

Lived Experience of Malaysian Parents in Handling Young Children with Autism (Below Age 6)

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Abstract – Autism Spectrum Disorder (ASD) is a neurodevelopment childhood disorder associated with cognitive and language impairment. This qualitative research study explored the Malaysia Parents experience in handling their ASD child during diagnosis process, looking for Early Treatments and Interventions and the amount of stress involved during the time. Parents were personally interviewed using semi-structured socio-demographical questionnaires. The interview were participated by 10 parents of ASD children (5 Malays, 3 Indians and 2 Chinese). This interview investigates the handling experience, stress involve during handling their ASD child, feeling of social support and self-care technique. The objective of this study is to gain better understanding of the parents' experience and the stress involve and to gain insight about into where they need more support. The content of the interview transcribed, and themes were separated for an in-depth analysis to get a valid conclusion about their handling experience. The result shows that, the parents stress level reduced as the child attending therapies and starting preschools. Parents are more open minded to accept the child's condition and took necessary steps to help them. Parents do worry about their child's future. The Malaysia Government Hospitals and Education System plays major roles in this research result.

Keywords – Autism Spectrum Disorder (ASD), Parenting Experience, Diagnosis, Stress, Early Intervention & treatment

I. INTRODUCTION

Autism Spectrum Disorder (ASD) is a neurodevelopment disorder characterised by impairment in communication, behaviour and social functioning beginning in childhood (Daniella Canu, 2021). Approximately 52 million cases of Autism Spectrum disorder (ASD) have been reported globally (Baxter,2015). 1 in 36 children in the U.S. have autism, up from the previous rate of 1 in 44, (Centers for Disease Control and Prevention (2023).

There are no local epidemiological studies on ASD prevalence in Malaysia (Ministry of Health, 2014, Dr Sathyabama,2019). According to MOH (Ministry of Health) data, the number of ASD risen from 562 children in 2020 to 589 children in 2021. Malaysia is a developing, middle-income country with multi-ethnic population comprised of three ethnicities as well as indigenous tribes. Malaysians have very limited awareness and support resources for raising a child with ASD available (Neik, Lee, Low, Chia & Chua,2014); (Chu SY, 2021).

A qualitative methodology was used to capture the lived experiences of the participants on handling young children with autism in Malaysia. This research investigates the lived experiences of Malaysian parents of a young child with autism, in identifying, handling and receiving early treatment services. This handling experiences includes to know their stressed level and challenges faced during diagnosis, early intervention and early treatment.

As the result, the research findings of this study offer insight into parents' perspectives about Early Intervention for their very young child with autism. A qualitative approach will enable an in-depth understanding in any research (Lazard L., McAvoy J. (2020).

“Sustaining Parents” health and well-being is a necessity for the prime care of their children with autism (Keen,2014; Amira, K. M., & Amra, M.,2021). Higher parental stress indicated lower level of sensitivity and poorer quality of parental-child relationship (Lim Pei Tien,2022). This research explained the lived experiences of parents of children under age 6 with autism. The results provided insight into the experiences of parenting and experiences with EI (Early Intervention) and early childhood special education (ECSE).

II. PROBLEM STATEMENT

Generally speaking, most parents stress begins with that “Something is wrong” moment when they realize that their child isn't talking, interacting or playing like other toddlers (Amita Shroff, MD,2022). Autism spectrum disorder is a lifetime, generally stable condition that involve persistent impairment in language, social skills and daily life activities (Miranda,2019). Difficulties in child-rearing, which are present from early ages, put a strong pressure on parenting skills (Miranda, 2019). Many parents are very focused on their children's needs, hardly think about their own health. Parenting stress affect their children too (Sarris,2019). Research finds that highly-stressed parents have more trouble following their children's behaviour plans and implementing interventions (Sarris,2019).

Parents of autistic children experience increase levels of financial, emotional and physical (Mishra,2018). In Malaysia, many parents face a significant burden in attempting to provide basic intervention for their children. The financial burden of ASD mentioned as major issue (Jing Xin Teo, 2019). Child development experts agree that a child with autism should receive treatment as soon after diagnosis as possible (Maureen Dillon,2021; Slavica Maksimović, 2023). There is no cure for autism, but early intervention using skills, training and behaviour modification can yield excellent result (Bhandari,2018). In Malaysia, most parents are unable to involve in their child's daily intervention and overall education programme due to time constraints such as work, sibling care and other responsibilities (Jing Wen Teo, 2019).

Parents involvement in early intervention is very important and prominent but not all the parents are capable of it (Jing Xin Teo & Lee Theng Lau 2018). The National Early Childhood Intervention Council (NECIC, 2019) refers to a news portal that highlighted the lack of early

intervention services to cater to the increasing number of children with autism in Malaysia.

Common autism treatment includes behaviour therapy, speech-language therapy, play – based therapy, physical therapy, occupational therapy and nutritional therapy (Sarris, 2019). Lastly in diagnosis, early intervention and also treatment of autism children, it is important to have parents involvement in order to success.

This research is to illustrate a deeper meaning of parenting a very young child with autism and the role of Early Intervention in family life. A qualitative method allows for using multiple sources such as interviews, documents, observation and artefact of parental lived experiences associated with family culture, personal history and societal views of autism.

III. LITERATURE REVIEW

The condition known as autism spectrum disorders first described by Leo Kenner in 1946 as an “Inborn Autism Disturbance of Affective Contact” (Bangertner,2019). Like other characteristics of autism, the children had stereotyped behaviour as well as being hyperactive towards sounds and also sleep problems, but it was the loss of speech that parents notice in their children that got them thinking that something was not right with their children (Keller R 2021).

In Malaysia, service delivery is face with many challenges, including uncoordinated service provision by different agencies (Shin, Syamin, Grace & Suseel 2018) . Lacks understanding of what family centered practices among professionals and late entry into early intervention (Gentles J.S, 2019) Malaysian parents have no knowledge and prior experience in handling a child with ASD till they have diagnosis for their own children (Shin, Syamin, Grace & Suseel 2018). Their research also emphasized most Malaysian parents with ASD Child, experience stress when finding difficulties in obtaining additional information about ASD, long wait time for assessment, treatment and interventions in government service and the services are expensive at private ASD services (Shin, Syamin, Grace & Suseel 2018).

The Psychological Theories of Autism

Theory of Mind

The term “Theory of Mind” was coined by USA psychologist David Premack in a famous article reporting experiments carried out on the chimpanzee, Sarah (Premack & Woodruff 1978). Theory of Mind is an important social-cognitive skill that involves the ability to think about mental states of our own and those of others (Cherry, 2020). It encompasses the ability to attribute mental states, including emotion, desires, beliefs and knowledge. Theory of Mind not only thinking about but it also refers to the ability to understand that other people’s thoughts and beliefs (Schaafsma SM, 2015). The emergency of a theory of mind is vital during the development process. Very young children tend to be more egocentric and are often unable to think about the mental states of others. As people age, their theory of mind emerges and continues to develop (Cherry, 2020).

It is an ability to understand the people’s points of views like, believes, motivational and goals. This phenomenon of “ Mentalizing” has been called The Theory of Mind. This theory has been developed in relation to Autism by Baron- Cohen (1993-1995) and Frith & Happe (1994). The studies over 20 years have found that there is an association between individuals with Autism and deficits with the Theory of Mind with in clinical trials in neurological testing.

The greatest growth of this ability to attribute mental states is believed to take place primarily during the preschool years between the ages of 3 and 5 (Cherry,2020). Furthermore to his research, Theory of Mind as children gain greater experience with social interactions. Play, pretend, stories and relationship with parents and peers allow children to develop stronger insight into how other people’s thinking may differ from their own social experiences also help children learn more about new thinking influence actions.

Theory of Mind (ToM) of autism elopement proposes that ToM in a core deficit, which links both the precursor skills, such ASD joint attention and emotion recognition and to subsequent abilities such as making friends and understanding metaphorical language (Fletcher,2014). According to the research, it is possible that the continuing refinement of the ToM will lead to better interventions which have a greater on development than other interventions.

Theory of Executive Dysfunction

Executive function is a terms that is widely used in autism circles to describe a broad array of skills that have to do with individual cognitive function (Maureen,2018). It mainly supported by the prefrontal cortex, which regulates lower level processes (eg: perception , motor responses) and thereby enable self-regulation and self-directed behavior towards a goal, allowing us to break out habits, make decisions and evaluate risks (Miyake,2012).

Several cognitive models of executive function have discriminated between automatic and controlled cognitive process, that are regulated by discrete attention system (Goldstein, 2014). Executive dysfunction was proposed as a model for understanding behavioral problem in ASD, including impaired Theory of Mind. Elani (2019), assumed there are four core executive dysfunction domains. Therefore,

- i) Planning
- ii) Mental Flexibility
- iii) Inhibition
- iv) Self-monitoring

i) Planning is the ability to forward think and choose the necessary actions to reach a goal, decide the right order, assign each task to the proper cognitive resources and establish a plan of action. (Maureen,2018). Those on the spectrum can have difficulty formulating plans to get through their days and organize task into completable section (Maureen,2018).

ii) Mental flexibility or cognitive flexibility in simple terms is the ability to roll with the punches. In fact, difficulties in cognitive flexibility in autism are related to deficits in the theory of mind, communication skills and maladaptive behaviour (Memari&Ziaee, 2013) which are associated with quality of life (de Vries&Geuts,2015).

iii) Inhibition is impulse control, the ability to have emotion, cognitive or physical reactions that aren't acted upon in the moment (Maureen, 2018). This would be lack of cognitive impulse control. Emotional outburst, hand flapping or stimming can be emotional and physical ways that impulse control isn't in place. Children with ASD cannot control the impulse sufficiently to participate in structured situation (Maureen, 2018).

iv) Self-monitoring is a key element in interpersonal interactions, guiding how people monitor and adjust their social behavior (Tyler, 2016). Monitoring is normally an unconscious process that kicks when we are on auto pilot doing normal tasks (Maureen,2018). For someone with executive function issues, if they were tired or overloaded, they would suddenly have problem with the 'auto-pilot' setting on basic activities, dropping or bumping into things or simply not being able to pay attention in ways that could be hazardous like walking out onto the busy street (Maureen,2018).

Effective dysfunction is an important in the study of ASD and with great potential as endophenotype (Eleni,2019). Executive functions, as described are skilled associated with the capacity by the use of internal, mental progresses. It is a useful theory in that it helps to explain both the cognitive and motor behaviour observed in many individuals with Autism (Ozonoff,1995)

Literature Review

The literature on parenting a young child with autism receiving Early Intervention and Early Childhood Special Education (ECSE) services. To understand participants' experiences as parents and recipients of early special education services, researcher planning to review the parenting experience and their stress in handling ASD child's diagnosis, early treatment and the early intervention. The goal of this review is to examine research evidence related to the impact on parenting stress in finding of diagnosis , Early Treatment and Early intervention of their ASD children. Five major sub-topics are emerged from the literature: (a) characteristics and causes of autism (b) Early Treatment (c) Early Intervention d) Parenting experience e) Parenting stress in handling ASD Children . The bodies of research represent the research findings about parents with a very young child with autism. This literature review is organized around these 4 sub-topics.

Characteristics and causes of autism.

ASD is an umbrella term that account for a number of neurodevelopment conditions (Nail R, 2018). In the newest edition of the American Psychiatric Association's

guideline for diagnosis, known as the Diagnostic and Statistical Manual Disorders (DSM-V), they have added the following disorders into the category of ASD:

- Asperger Syndrome
- Childhood disintegrative disorder
- Pervasive development disorder-not otherwise specified

While different types of ASD occur, the common experiences among people with the condition include impairment in social situation and the adoption of repetitive behaviours (Nail R, 2018). Some autistic children might seem to show symptom from birth, while others may develop more obvious signs as they become older (Nail R, 2018). Autism also has links to other medical condition such as epilepsy and tuberous sclerosis complex (Nail R, 2018). Autism Symptoms typically become clearly evident during early childhood, between 12 and 24 months of age (Cherney,2019). Early symptoms may include a marked delay in language or social development (Cherney,2019).

By analysing the national gross birth rate per year, we are looking at around 8,000 to 9,000 born yearly that may have autism in Malaysia (NASOM, 2019). Autism is a neurodevelopmental condition affecting 1 in 68 children in the United States (CDC,2017). Autism is lifelong condition with an age of onset sometime after 12 months . Autism is various and as a result, symptom presentation can vary across several core areas of development (i.e., social, language, patterns of interests) (American Psychological Association,2013).

Characteristics of autism spectrum disorder fall into two categories (American Psychological Association,2013) :-

i) Social interaction and communication problem including difficulties in normal back-and-forth conversation reduced sharing of interest or emotions. Challenges in understanding or responding to social cues such as eye contact and facial expression, deficits in developing, trouble making friends with others.

ii) Restricted and repetitive pattern of behaviours, interest or activities : hand flapping and toe-walking, playing with toys in an uncommon way such as lining up cars or flipping object, speaking in a unique ways such as using odd patterns or pitching in speaking on scripting from favourite shows, having significant need for a predictable routine in activities, exhibiting intense interests in activities that are uncommon for a similarly aged child, experiencing the sensory aspect of the world in unusual or extreme way such as indifference to pain, excessive smelling or touching of objects, fascination with light and movement, being overwhelmed with loud noise and others.

Also while many children with autism have normal intelligences, have mild or significant intellectual delays. Additionally, some will have some medical condition such as sleep problems, seizures and mental illness (J. Nathan,2018). Autism often associated with tantrums that is more likely to occur in public places (Meiriawan,2017). They release all form of agriness by crying hard, screaming,

shouting, hitting, kicking, lying and rolling on the floor, running, biting themselves, throwing things (Meiriawan,2017). The behaviour of temper tantrum indicates that autistic children feel frustrated. This is usually because of their desire is not fulfilled (Meiriawan,2017).

The exact causes of autism are currently not known, but significant numbers of studies are underway with a view to learning develops (Cherney,2019). According to Cherney (2019), the most research demonstrates that there's no single cause. Some of the suspected risk factors for ASD includes:

- i. Having an immediate family member with autism
- ii. Genetic mutations
- iii. Genetic disorders
- iv. Being born to older parents
- v. Low birth weight
- vi. Metabolic imbalance
- vii. Exposure to heavy metals and environments toxin
- viii. A history of viral infections
- ix. Fatal exposure to the medication Valproic acid (Depakene) or Thalidomide (Thalomid)

Researcher have identified several genes that appear to have connection to ASD (Nall,2018). Seattle Children Research Institute (2012) has identified that, several genes that appear to have connection to Autism Spectrum Disorders. Sometimes this gene arises by spontaneously mutate. Usually a combination of gene mutations, which increase the risk of developing autism by enlarged brain. Environmental factors further increase the of developing such as older parents mainly father's side , if the mother was sick during the pregnancy or difficulties during birth especially those that involve oxygen deprivation to the baby's brain (Christian Nordq, Medical News Today, 2012). He added that, air traffic pollution during pregnancy, family history of bipolar disorder or schizophrenia and very unlikely to be linked to vaccinations may increase the risk of developing autism (Christian Nordq, Medical News Today, 2012).

Treatments for children with autism.

There's no way to cure autism naturally, but complementary and alternative treatments exist (Gradin,2015). Some of the most common co-occurring conditions people with autism experience are anxiety, depression, obsessive-compulsive disorder, seizure disorder, bipolar disorder and gastrointestinal disease. A combination of therapy and medicine is used typically to treat these conditions. The Interactive Autism Network and Kennedy Krieger Institute of Autism states, "No medication is currently approved to treat the core symptoms of autism". Medication that used to treat symptom of autism are sometimes use "OFF-LABEL" meaning that the medication were not originally developed to be used to treat symptom of autism but to treat symptoms that might co-occur with a variety of disorders such as anxiety or mood fluctuations (The Interactive Autism Network, Medicine 2016). Malaysia Health Ministry (2019) states, that the drugs which given to ASD children's, not for cure autism but for some symptom that occur with autism , such as aggressive behaviours ,

Hyperactive and anxiety. The medicines are to calm down them to undergo the invention services.

Therapies and behavioural interventions are designed to remedy specific symptoms and can substantially improve those symptoms. The ideal treatment plan coordinate therapies and interventions that meet the specific need of the individual. Most health care professionals agree that the early the intervention the better (National Institute of Neurological Disorder and stroke,2020). Many treatments approach involves therapies such as:

- Behavioural Therapy
- Play Therapy
- Occupational Therapy
- Physical Therapy
- Speech Therapy

Massages, weighted blanket, clothing and meditation techniques may also induce relaxing effect. However the treatment result will vary. There are alternate medication for managing autism, include:

- High dose vitamins.
- Chelation therapy, which involves flushing metal from the body.
- Hyperbaric Oxygen therapy
- Melatonin to address sleep issues.

At the same time, some dietary treatment has been developed to address ASD symptoms. Changes in diet include removing certain food from a child diet and use vitamin and supplements. Dietary treatment is based on the idea that food allergies or lacks of vitamins and minerals causes symptoms of ASD. Some parents fee that dietary changes make differences in how their child act or feel (Sathe,2017).

Autism treatment models for older toddlers and preschool age children (36 to 60 months) are available and evidence based. Research indicates these treatments positively affect developmental outcomes in children with autism as young as 18 months, particularly in social-communication (Rogers&Dawson,2010). Parents, use of Complementary Health Approaches (CHA) for children with Autism spectrum Disorder (ASD) are common despite the uncertain evidence of its benefit (Jun Jean Ong, 2019). Use of the CHA was improved in child's behaviour (85.5 per cent), Social skills (83.3 per cent) and motor skills (77.1 per cent) (Jun Jean Ong, 2019).

Children diagnosed are subsequently managed with the occupational and speech language pathologist available in the state hospitals or health clinics (Academic of Medicine Malaysia, 2019). The most common interventions implemented by occupational therapist in Malaysia are play therapy. Followed by sensory integration training, sensorimotor stimulation, preschool training, early intervention and Snoezelen training (Mazne Kadar, 2015). In Malaysia, the treatment used interchangeable with traditional medicine which are practises based on the theories, believes and experience indigenous to different cultures (WHO,2019). Parents from middle and higher income may decide to send their child for additional regular

private treatment are costly and not supported financially by the national health care (Fikry&Hassan, 2016). Medication used to treat attention deficit disorder to help decrease impulsivity and hyperactivity in children with ASD. J Nathan (2018), insisted that, use of complementary and alternative treatments is common among children with ASD, for example nutritional supplement and diets.

Early Intervention (EI)

Intervention approaches for young children with ASD are behavioural and educational as there is no medical cure for core ASD impairment (Kaplan& McCracken,2012; Rebecca J. L., 2018).

In Malaysia, The National Early Childhood Council (2019), agrees that the public and private sectors need to boost effort to ensure we are lacks in collaborating parents in the ASD interventions. ASD Early Intervention had given the parents an important role. Parents of ASD children are involved in identifying development difficulties, arranging development testing and diagnosis evaluation with specialist and joining with an interdisciplinary team to implements early interventions (Estes,2019). The effects of early intervention for young children with ASD bring both negative and positive experience for parents (Estes,2019).

All the literature reviews, emphasising two main approaches in Early Intervention (Hyman, 2019). There are behavioural approach and development / communication approaches (Hyman, 2019). Both approaches help young children with ASD are those that provide structure, direction and organization for the child in addition to family participation (Hyman, 2019). There are different interventions being used widely :

i. Applied Behaviour Analysis (ABA)

ABA is effective for teaching skills to individuals with ASD and reducing challenging behaviour like tantrums and aggressiveness. The ASD child's progress will be tracked and measured. There are different types of ABA (Brennan,2019).

a) Discrete Trial Training (DTT)

DTT is a style of training that use a series of trials to teach each step of a desired behaviour. Lesson are broken down into their simplest parts, and positive reinforcement is used to rewards correct answers and behaviour. Incorrect answers are ignored.

b) Early Intensive Behaviour Intervention (EIBI)

This is a type of ABA for very young children with ASD , Usually younger than 5 and often younger than 3. EIBI uses a highly structured teaching approach to build positive behaviour such as social communication and reduce unwanted behaviour such as tantrum, aggressiveness and self-injury. EIBI takes place in one-on-one adult environment under the supervision of a trained professional.

c) Early Start Denver Model (ESSDM)

This is a type ABA for children with ASD between the ages of 12-48 months. Through ESSDM, parents and therapists use play and joint activities to help children advance their

social, language and cognitive skills.

• Pivotal Response Training (PRT)

PRT aimed to increase a child's motivation to learn, monitor their own behaviour and initiate communication with others.

• Verbal Behaviour Intervention (VBI)

VBI is a type of ABA that focuses on teaching verbal skills.

ii) Assistive Technology

Assistive Technology, including devices such as communication boards and electronic tablets can help people with ASD communicate and interact with others. For example, the Picture Exchange Communication System (PECS) (Rudy L.S, 2023). Uses picture symbols to teach communication skills (Rudy L.S, 2023) .

iii) Developmental, individual Differences, Relationship Approach (Floortime)

Floortime focuses on emotional, relational development (feelings and relationship with caregiver) and on how the child deals with sights sounds and smells (Wiede,2003). TEACCH (Treatment and Education of Autistic and Related Communication-Handicapped Children) uses visual cues to teach skills (Victoria Shea ,2021) .

iv) Occupational Therapy (OT)

OT teachers skills that, help the person live as independently as possible. Skills may include dressing, eating, bathing and relating to people (Novak,2019).

v) Social Skill Training

Social skill training teaches children the skill they need to interact with others, including conversation and problem-solving skills (Cuncic,2020).

vi) Speech Therapy

Speech Therapy helps to improve the child's communication skills. Some people are able to learn verbal communication skill. For others, using gestures or picture board is more realistic (Rudy,2020).

According to, Hampton&Kaise(2016); Sofia Daniolou (2022), the literature reviews has concluded that Early Intervention has positive effect on development in young children with ASD.

Parenting experiences with a young child with autism.

ASD is a development disorder involving abnormal communication, repetitive and restrictive interest and impaired social functioning ASD can have a profound impact on family life, including roles and responsibilities that parents assume (DePape,2014). The quality of relationships and attachment between a parent and a young child with autism is as strong as with other populations of parents / young children (Hobson&Hobson,2013). In some ways, parenting a child with autism adds uniquely positive experiences to family life (Patterson&Klein, 2012). At the same time parenting a child with autism is associated with increased stress. Qualitative investigations of parent

perspectives suggested that there is increased stress related to the number of services involved in treating autism and the ways information about autism are provided (Patterson&Smith, 2011).

Having a child with ASD does not only affect parents but it also poses a threat to the well-being of the family (Gobrial,2018). The current literature review exploring parent's experiences with a child with ASD points to impairment of family functioning such as giving up normal family activities, and outing , lack spontaneity or flexibility in family life, lack of personal social activities, stress surrounding the marital relationship and difficulties to maintain employment or to follow outside activities (Gobrial,2018). Parents with ASD child experience less spontaneous or flexible family life (Walton ,2018). They unable to lead a normal family life. They unable to lead a normal family life. To make life liveable for the ASD child, every outing is minutely planned. Some parents have given up normal family activities (Walton ,2018).

Mostly mothers need to quit job to take care ASD child. They spend their time with transporting the child to and from therapy or a special school (Dimitrios P, 2021). They experience restricted in their leisure time (Meirsschaut,2010). Furthermore, the parents also experience lack of understanding from environment of what ASD is and what consequences are constantly under heavy criticism (Abolkheirian S.,2022). Parents need to deal with the denial and disbelief about their ASD children. As for some families, a lack of understanding about the ASD of their child, causing isolation from their relatives (Abolkheirian S.,2022). Besides that, some parents experiencing marital strain because of the conflicts about their child's upbringing. Furthermore, parents need to concerns about decisions making difficulties, worries about their child's future and concern about impact on their other children. Every time, the parents with ASD child confronted with the pressure of autism (Meirsschaut,2010).

According to all the above literature reviews, parents with ASD child experiencing grief and sorrow, total exhaustion because of inability to regulate their child's behaviours, social isolation and negative effect on the child's siblings (Abolkheirian S.,2022)

Parenting Stress in handling ASD children

Parenting stress was the last theme within the literature. Stress is a particular response of the environment, where the individual appraises that certain demands are overextending resources, and thus threatening wellbeing (Al-Oran,2016; Onyishi C.N (2023). The daily challenges of caring for the child are endless and affect all aspects of the child's care as well as the parent's mental health and ability to manage the needs of the child and family (Bonis, 2016; Onyishi C.N (2023). Parents of children with autistic disorder experience negative psychological distress, such as confusion , feeling of helpless, frustration, sadness , anger and fear (Onyishi C.N (2023). Finally, parenting stress may negatively impact the effectiveness of interventions for children with ASD. Parenting stress also was associated with poorer child outcomes after an ASD tailored treatment (Weiss,2015; Hart&Oien,2018).

Parents in South East Asia like Malaysia, identified that source of parenting stress comes from the severity of ASD symptoms, financial problem and parents concern about the future of their children (Ilias,2018). Compare to western countries, parents in South East Asia face challenges due to poorer policy and financial support for special needs and mental health (Ilias,2018). The most stressful things while parenting ASD children is not being able to communicate with them when they were small. There were a lot of tantrums because children couldn't express their needs (Sarris,2017). ASD children's sleeping problem will lead to parenting stress as well (Martin,2019). There is the significant need to support these parents due to the stress linked with having children with a ASD including social communication, emotional and behavioural difficulties, along with challenges of finding services to look after them (Ilias,2019).

On the other hand, in Malaysia that cultural stigma and negative perception from the society regarding ASD contributed to their stress. Some parents are accused to have made some past mistakes and that caused the disorder (Ilias,2019). Surprisingly, a report by Ilias (2019) indicated that Malaysian parents of ASD Children were initially very stressful, when they learned 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.

After reviewed all the relevant literatures used in the study of 'Parenting Experience in Handling young Children with Autism', the following research questions were developed, how do parents identify initially the problem of their child? What challenges and helping strategies do parents have to help their ASD child? How do parents perceive the importance of Early Identification and Early intervention of autism spectrum disorder (ASD) among children? How the parent with ASD children does experience much stress in handling them?

IV. METHOD

The research had utilized a qualitative research approach which looked at reflection of parents experience handling their kids with ASD. This study used structured and unstructured interview to collect data. In-depth interviews will be conducted. The study will use snowball sampling where the participants will recruit from known acquaintances and by referrals sampling as well. Qualitative methods needed to obtain rich and thick description of lived experience in handling the ASD children. It will obtain data and evidence through in-depth interviews which allowed participants to freely tell their life stories (Javier,2019). This study will explore the protective experiences, adaptability and acceptance of the parents , the stress , the adversity involves during early intervention and treatments , finally about the day to day handling experience of the parents. According to O'Donoghue and Punch (2003), Triangulation is a method of cross-checking data from multiple sources for regulations in the research data.

V. FINDINGS

To analyse the data , I examine interview transcript to get a better idea of information given by respondents. The data analysis was based on the study’s research questions. I narrowed down themes and sub-themes from parents’ experience in detecting signs and symptoms of autism, early intervention and treatment carried out . Lastly, the stress involved during handling them. Parents challenges looking after their autism children and how they come to the terms that accepting their children as having autism.

Data from interview was labelled as themes and sub-themes. All sentences that important were highlighted. The data analysis was based on the study research questions. I narrow down the concepts from parents’ experience in detecting sign and symptoms in their children and the stress involved. The experience finding intervention or daily routine intervention challenges and stress involved. The treatment and their approach in handling their autism children. The challenges looking after and how they can come to the term of accepting their as having autism.

TABLE I

No	Themes	Sub-themes
1	Signs and diagnosis of Autism	Something wrong / doubt Stop talking/ laughing Self-play / wandering Sensitive to sound Screaming Flapping hands Play in rotation No knowledge about ASD
2	Early Intervention & Treatment	Behaviour therapy Speech therapy Occupational therapy Parents Counselling
3	Alternative Treatment	Traditional treatment Modern medicine
4	Stress involved handling autism child	Can’t understand the child Social limits Financial down Career sacrifices Long waiting for government serviced High charges at private centres Working / No time
5	Challenges involved in seeking Early Intervention and Early Treatment	No sufficient knowledge Intervention centres are full Special schools are full Hard to find special needs children kindergarten. Long waiting procedures to get OKU card. Unable to join normal class in government schools Expensive private schools

Theme 1: Parents noticing sign in their children’s behaviours and diagnosis

The first research question dealt with parents’ experiences in detecting sign of autism, feeling of effectiveness to help and support their ASD child and their experience on early treatment. Parents confused why their child had different behaviours and expression. All the participants reported that, this is their first child with ASD

and they have no prior experience with ASD. Mostly diagnosed only by the government hospital child specialist.

R: How many different service providers evaluated your family member with ASD before you were given a diagnosis?

P1: I did self-discovery. By age 2.5 She is not responding as normal kids. I feel something wrong in her behaviour. She was silent, don’t want see my face, flapping hand and laughing on her own. So, I Google and read up and once bring her to psychologist. He confirmed that Rakshita having mind Autism. – (Anantajoth,36)

P2: I think.....until age 3 he was normal. Hmm... then slowly he doesn’t want talk... Senyap saje. Lepas tu , jerit dan pandang atas saje. I try Google to get information about his abnormal behaviour then bring him to Klinik Kesihatan. The doctor test after few times seen him, the doctor referred us to Klang GH... Sana.... Kita jumpa Specialist Kanak-kanak.... Dia suruh saya ambil appointment untuk speech therapy. Dekat ...dekat 4 tahun doctor kata, anak saya autism. - (Azimah,32)

The participants children were behaving like normal children, talking and smiling until they turned 2 years old and they slowly become silent and lost their eye contacts. The diagnosis process was longer as well. The children need to be tested, interviewed and observed in order to diagnosis correctly.

P3: ok.... Saya rasa anak saya normal saje. Dekat umur 2 tahun, perangai dia pelik sikit . Dia tak mahu tengok muka saya bila saya tegur, jerit tanpa sebab, tak mahu tidur dan mahu main sendiri. Hmmm lepas tu saya dan abang bawa dia ke klinik kesihatan. Doktor sana suruh kita jumpa pakar kanak-kanak di hospital besar Klang. Lepas itu, kita pergi speech therapy itu pakar suruh dekat-dekat 3 tahun doktor pakar cakap anak saya autis..pernah dengar ; tapi tak pikir anak saya pulak kena...(almost cried).- (Roslina,46)

The children need to attend therapies for speech before the doctors finalise. As the participants go through government hospital procedures, it may delay in diagnosis and treatments because need to wait for specialist appointments.

P4: hmmm...first I noticed my son was getting abnormal around 2-year-old. Before that he was OK... he doesn’t want to call “mama” “papa” and not asking for milk. Sometime, dia buat tangan macam terbang, susah tidur dan ketawa sendiri. So we bring him to Klinik Kesihatan. Lepas check, doktor suruh pergi ke Hospital Besar Klang. Kita tunggu appointment pakar. Pakar kanak-kanak, suruh ambil therapy untuk speech dulu. Lepas satu bulan kita dapat appointment untuk speech therapy. Lepas 1 tahun jumpa pakar dan ambil speech therapy doktor kata, anak saya autis.- (Azurah,36)

Working parents finds difficult to bring the children for treatment if the appointments fall on working days. All the participants’ diagnosis process stared at “Klinik

Kesihatan” from their place and later referred to Klang General Hospital. Except 2 of the participants was started at private hospitals.

P5: Actually, my wife told me, Afrina not talking or asking for food... she also playing alone not with her sibling. When I started to observe... yes ...true Afrina was in her own world. Then we brought her to see a private hospital paediatrician, he referred us to Klang General Hospital. From there we start speech therapy after confirmed Afrina is Autism child. We read up articles to know more about Autism and to help our baby. - (Farid,34)

According to this study, the Autism signs are included speech delay or communication problem, no eye contact, living in own world, likes to play alone or with small children. Some ASD children like to bang head or self-biting, late development or not meeting the milestones such as delay in walk. There are children like to play in round rotation and show tantrum or meltdowns. The most noticeable sign was speech delay and communication problem with others. The participants agreed that, the speech delay was the first concern to see the doctors and get the right diagnosis. At the same time all the ASD children facing sleep problem too. These findings are similar to Sathyabama (2019), who founded the clinical characteristic that speech regression noticed among 14.8% and 29.3 % having sleep problem among her ASD children’s patients in Penang General Hospital.

P7: At first, I am not fully understanding my son’s behaviour. My husband and I working 6 days and mostly come back late. My mother and mother-in-law take turn to look after him. They use to complaint he is very naughty and don’t want listen to them. Shouting and throwing things, beating and don’t want to sleep. We thought its normal for a child. When he get aggressive and be in his own world and stop see our face and talk, we bring him to Klinik Kesihatan. They check and send to Klang big hospital. After one year of check-up and speech therapy the doktor said , my son is autism and continue treatment.- (Chong Yi,36)

Unlike Ms Goh Wei Ru, an unmarried single mother, very busy with work and the grandmother look after him. She followed her mother’s advice to bring him to see traditional doctors and Shaman (witch doctor) to get cure. Only at the age of 4 she brings him to see doctor and started therapies. But still she stopped it halfway and started back the Chinese acupuncture treatment.

P9: My son was OK until age 11/2 years, once he falls down from stairs and banged head on floor. After that he started behave abnormal. After that he slowly become mute or making weird sounds he stops calling me “mama” or asking for milk “mummm”. We thought not serious and we go see Chinese shaman to get cure. His condition same only, he start play own his own, walking in round and round and still not talking. Scared of sounds.... Will run away and hide him-self. Age of 4, I bring him to see doctor, he said my have autism and start occupational therapy.... Then I feel if he goes to kindergarten he will learn to talk, so I put him to

preschool with day-care because my mother cannot handle him at home. -(Goh Wei Ru,34)

P10: mmmm my son born normal. When Diliban was 3-month-old he had “fit”. My husband brings us to Government hospital. Me and my son admitted for few days and discharged after treatment. But until age of 11/2 years he was still had his “fits” and we used to bring him hospital. After notice he is not talking or seeing our face when we talk to him. Not responding if I ask him to speak.

Comorbidity is defined as the co-occurrence of two or more disorder in the same person (Arlene, 2013). The analysis shows that, there are three comorbidities co-occurring between Autism Spectrum Disorder (ASD) and Attention Deficit Hyperactive Disorder (ADHD), ASD and Epilepsy, the third comorbidity was ASD and Cerebral Palsy (CP). The finding showed one of the daughters had been diagnosis with ASD and ADHD. Another participant’s son also hyper and epilepsy. Her son experienced epilepsy when he was 1 year old. Thus, epilepsy also can be associate with autism. This finding supports An Epidemiological in Shanghai by Anyi (2020) who also discovered that epilepsy in childhood is significantly associate with severe mental retarding and autism. Another participant’s son affected by Cerebral Palsy (CP) along ASD. According to Jansheki (2020), Autism sometimes coexist in children with Cerebral Palsy. Both problems originated in the brain.

Having the knowledge of comorbidity in Autism is important as it alerts and prepares the parents on how to manage their children who have two or three comorbidities at the same time.

P2: Doctor pakar kata Autism sahaja (Doctor said, only ASD) – (Azimah,32)

P5: Afrina... Autism and ADHD – (Farid,34)

P8: Cerebral Palsy with ASD.... It means my son has muscles weakness and autism – (Chitra,39)

P10: Ya teacher.... Doctor said Autism and hyper active until age 2 got “Fits” (Epilepsy) – (Lakshmi, 33)

According, Lajonchere (2013), recognition from health care professionals that comorbid medical conditions such as GI disturbances, sleep disorders and epilepsy were real issues that affect children with ASD.

Theme 2: Early Intervention services attended by ASD Children

The second research question deal with parents perceive the importance of Early Treatment and Early intervention of Autism Spectrum Disorder (ASD) among children. After the diagnosis was made, participants in the study had used different interventions to reduce their children’s challenging behaviours and decrease their stress level. The inventions are made up to help the ASD children to improve their behaviour, speech and motor skills. Basically, there were 4 different types of intervention used

as treatment for ASD children. Types of intervention widely used in Malaysia.

Table II

Types	Skills
Behavioural Intervention	<ul style="list-style-type: none"> Toilet training and self-help To gain eye-contact To reduce tantrum, meltdown Giving Instructions Ask questions
Therapy Based Intervention (Communication)	<ul style="list-style-type: none"> Picture Exchange communication Massaging for speech improvement Visuals Make a schedule
Complementary and Alternative Intervention	<ul style="list-style-type: none"> Diet and food intake Supplements Medical intervention
Developmental Intervention	<ul style="list-style-type: none"> Improving social skills Indoor / outdoor activities
Prayer / Traditional Intervention	<ul style="list-style-type: none"> Pray, "Doa" Acupuncture, oil bath Herbal medicine

P1: I started to Google and find the therapies' and bring her for Occupational Therapy and Speech Therapy. I went for Nutrition counselling. Her food I Google and giving her the suitable diet food for her. She allergy to eggs...- (Anantajothi,36)

P2: Saya ikut ape yang nasihat oleh doktor di hospital. Hanya occupational therapy. Anak pergi ke Government Preschool SPED. Dia ada improvement lepas masuk sekolah. Dah berhenti speech therapy. - (Azimah,32)

P10: I follow Government Hospital paediatrician advice. My son, go for occupational therapy and speech therapy. I do take him to extra private therapy as government therapies is one a month only. Government doctors will give advice on ways to handle him also. He is in Community Based Rehabilitation Program / PDK. He is showing good improvement. He able to tell if he wants to go to toilet... he grasping fast if teach him new skills. - (Laksmi,33)

From the analysis done, intervention which parents carried out with a purpose to reduce their tantrums, aggressiveness behaviours and self-injury behaviours. Every participant agreed that, it is the big challenge to teach new skills, with children's problem would influence the intervention uses by the parents. Improvement in the children's behaviour gives positive impact on the parents. It is easy to handle their children and their stress level much lesser.

P1: She plays with her younger brother only. Indoor with toys or water play at house garden only. If bring out of house, can't control daughter's tantrum. Sometimes she not comfortable with new place or new faces. Weekends she has piano classes. - (Anantajothi,36)

P2: I do bring to nearby park but cannot stay too long. He plays alone. Tak boleh kacau. - (Azimah,32)

P3: No outdoor activities.... Sometimes to shopping or restaurant but can't be too long. So, better at home only. Father will get tension also. -(Roslina,46)

P4: Not much outdoor just play with siblings... very hard to take care. -(Azurah,36)

ASD children most likely to have more indoor activities than outdoor activities. My participants do not prefer to have outdoor activities due to their tantrum. This study agreed with the study done by Meera Murgesan (2018), who discovered that many Malaysian ASD children were mostly kept at home.

TABLE III: EARLY INTERVENTION SERVICES ATTENDED BY ASD CHILDREN AND PARENTS

No	Treatment / Intervention													
1	Behaviour Therapy/ABA													
2	Occupational Therapy													
3	Mental Health Counselling													
4	Nutritional Counselling													
5	Parenting Skills													
6	Physical Therapy													
7	Social Skills Training													
8	Speech Therapy													
9	Early Childhood Education Program													
10	Private Preschool													
11	Government Preschool SPED													
12	Autism specialist / Paedestrian / psychiatric													
No	Services Participants	1	2	3	4	5	6	7	8	9	10	11	12	Total
1	Anantajothi	/	/	/	/	/	/	/	/	/	/	/	/	6
2	Azimah	/	/	/	/	/	/	/	/	/	/	/	/	3
3	Roslina	/	/	/	/	/	/	/	/	/	/	/	/	3
4	Azurah	/	/	/	/	/	/	/	/	/	/	/	/	3
5	Farid	/	/	/	/	/	/	/	/	/	/	/	/	5
6	Hakidah	/	/	/	/	/	/	/	/	/	/	/	/	3
7	Chong Yi Ling	/	/	/	/	/	/	/	/	/	/	/	/	3
8	Chitra	/	/	/	/	/	/	/	/	/	/	/	/	4
9	Goh Wei Ru	/	/	/	/	/	/	/	/	/	/	/	/	5
10	Laksmi	/	/	/	/	/	/	/	/	/	/	/	/	5

According to this study the parents choose Occupational Therapy as their main therapy choice. Analysis, clearly showing that none of the parents attending Behaviour Therapy which is very important to prepare the ASD children to school. They more concern on children walking, motor skill and speech first.

Theme 3 : Alternative Treatments That Attended by ASD Children

Herbal medicine and acupuncture are commonly used in the treatment of children in ASD (Chai,2015). The other Traditional Chinese Medicine treatment included are acupuncture, acupoint injection, Chuna Therapy and acupoint massage (Bang 2017). Ayurveda gives new hope in the management of Autism Spectrum Disorder with its holistic and authentic approach. A combination of Panchakarma Therapy, yoga therapy, music therapy and nutritional diet modification with herbal medicine treatment

have shown improvement in the quality of life of autistic children up to a great extent (HBG Medical Article, JIVA Ayurveda 2020). Brahmi leaf , Centella leave or Vallarai are stand out herbal for brain nerves system , it has a host of benefits for neurological recovery and cognition (Vijayalakshmi, 2015).

R: Did you receive training from a professional on how to provide therapy at home for your family member with ASD?

P1: *Not at all. Self-learning. Through Google only. I am giving Ayurveda medicine, weekly oil bath, I'm giving her virgin coconut oil to drink..... all this I found from internet only. - (Anantajothi,36)*

P2: *uhhmm..... tak de la cikgu, awal awal orang kat rumah kata... anak saya kene rasuk... jadi pergi jumpa bomoh.. tapi sama aje. lepas itu saya ikut cakap doktor saje..- (Azimah, 32)*

P10: *I did visit shaman and temple priest to treat my son but nothing helps after that I follow doctors and therapist advice only... I and my husband get information from internet also... past 1 year I am taking Ayurveda Medicine ... the doctor asked us to take "vallarai" (Centella) leaves and walnuts to boost the brain cells.... I can see lot of improvement too...- (Lakshmi,33)*

The study shows that many options exist about herbal medicine, acupuncture and oil bath for the treatments for the ASD children but it still in an experimental stage when it comes to treat and cure autism. Traditional treatment holds great promise for supporting health and life of autistic children. The treatments do not adverse any side effects. According to participants this promotes a positive change in their ASD children to digestive, cognitive, emotional and brain balance concerns.

Theme 4 : Stress involved in Handling ASD Children Stressed on Early Detecting and Diagnosis Period

Dr. Lenny Thornton is a consultant child and adolescent psychiatrist at The Cheshire Autism Centre, UK stated that, “ Parental stress a common occurrence at risk of becoming psychologically stressed and significantly higher levels of mental health.” (Elder, 2016) , sources of stresses report indicates that parents and family members support, and direction can experience extremes stress, especially the tumultuous time of diagnosis. Parents expressed anger and ask, “Why us?” “Why our child?” “I was very faithful to God”. All these are initial part of anger, which part of the grieving processing when noticing the sign of my child is not normal (Elder, 2016). The parents are much younger at the time they started to notice behaviour changes in their child, especially the mothers.

This study found that long waiting periods before the diagnosis can be described as the most difficult time for them parents. The time gap between detecting and the diagnosis period is almost 6 – 12 months (Penner M., 2018). . During the gap the parents find they over stressed to handle the new situation. Parents have noticed abnormalities earlier but had to wait until their children to reach 3 or 4 years to be diagnosis (Penner M., 2018).Therefore the waiting time periods to diagnosed autism in their children and to bringing them for regular check-up, delay starting in treatment and

intervention put the parent in much stressed(Penner M., 2018). The more time passes the more the stressed about children’s future (Penner M., 2018).

This makes way for them to Google and try own treatments or seeks shaman/witchdoctor’s help to cure their children. Preparing them for the appointments also makes the parents stressed. ASD children’s sudden change of mood, tantrum and meltdown increases parents stress level (Illias K ,2018). They stressed over their inability to control their ASD child. Parents also experiences denial, anger and depression (Illias K,2018).

R: What is the length of time (number of months) between your first concern and receiving a diagnosis for your family member with ASD? Prompt: How was your stress level?

P1: *Around 1 ½ to 2 years I felt Rakshita, less responding than I had doubt that she is not like normal children. I brought her to a psychiatrist then after few check-ups, she said my daughter having mild autism. That was around 2 ½ years old. So it took about 6 months’ time. Very hard for me understand and manage her...- (Anantajothi,36)*

P2: *lebih kurang 3 ½ tahun saya rasa, dia banyak berubah....jumpa doctor beberapa kali... ambil terapi... 4 tahun doctor sah kan la....ambil masa 6 bulan... memang tak tahu macam mana nak ajar dia... appointment doctor kena tunngu lama... susah nak adjust masa..- (Azimah,32).*

TABLE IV: TIME GAP

No	Participants	Children’s age when Autism detected	Aged of child diagnosis with Autism	Time gap between parents concern and detection of autism
4	Azurah	2	3	12 months
8	Chitra	1 ½	3	18 months
9	Goh Wei Ru	4	5	12 months

Malaysian parents are stressed after the day to day works and in handling their ASD children (Illias K,2018). They do not have own sweet to time to relax and rest. Too much stress is bad for parent health. Malaysia in particular, Parents of ASD children were found to have significantly higher stress in the dissatisfaction of their interactions with their children (Lee,Ong&Faizal,2017). They were urged by some family members to see witchdoctor. This kind of irrelevant advice being forced to follow and its gives lot of stressed.

ASD Children Behaviour that caused stress

Due to the broad range of difficulties and behavioural problems that these children face, raising a child with an ASD produces chronic stress and strain on parent (Rebecca,2013). According to BabyBonus Magazine 2018, family with ASD children often experience more stress than other families. They are stresses because they are finding hard to manage daily life with children with ASD and doing things with a child with ASD can simply take longer and can often quite frustrating (Illias K,2018) .

Mothers are often more stressed than fathers, possibly because mothers tend to be the primary caregiver in many families (Deweerd,2020). Particular source of stress for mothers include children’s unpredictable sleeping patterns, difficulties with social skills, limited ability to express emotion and fussy eating (Rudy,2019) . As for fathers, their children’s difficult behaviours often seem to be a cause of stress (Rudy,2019). Sibling of ASD children also experience ASD related stress. They are bothered by the ASD sibling’s behaviour difficulties (Deweerd,2020). “Autistic” behaviour is usually self-evident because they are generally quite different from typical behaviours (Rudy,2019). As a result, we can be able to tell at a glance autistic symptom:

- a. Self-Stimulation (Stimming)
- b. Lack of eye-contact
- c. Self-abuse
- d. Lack of focus
- e. Noisemaking
- f. Social Communication

This study revealed that all the participants also stressed over their ASD child’s behaviours. Poor academic performance, sleeping problem, Show tantrum/meltdown in public place, speech delay and toilet training. They also worried about other child influenced by ASD child behaviour, such as the younger one’s try to imitate the way the ASD child making sounds and playing in rotating. My participants, feels sad that, the elder kids get annoyed and felt they have been neglected by parents. Another mother shared that, her younger son follows ASD sister’s attitude like , play in rotating , flapping hands and so on.

R: What do you feel are the biggest struggles with your child in your day-to-day living?

P1: *At the beginning everything was being struggle..... Understanding her needs. Now her motor skills bad... can't hold spoon or pencil to write. She still wearing her diaper... she will scream if need anything... she likes to flaps her hands and play in rotation. Her younger brother is 2 years old, following her behaviours... he is normal child... I am worried about it.... – (Anantajothi,36)*

P2: *..... belum boleh pergi toilet...menjerit.....tak tidur malam.. belum pandai menulis...- (Azimah,32)*

P3: *..... like to lick the floor Every day I need to shout at her.... her mood will change ...- (Roslina,46)*

P4: *He will be restless at new place.....sometime cry and scream.... - (Azurah,36)*

P5: *hard to understand her because cannot communicate.....we need to guess what she trying to say...- (Farid,34)*

P9: *he is very picky eater...very hard to make him eat...he not able to go to toilet... very hard – (Goh Wei Ru,34)*

As per this study, the main aspects and stressors based on my participants facing as follows: -

TABLE V: THE MAIN ASPECTS AND STRESSORS

No	Aspects	Stressed over
1	Stressed on Early Detecting and Diagnosis Period	<ul style="list-style-type: none"> • Confused over the early symptoms. • Wrong advises from other people like urging them to see witchdoctor. • The time gap involves after consulted and diagnosed by doctor. • Time gap to start early interventions. • No idea real way to handle them. • The noise and sounds.
2	Stresses involved while handling autism child	<ul style="list-style-type: none"> • Can't understand the child and their tantrums/ meltdowns. • Social limits • Financial down and guilty over can't effort to provide supplementary interventions. • Career sacrifices; don't have self-leisure time. • Not enough sleep for parents • Travelling to bring to school and intervention. • Worried over the child's future. • Worried about whom take will care them, once they are not around.
3	ASD Children Behaviour that caused stress	<ul style="list-style-type: none"> • Poor academic performance • Sleeping problem • Show tantrum/meltdown in public places. • Speech delay • Toilet training • Other siblings disturbed by ASD child behaviour .Younger one's try to imitate them. Elders get annoyed sometime feels neglected.

Theme 5: Challenges involved in seeking Early Intervention and Early Treatment

After the diagnosis was made, participants of this study adjusted their plans and routines along with expectations for their children’s future (Tina,2018). As time passes, they end up waiting for the therapy and treatment to start. In Malaysia, due to the long list in public centres, it is common for parents to seek treatment from NASOM (National Autism Society of Malaysia) which is as non-governmental organization or privately owned entities (Tina,2018). Parents would need to pay a certain amount of fee for the treatment at these centres (Tina,2018). Genius Kurnia, A holistic Government Sponsored Autistic Centre but it always full.

R: How many months after diagnosis did it takes before you could begin intervention therapy for your family member with ASD?

P1: *I didn't wait too long.... after diagnosis ...I start immediately the speech and the Occupational therapy. I went to private intervention immediately I get appointments. – (Anantajothi,36)*

P2: *uhhh Rasa Nya.... selepas sebulan agak nya... NASOM centre yang dekat pun penuh.... Ramai yang masuk treatment.... susah nak dapat kindergarten for special kids...*

I wait until my son 6 years old and put him into government preschool.... - (Azimah,32)

P3: appointment at GH taking long time ...I try to get Program Pemulihan Dalam Komuniti (PDK)...its full also..... I wait for GH therapy only.....- (Roslina,46)

P4: ...Yes, I just waited for GH Therapy.... Then I also tried for preschool but hardly find preschool for Special Kids... normal kindergarten not accepting special kids.... Then need to wait until reach 6 years and put into Sekolah Kebangsaan Preschool....- (Azurah.36)

P9: I go Chinese treatment first... after 3 or 4 months start occupational I don't really know what to do.... - (Goh Wei- 34)

P10: ... I can't remember much ... if not mistaken more than a month.... Need to get OKU card ... at first, I try normal kindergarten but they asked us to go to PDK centre... we able to get place there..... - (Lakshmi,33)

According to Norhidayah(2018) , although there are many Malaysians familiar with the terms of Autism however still many of them do not really know the characteristic of children with Autism. The most important matter is, to start intervention as early as possible. The diagnosis gap and the treatment gap make the children behaviours worst at the same time the stress level increases as well in handling their children (Norhidayah,2018). This study found that, participants had to endure long waiting time at government hospital, which contributed to further delay in receiving a diagnosis and intervention for their children. My participants stressed over the time gap between they noticed and the diagnosis by doctors. The gap makes them stress because they have no clue to handle their ASD child.

This finding is supported by the Asian Research News (2020), inadequacies in the medical and education system contributed to a significant amount of parental stress. There are not many parental interventions or counselling programs for the parents to educate them about Autism and the ways to handle them (Asian Research News,2020). All the participants never been advised about it and most of them did self-learning, and the knowledge were insufficient. Parental involvement in autism early intervention has been proven to improve children's communication as well as reducing the severity of symptoms, (Asian Research News ,2020).

R: Did you receive training from a professional on how to provide therapy at home for your family member with ASD?

P1: No...Only self-learning...- (Anantajothi,36)

P2: Tak pernah.... Hanya perlu tengok dia orang buat dan cuba kat rumah...- (Azimah,32)

P3: Not really...- (Roslina,46)

P4: Therapist will ask us to observe and do at home.....- (Azurah,36)

P8: I'll assist the therapy during session and learn from there only.... And my husband mostly Google and get him toys and give training at home...- (Chitra,39)

P10: Nothing like counselling or training. The therapist will ask us to see and learn to give training at home...I can't buy the same items but I bought for him some toys for him to play with...- (Lakshmi,33)

According to this study, the Malaysian parents are not given any training or involve in interventions. The child interventions will be more effective if parents involve in it. The parents took own initiative and bought toys and blocks to give training at home. If parents involve in the child interventions programmes, parents can be the best trainers at home. They found it difficult to find support, interventions and therapies due to a lack of knowledge about autism among health professional. Poor information and resources characterised to entire journey, from diagnosis to trying to access treatment and support (Asian Research News, 2020).

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 should give excessive training to support and help parents of ASD children with the diagnosis process, conduct therapies and perform treatment intervention (Ilias,2019). This study supported by Department of Statistic Malaysia (2017), the high cost of private intervention becomes a financial burden in their pursuits of better services for their child.

TABLE VI: SUMMARY OF CHALLENGES INVOLVED SEEKING EARLY INTERVENTION, PRESCHOOL & EARLY TREATMENT

- No knowledge about other intervention needed or about other government centres.
- Waiting period and delay in starting the treatment and intervention.
- Long waiting for government serviced
- High charges at private centres
- No sufficient knowledge
- NASOM centres are full ,PERMATA is full, PDK is always full
- Hard to find special needs children kindergarten.
- Long waiting procedures to get OKU card.
- Not able get into mainstream school
- Expensive private preschools
- Don't have a holistic special need school, where intervention and academic provided together.

This research has gathered qualitative data on the lived experience of parents handling their ASD children. The five themes that emerged from this research were a) Sign and diagnosis of autism b) Early intervention and treatment c) Alternate treatment d) Stress involved handling autism child and e) Challenges involved in seeking Early Intervention and Early Treatment. Respondent reported that, overall their stress levels have increased. Common stressors included distress over lack of time spend with other children and spouse, financial stress, before and after the diagnosis process, waiting time to see doctors , to find right or extra intervention , treatment or preschools and finally lack of own leisure time. This analysis also found that parents with ASD children needs self-care skills such as exercise, meditation,

time alone with friends and learn relaxation techniques to manage their stress level.

VI. DISCUSSION

The information from the research obtained is in line with the literature review. As cited in the literature review. Most parents had noticed the behaviour differences at their children but did not know it is the symptoms of autism (Ting and Chuah,2010). According to BERNAMA,(2014), it is estimated that 1 out of every 600 children in Malaysia is born with autism. Finding shows that, parents' first notice that their child not speaking and also they lack of eye contact. They not respond to any instructions given by their parents. Iris Lee (2016) stated that, the ASD child will fail to make eye contact, being irresponsive to her/his name and tendency to play with toys in unusual repetitive way. Autism often related to the Theory of Mind which an important social-cognitive skill that involve the ability to think about mental state of our own and those of others (Cherry,2020).

Malaysian parents referred to hospital and clinics to get diagnosis (Ilias,2018). Some went to private hospitals and mostly went to government hospitals. This shows Malaysian parents are very concern about their children's health condition. At the same time, their ASD children become new challenge in their daily life (Ilias,2018). They start to Google and get more information to overcome the challenges. Malaysia parents experience stress upon learning about their children's diagnosis (Ilias,2018).

The finding and analysis show that, Malaysia parents with ASD child stresses over the early diagnosis process and facing self-challenging situation to handle and to treat their ASD children and the comorbidities. Moreover, there are long time gap between noticing periods, diagnosis period and to start intervention or treatment period. It clearly stated in literature review, Malaysian parents have no knowledge and prior experience in handling a child with ASD till they have diagnosis for their own children (Shin, Syamin, Grace & Suseel,2018). After the diagnosis Malaysian Parents adjust their plans and routine and waiting for the treatment starts. Parents of ASD children are involved in identifying development difficulties , arranging development testing and diagnosis evaluation with specialist and joining with an interdisciplinary team to implements early interventions (Este,2019).

The important of early intervention and treatments given by the parents. ASD Early Intervention had given the parents a important roles. Malaysian parents give extreme important to the interventions and therapies. Children diagnosed are subsequently managed with the occupational and speech language pathologist available in the state hospitals or health clinics (Academic of Medicine Malaysia, 2019). The most common interventions implemented by occupational therapist in Malaysia are play therapy.

Followed by sensory integration training, sensorimotor stimulation, preschool training, early intervention and Snoezelen training (Mazne Kadar,2015).

This finding also shows that, Malaysian parents are going for traditional treatments. In Malaysia, the treatment used interchangeable with traditional medicine which are practices based on the theories, believes and experience indigenous to different cultures (WHO,2019). As per literature review, the Chinese parents following Chinese treatment, herbal medicine and acupuncture are commonly used in the treatment of children in ASD (Chai,2015). The other Traditional Chinese Medicine treatment included are acupuncture, acupoint injection, Chuna Therapy and acupoint massage (Bang,2017). As per Indian parents, they prefer Ayurveda treatments and diets. Ayurveda gives new hope in the management of autism spectrum disorder with its holistic and authentic approach (HBG Medical Article, JIVA Ayurdeda 2020). A combination of Panchakarma Therapy , yoga therapy , music therapy and nutritional diet modification with herbal medicine treatment have shown improvement in the quality of life of autistic children up to a great extent (HBG Medical Article, JIVA Ayurdeda 2020)

At the same time current research finds, Malaysian parents in this study are not aware that the Behaviour Therapy (ABA) is an important intervention which needed by their kids. It will help the kids to learn daily life tasks and get them ready for schooling. This finding shows that parents are lack of knowledge and very poor of information. Asian Research News, (2020) supporting this finding saying that, Malaysian parents found it difficult to find support, interventions and therapies due to a lack of knowledge about autism among health professionals.

The parents in this study were asked directly about their stress level in handling their ASD child. The study revealed an unexpected finding. Parents this study experience stress upon learning about their children's diagnosis. They admitted that the time gap from the noticing period to diagnosis and to start the intervention and treatment makes they stressed. According to them, the diagnosis gap and the treatment gap makes the children behaviours worst and they don't know the ways to handling their children properly. This finding is supported by the Asian Research News (2020) , inadequacies in the medical and education system contributed to a significant amount of parental stress. None of the parents of this study attended any counselling or parents' interventions to handle their stress. In Malaysia there are not many parental interventions or counselling programs for the parents to educate them about Autism and the ways to handle them and to overcome the parents' mental pressure.

The most stressful things while parenting ASD children is not being able to communicate with their child when they were small. The ASD child will show a lot of

tantrums because children couldn't express their needs (Sarris,2017). There is the significant need to support these parents due to the stress linked with having children with a ASD including social communication, emotional and behavioural difficulties, along with challenges of finding services to look after them (Ilias,2019). Mostly all the research highlighted the sleeping problem as the main problem. Same goes to the parents in this study, where they also going through sleepless night for few years until now. They can't sleep until their child sleep. This makes them very tired and stressed. Clearly stated in the literature review as, ASD children's sleeping problem will lead to parenting stress as well (Martin 2019).

In addition, this study also discovers that, the Malaysian parents in this study, are tired of travelling to bring their ASD child to different places for interventions and preschools. They feel it would be better if have holistic school for ASD children with combination of school and interventions. Now there is only one centre called PERMATA . The most famous holistic intervention centre in Malaysia is Genius Kurnia formerly known as PERMATA, which provide, early intervention, pre-school and community education for free. It is government aided centre (Sazlina,2019). It's does not accommodate the number of ASD children who are increasing rapidly in Malaysia. We need more Genius Kurnia services in all over Malaysia. According to Nasom, Chairman Failina by analysing the national, " we are looking at around 8,000 to 9,000 born yearly may have autism in Malaysia" (The Sunday Star (15th Sept,2019). Academic and interventions should be in ONE preschool / centre and it should be done by government in order to benefits all in needs. A Holistic Early Childhood Special Education is one of the solutions for the parents and the ASD Children. The fact that , government based Special Needs Preschools, Interventions and Treatments helps the most Malaysian parents with ASD children to lead a less stressed life, is very true.

VII. CONCLUSION (OR LIMITATION OR SUGGESTION FOR FURTHER STUDIES)

Given the paucity in exiting literature in this area, especially regards to Malaysia, the study no doubt makes a valuable and significant contribution. However, it is important to address some of the study's limitation. First, although it has a variable sample for qualitative study of nature, it was still relatively small when we consider the amount of ASD children across Malaysia. Second, all the participants drawn randomly from Klang, Selangor only. This makes the finding less generalizable across other parts of Malaysia.

Finally, the finding from the present study can be used to inform and guide program concerned with improvement

of quality of life of ASD parents. Psychologist can contribute effective intervention program to address the cognitive and emotional needs of these parents with ASD children. Future research needs to be completed to access where else more intervention strategies or support system can be put in place for parents with ASD children. They required greater support than what the broader community and friends can offer.

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