

Social support can act as an effective buffer from stress development in parents who cares for an ASD children (Benson and Karlof, 2009). Ingersoll & Hambrick (2011) highlighted in their study that parents with severe ASD children reported less social support. Social support by immediate family and society has potential to facilitate parents with ASD children to accept their child's disability. In any circumstances where societies

do not provide good support to the caregivers, the chances of them to develop depression and anxiety are higher (Boyd, 2002). Smith et al. (2012) in their study concluded that social support is one of the predictor of psychological well-being.

#### ***2.4 Child Demographic Variables Related to Parental Stress***

Child's demographic characteristics are another variable that need to be considered as the predictor of parental stress. Age, sex, age at diagnosis, education, and primary caregiver are among characteristic that are essential in assessing the presence of relationship between ASD and stress among parents.

With the diagnosis of ASD being recognized early due to improvements in the health care policies of various countries, the age of children diagnosed with ASD are getting younger (Ministry of Health Malaysia, 2006; Zwaigenbaum *et al.*, 2009). ASD children at different age group pose diverse outcome towards their parent's psychological wellbeing. Hastings and Brown (2009) reported that ASD children of a younger age had more effect on parental stress as compared to the older one. The observation was supported by identical conclusion made by Schieve et al. (2011). Tehee et al. (2009) however found no difference in parent's perceived stress in various child's age group.

Early intervention is fundamental in management of ASD (Peters-scheffer *et al.*, 2011; Warren *et al.*, 2011). Delay in diagnosis would mean delay in starting of intervention and this could possibly increase stress in the parents. Hence, the age at diagnosis is critical to ensure timely intervention program could be scheduled. Various available studies reported mean age at diagnosis between 2 years old to 4 years old (Davis and Carter, 2008; Mori *et al.*, 2009; Moh and Magiati, 2012). Nicholas et al. (2008) reported in their study that delay in making diagnosis was a result of delayed access to

related professionals. Meanwhile, a study done in the UK had come to an exceptional conclusion in which making an early ASD diagnosis predicted a undesirable degree of parental stress (Osborne *et al.*, 2008). This contradicting outcome could be a result of methodological and sociodemographic differences.

The ability of an ASD children to be in formal education can be an indicator for the severity of the disorder. Depending on their intellectual ability and degree of undesirable behaviour, the type of education may vary from normal school to special education program. Derguy *et al.* (2016) concluded in their study that absence of child schooling is a significant predictor of parental stress. Lee *et al.* (2008) highlighted that children with ASD had higher odd of being absent from school, being bullied, and to repeat grade as compared to ADHD children, and these problems are significantly related to parent's concern.

## ***2.5 Child specific ASD characteristic as predictor to parenting stress***

When examining behaviour characteristics of ASD children, researchers usually described child's ASD severity and related non-specific symptoms. ASD severity are usually rated according to the core symptoms that defines the disorder based on available diagnostic classification. Meanwhile, non-specific behaviours are maladaptive behaviours in ASD children which also concern the parent. The core ASD symptoms as been defined in DSM-5 (American Psychiatric Association, 2013) are persistent deficits in social communication and social interaction across multiple context and restricted, repetitive patterns of behaviour, interests or activities. Viewing at similar context, Mehling & Tassé (2016) considered cognitive, language, behaviour, and adaptive functioning as important domains in determining the severity of ASD.

Various studies in different settings had demonstrated that ASD severity and child's behaviour had a direct impact to stress among parents (Herring *et al.*, 2006; Lecavalier, Leone and Wiltz, 2006; Estes *et al.*, 2009). Lecavalier *et al.* (2006) in their study highlighted hyperirritability, self-injurious behaviour, cognitive level, presence of seizures and dysmorphic features as the predictors of ASD severity. In a study conducted by Nicholas *et al.* (2008), apart from the core symptoms of ASD defined in standard classification criteria, additional behaviour related to ASD that are commonly observed were hyperactivity, delayed motor functions, abnormal affects, abnormal eating and sleeping pattern, and temper tantrum. All the behaviour were seen in more than 50% of respondents from the study (Nicholas *et al.*, 2008).

As part of the defining symptoms in the classification criteria, eliciting repetitive behavior is a vital observation in ASD children. A US based study had highlighted repetitive behavior as a predictor to maternal's negative affect (Bishop *et al.*, 2007). Richardson (2010) in her study conducted in the US managed to identify repetitive behavior and sensory behavior as predictors of parental stress in the parents of ASD children. Wisessathorn *et al.* (2013) in their study had established a significant relationship between deficit in *repetitive behavior* and *verbal communication* and negative parental psychological outcomes.

Intellectual disability is an important specifier in ASD diagnosis due to its weight on determining the severity of the disorder (American Psychiatric Association, 2013). Various studies had agreed upon deficit in Intellectual functioning as a predictor to parental stress. A Spanish study concluded that the parental stress of parents with ASD children was predicted by child's intellectual performance (Pastor-Cerezuela *et al.*, 2015). On the contrary, both *Davis* and *Rao* in their studies did not find any relationship between



Intellectual deficit in ASD children and parental stress (Davis and Carter, 2008; Rao and Beidel, 2009).

Hyperactivity or increased activity level is a symptom frequently co-exist with ASD. Lecavalier et al. (2006) found that about 40% of ASD children under his observation had hyperactivity symptoms. In a study involving a group of Swedish parents with *Asperger's Syndrome* children, hyperactivity was observed to be significantly associated with parental stress (Allik *et al.*, 2006). Similarly, a study conducted in the UK had also concluded that hyperactivity symptoms in ASD children had significant effect on maternal mental health (Totsika *et al.*, 2011). In a study conducted on 150 Dutch parents with ASD children, hyperactivity was confirmed to have linear association with parental stress (McStay *et al.*, 2014).

Davis & Carter (2008) in their study conducted in Boston USA concluded that *deficit in social relatedness* in ASD children had a significant association with parental stress. A study comprising of 108 mothers of ASD children in North Carolina was able to prove that variables *relating to people, emotional response, expressions of fear or nervousness, and verbal communication* from Childhood Autism Rating Scale (CARS) were able to predict parental stress in the population of interest (Phetrasuwan and Miles, 2008). In addition, a study based in the Netherland investigating the association between child's ASD characteristic and maternal stress came up with two characteristic which were *behavior inflexibility towards object* and *deficit in initiating social relation* as the predictors for their observation (Peters-Scheffer, Didden and Korzilius, 2012).

Based on rating on Nisonger Child Behaviour Rating Form (NCBRF), both Lacevelier and Huang found that 'conduct behaviour' and lack of 'prosocial behaviour'

significantly explained the variance of parental stress in their studies (Lecavalier, Leone and Wiltz, 2006; Huang *et al.*, 2014).

## **CHAPTER THREE**

### **OBJECTIVES AND RESEARCH HYPOTHESIS**

#### **3.1 *General objectives***

To determine the prevalence of stress and to understand the factors associated with level of stress among parents of children with Autism Spectrum Disorder (ASD) in Child Intervention and Enrichment Centre (CIEC), Kota Kinabalu Sabah.

#### **3.2 *Specific objectives***

1. To determine the prevalence of stress among parents of children with ASD in CIEC, Kota Kinabalu, Sabah.
2. To determine factors associated with parental stress among parents of children with ASD in CIEC, Kota Kinabalu, Sabah.
3. To determine the specific characteristics of ASD behaviour that influence the parental stress among parents of children with ASD in CIEC, Kota Kinabalu, Sabah.

#### **3.3 *Research questions***

1. Do parents of children with ASD in CIEC, Kota Kinabalu experience clinically significant parental stress?
2. What are the factors associated with parental stress among parents of children with ASD in CIEC, Kota Kinabalu, Sabah?

3. Are there any specific characteristics of ASD behaviour that influence the parental stress among parents of children with ASD in CIEC, Kota Kinabalu, Sabah?

### **3.4 *Research hypotheses***

1. Parents of children with ASD in CIEC, Kota Kinabalu experience clinically significant parental stress.
2. Parental stress among parents of children with ASD in CIEC, Kota Kinabalu are associated with parent's and child's sociodemographic profile, and severity of ASD symptoms.
3. There are specific characteristics of ASD behaviour that influence the parental stress among parents of children with ASD in CIEC, Kota Kinabalu, Sabah.

### **3.5 *Null hypotheses***

1. Parents of children with ASD in CIEC, Kota Kinabalu do not experience clinically significant parental stress.
2. Parental stress among parents of children with ASD in CIEC, Kota Kinabalu are not associated with parent's and child's sociodemographic profile, and severity of ASD symptoms.
3. There is no specific characteristic of ASD behaviour that influence the parental stress among parents of children with ASD in CIEC, Kota Kinabalu, Sabah.

### 3.6 Conceptual Framework

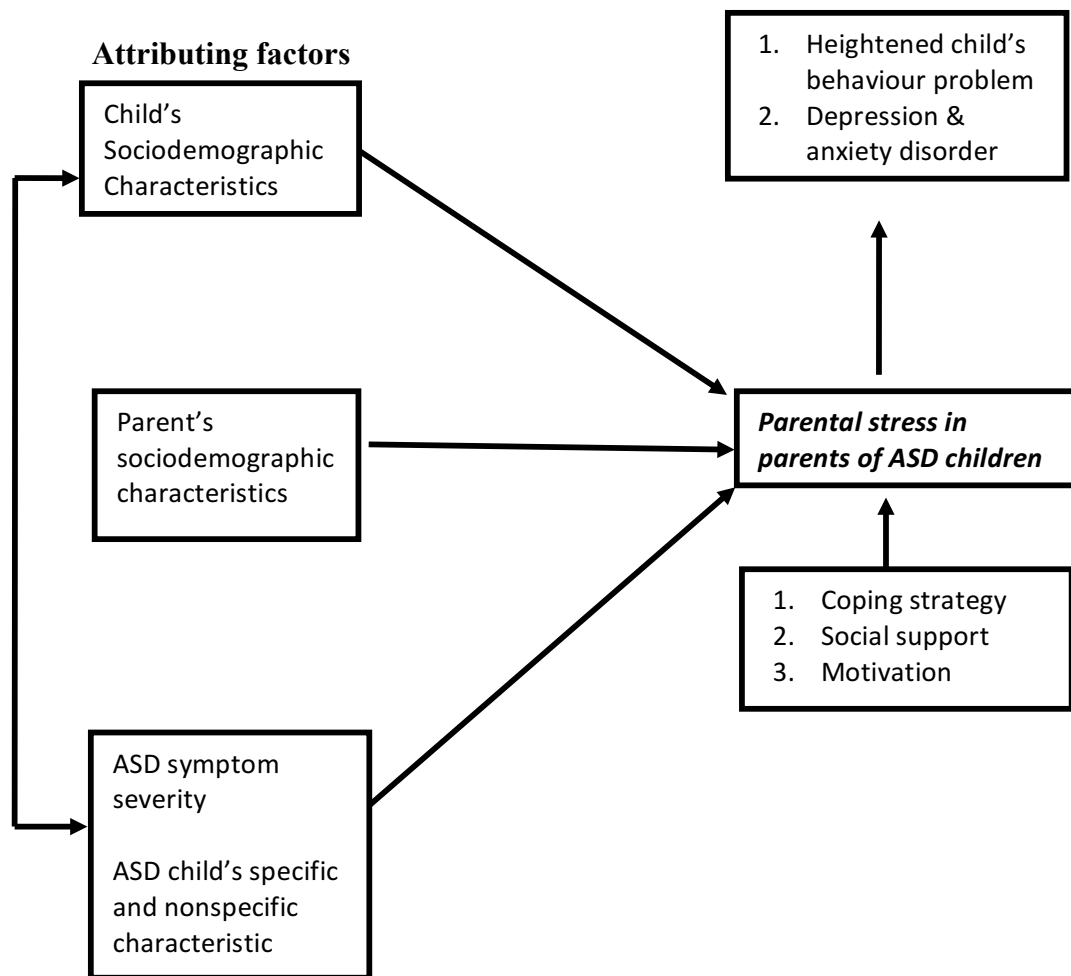


Figure 1 Conceptual model for parental stress among parents of ASD children

## **CHAPTER FOUR**

### **METHOD**

#### ***4.1 Study Design and Study Period***

This is a cross sectional study conducted from August 2016 to October 2016

#### ***4.2 Study Setting***

The study was conducted at the Child Intervention and Enrichment Centre (CIEC), Hospital Mesra Bukit Padang, Kota Kinabalu, Sabah. CIEC is a specialized intervention centre within Hospital Mesra Bukit Padang that offers services for children with neurodevelopmental disorders in Kota Kinabalu, Sabah and adjacent districts. CIEC operates 5 days a week from Monday to Friday, from 8 am until 5 pm. The centre is run by specially trained staff which comprised of 2 resident occupational therapist, 5 staff nurses, and a health attendant. The whole operation of the centre is overseen by a child psychiatrist. Among the interventions offered by the centre are early intervention program, developmental stimulation, gross motor therapy, fine motor therapy, multisensory therapy, and play therapy.

#### ***4.3 Reference Population***

All parents of children with Autism Spectrum Disorder in Kota Kinabalu

#### **4.4 Source Population**

All parents of children with Autism Spectrum Disorder who attend the Children Intervention & Enrichment Centre (CIEC), Hospital Mesra Bukit Padang, Kota Kinabalu, Sabah. The total number of ASD parents who send their children to CIEC are 454.

#### **4.5 Sampling Frame**

All parents of children with Autism Spectrum Disorder who attend the Children Intervention & Enrichment Centre (CIEC), Hospital Mesra Bukit Padang, Kota Kinabalu during study period and fulfil the selection criteria.

#### **4.6 Study Sample**

Parents of children with Autistic Spectrum Disorder who attend the Children Intervention & Enrichment Centre (CIEC), Hospital Mesra Bukit Padang, Kota Kinabalu who fulfilled the selection criteria and agree to participate in the study.

#### **4.7 Selection Criteria**

##### **4.7.1 Inclusion Criteria**

1. Parents of children who are clinically diagnosed as ASD based on DSM-5 criteria (American Psychiatric Association, 2013)
2. Parents whose child age range from 2 to 12 years old

#### 4.7.2 Exclusion Criteria

1. Severe communication problem i.e. parents unable to communicate in English or *Bahasa Malaysia*, mutism, and deafness.
2. Parents with history of severe mental illness e.g. Major Depressive Disorder, Schizophrenia, and Bipolar 1 Disorder.
3. Parents whose child has concurrent physical handicap or disability.

#### 4.8 *Sampling Method*

Convenient sampling was chosen as the sampling method for this study due to time and resource limitation. The parents of ASD children who accompany their children for regular therapy session at CIEC were approached and invited to be involved in the study. For those who fulfilled the selection criteria and keen to give written consent were included in the study.

#### 4.9 *Sample Size Calculation*

Sample size calculation were done based on objectives:

*Objective 1,*

Sample size was calculated for PSI-SF

Calculation was done using single proportion formula:

$$n = \frac{z^2 \rho (1 - \rho)}{\Delta^2}$$