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# A PARENTAL PERSPECTIVE OF ASD EARLY DETECTION PROBLEMS AND COPING MECHANISM

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**Abstract**: *Autism Spectrum Disorder (ASD) is a neurological and developmental disorder, appeared in early childhood. The need to have early identification is important to reduce the difficulties of the ASD person and bring positive impact on the well-beings of the caregivers. Problems in early detection of ASD, however, lead to the development of negative impact on the parental well-beings and increase levels of stress among parents to engage in low quality of life. The current study aimed to explore the experiences of parents with ASD children in early detection problems and their coping skills, living with the challenges. The purpose of this study was to identify the problems in early detection of Autism Spectrum Disorder (ASD) from the parental perspective and how the problems could be managed throughout life experiences. A semi-structured interview was conducted to 5 selected parents, age ranging from 30 to 45 years, with ASD children aged 3 to 5 years, using a purposive sampling procedure. Thematic Analysis enabled the identification of key components of early detection problems and the coping mechanisms as the generated themes for the study. The finding from the two research questions was identified across the generated themes; 1) Parental negligence, lacking knowledge and awareness, Feeling sensibility, Societal judgment, Familial relation problem, 2) Positive mindset, Self-encouragement, Family support, Social support, Treatment and services, School placement. Research Implications for the improvement of the problems and development of interventions were also discussed across these themes.*

**Keywords:** *Early detection, Coping mechanism, ASD, Well-beings*

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## Introduction

Autism Spectrum Disorder (ASD) is a neurological disorder with deficit in social communication and interaction across different context with the presence of restricted patterns of behavior and activities (APA, 2013). The diagnostic criteria of ASD in DSM-5 have divided into two main components which are persistent deficits in social interaction and communication and restricted patterns of behavior or activities. According to World Health Organization (2017), some people with ASD can live independently but those who with severe disabilities need life-long care and support from their family members. Therefore, the early identification and intervention are vital to reduce the difficulties of the ASD person and bring positive impact on the well-beings of the caregivers (World Health Organization [WHO], 2017). The symptoms of ASD can be identified during the second year of life or even earlier as if the developmental delays are severe based on the Diagnostic and Statistical Manual of Mental Disorder fifth edition (DSM-5) (APA, 2013). However, Neik, Lee, Low, & Chua (2014) reported that diagnosis is often done much later due to the insufficient of knowledge on ASD among Malaysia parents. The finding is in line with Ilias, Liaw, Cornish, Park, & Golden (2017) who reported that awareness of ASD in Malaysia and certain other countries in Asia is still limited. Previous researches had also found the negative impact of raising an ASD child on parental well-being (Dardas, 2014; Mcstay, Dissanayake, Scheeren, Koot, & Begeer, 2013). Parents who are raising and caring children with ASD tend to have high levels of stress and always engage in low quality of life (Zablotsky & Anderson, 2013). In order to reduce the daily stress in a probable manner, life coping mechanism are very important for those affected family members, especially parents (Gour & Pandey, 2016).

There was about 1 in 160 children in the world who been diagnosed with ASD (WHO, 2017). Boys were four times more common than girls to be identified with ASD. It can be happened to anyone regardless of race, ethnic or socioeconomic groups. In Malaysia, there were 1.6 percent of children who aged from 0 to 59 months failed in M-CHAT screening with 0.6 percent higher than the feasibility study in 2005 and the statistics showed that the prevalence in Malaysia was increasing as well. (National Health and Morbidity Survey, 2016). According to Zwaigenbaum et al. (2013), late diagnosis is not only related to the increased level of stress among parents but it also limits the ASD children to receive the early intervention. In addition, providing with the diagnose at old age causes other related psychological problems both parents and the child (Camarata, 2014). Researches showed that delay in diagnose leads to the direct increase in the number of ASD symptoms and monetary burden of the families (Horlin, Falkmer, Parsons, Albercht, & Falkmer, 2014).

Parenting a typical child can be stressful but parenting an ASD child can be even more traumatic and burden (McStay et al., 2013). The ASD child needs a lot of attention, support and care due to their special needs (Van Tongerloo, van Wijngaarden, van der Gaag, & Lagro-Janssen, 2014) with significant tension (Gaur & Pandey, 2016; Gona et al., 2016; Lai & Oei, 2014; Luque Salas, Yanez Rodriguez, Tabernero Urbieta, & Cuadrado, 2017) and higher levels of depression compared to those parents of a typical child (Hayes & Watson, 2013). Furthermore, numerous researches had found the negative impact of raising an ASD child on parental well-being (Dardas, 2014; Mcstay, Dissanayake, Scheeren, Koot, & Begeer, 2013) with high levels of stress and engage in low quality of life (Zablotsky & Anderson, 2013). Therefore, parents of children with ASD need to further develop self-coping strategies to cope with the challenges in raising the child (Gour & Pandey, 2016).

Indeed, ASD can be reliably diagnosed as early as age two by experienced clinicians (Steiner, Goldsmith, Snow, & Chawarska 2012). Unfortunately, there are still many children are diagnosed at older ages due to different factors like community, family and health care system barriers (Zuckerman et al., 2014). In Malaysia, the diagnosis is often done much later due to the lack of knowledge among affected families (Neik et al., 2014). Currently limited researches had been conducted for the purpose of analyzing the challenges of early detection problems among parents of ASD children in Malaysia. Therefore, the current study aimed to explore the experiences of parents living with their ASD children. The study also aimed to investigate problems of early detection of ASD among parents which could lead to further identification of psychological degradation affecting their mental health and other stress related issues, living with ASD children. In its effort to expose the ASD problem in early identification, the current research produced the richness of the data from the theoretical based explanation and other researches for the purpose of deriving the generated themes.

## Literature Review

### The Ecological System Theory

In the current study, the ecological systems theory, developed by Urie Bronfenbrenner (1917-2005) was used to examine life experiences of ASD parents. This theory views the developing person within a complex system of relationships, influenced by multiple levels of the surrounding (Berk, 2018). Thus, the Ecological Systems Theory can be helpful in understanding and explaining the family dynamic with ASD child and the potential impact of the family system on those affected parents. The ecological systems theory states that environment exerts influence on a person's development and there is reciprocity in the person's effect on his or her surrounding (Bronfenbrenner, 1979). In other words, the person impacts his or her immediate environments and those environments affect each other to create a dynamic system of interacting elements (Brofenbrenner, 1979).

There are five major systems in Bronfenbrenner's theory which include microsystem, mesosystem, exosystem, macrosystem and chronosystem. Microsystem is the primary system that a developing person interacts with the most often. It consists of activities and interaction patterns experienced by the developing person in the person's immediate environment (Berk, 2018; Bronfenbrenner, 1979). In current study, parents are the one who often interact with their ASD child in the family. When a person who lives in an environment with a child with ASD, it will impact the person in different ways. Past research found that parents who raising and caring the child with ASD tends to experience high levels of pressure and low quality of life (Weiss, Wingsiong, & Lunsky, 2014; Zablotsky, Anderson, & Law, 2013). Dardas (2014) also agreed that caring a child with chronic disability like ASD is considered as significant stressors that involve psychological and physical tension for parents. Therefore, interaction with ASD child within the family will affect the parents' well beings.

The second level of Bronfenbrenner's model is known as mesosytem which involves the connections between the structure of microsystem in which the developing person actively participates such as family, work or social life (Bronfenbrenner, 1979). An example pertaining to the current study would be the influence on parent's working or social life within the family with ASD child. Parents have difficulties to engage in social activities with friends due to their ASD child's challenging behaviours and problems in social interaction (Ludlow, Skelly, & Rohleder, 2012). In addition to that, Omar, Ahmed and Basiouny (2017) also found that there is a lack of social visits to family or friends due to being embarrassed, custom or traditional constraints. This is in line with Gona et al. (2016) who found that parents were lack of sufficient time for paid work and other activities due to the caring responsibilities on their ASD child. Hence, parents' social and work life will also be challenged, living with an ASD child.

The exosystem is the third layer which refers to different social structures that the person does not involve directly, but that impact of the events occurs in the person's immediate setting (Bronfenbrenner, 1979). These can be formal organization like community health and welfare services, friends or extended family member (Berk, 2018). In current study, the lack of therapeutic services or government support can also be the challenges of the parents with ASD. Ilias et al. (2017) reported that there is a lack of treatment and therapy services for children with ASD in Malaysia. Parents have to seek for treatment from private settings which are costly. Indirectly, parents have increased the burden of financial due to the high cost of treatment. The macrosystem is the outmost level of Bronfenbrenner's model which consists of cultural values, laws and resources (Berk, 2018). Estrada and Deris (2014) conducted a phenomenological study of Hispanic families that describing the influences of culture on the parents' ability to obtain a diagnosis and treatment. In current study, the way that parent raise a child with ASD can also influenced by cultural values or beliefs, resources or laws. Most parents of ASD as being stigmatized and sometimes blamed for their child's unusual condition and behaviour (Gona et al., 2016). The insufficient knowledge of ASD brought the people in society to rely on traditional cultural beliefs (Ilias et al., 2017).

Brofenbrenner added the chronosystem into the model in 1986. The chronosystem takes into consideration the main events that occur throughout the person's life. The chronosystem entails environmental influences. According to Berk (2018), the life changes can be imposed externally or happen from within the person since he or she can choose, transform and generate many of their own settings and experiences. In current study, the process of raising a child with ASD is an endless effort. Weiss et al. (2014) stated that parents who always reported high levels of stress and mental health problem are related to the challenges of caring the person with special needs and seeking for multiple services across the life course. Thus, the support and coping strategies are needed by the parents, living with ASD. Figure 1.1 explains the interactive stages of ecological social theory.

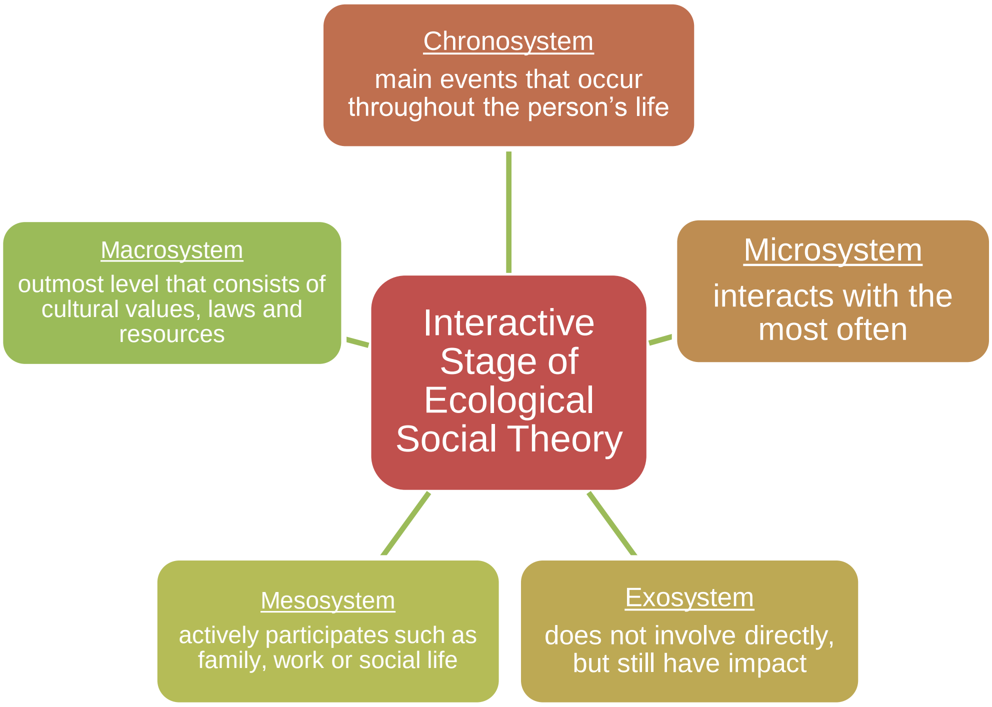

**Fig 1 Title of the figure:** Ecological Systems Theory, (Urie Bronfenbrenner, 1917-2005)

The current research developed two main research questions for the purpose of investigating the challenges of parents in identifying the problems of early detection of ASD and the coping mechanisms they developed for the purpose of enhancing and empowering their lives with resilient strategies to have the equilibrium of living with psychological well-beings and mental readiness.

## Application of the Theory

### (a) Parents

There are many studies have highlighted the challenges experienced by parents of a child who has ASD and the negative impact of raising a child on parental well-being has been documented (DePape & Lindsay, 2015; Gomes, Lima, Bueno, Araujo, & Souza, 2015; Ilias et al., 2017; Ludlow et al., 2012; Mcstay et al., 2014; Omar et al., 2017; Van Tongerloo et al., 2014). Parents of ASD child are faced with numerous challenges such as caring and financial burden, difficulties in handling the behavioral symptoms and lack of support in raising the child with ASD (Gona et al., 2016). Due to the different kind of challenges, parents of children with ASD reported that they experience higher level of pressure, anxiety and depression compared to parents of typical child (Bonis, 2016; Weiss et al., 2014)

In the study of Omar et al. (2017), they found that high cost of normal follow-up and medication treatment were the most perceived stressors. Most of the mothers were housewives and had no sufficient income for the treatment of their ASD child. In addition, the decrease income in the family due to one parent needs to stay at home to take care of their ASD child. Hence, the financial instability among the families of child with ASD together with the additional financial issues would explain the higher level of stress among mothers of ASD. In line with the findings of Omar et al. (2017), Gona et al. (2016) also found that the need for taking care of the child with ASD had negative financial impact on the parents. The findings showed that parents of ASD on the Kenyan Coast spent almost all the money they had towards the treatment for their ASD child. Besides that, parents also shared the opinion that they lacked of time for generating income due to the caring responsibilities as their ASD child lack of daily living skills. Parents also experienced stress and fatigue when dealing with behavioral challenges. One study in Malaysia reported parents of ASD expressed the concerns and difficulties in handling their child’s behavioral symptoms of ASD such as hyperactive, communication problems, tantrums, aggression, learning difficulties as well as sleep problems (Ilias et al., 2017). Research in Netherlands also reported parents had same difficulties in handling their child’s behavioral problem which beyond its control related to its disorder (Van Tongerloo et al., 2014). Past research found that parents experience guilt and blame for the ASD child’s behavioral problem (DePape & Lindsay, 2015; Van Tongerloo et al., 2014).

In regards to lack of social support, Ludlow et al. (2012) reported that parents expressed a sense of fatigue with little break due to the lack of support and understanding from grandparents at home. Grandparents who did not understand the ASD might regard the child’s behavior as a response to bad parenting. Unlike previous research, Van Tongerloo et al. (2015) found that the female main caregivers were not getting sufficient support from their partner and they had to give up their job which against their will. Besides of the support from family members, Ludlow et al. (2012) also reported that parents lack of support or resources from external organization. Consistent with this, Ilias et al. (2017) also reported that parents of ASD need for more support from the government in terms of therapeutic services, more special schools for their children, financial support and employment opportunities. Parents who stay in rural area found more challenges in finding the resources (Ilias et al., 2017). In parallel with the previous research, Antezana, Scarpa, Valdespino, Albright and Richey (2017) reported that the geographic distance between families and service providers, low reliance on health care providers lead to the diminished availability and utilization of services for parents with ASD child in rural communities.

### (b) Siblings

Living with a child with ASD not only had tremendous impact on parents but also his or her siblings. According to Ward (2016), those with autism spectrum disorder (ASD) have an impact on siblings in both positive and negative ways. Research indicates positive attributes include responsibility, less quarrelling and competition, respect for the person with ASD and satisfactory sibling relationships. Negative attributes include fear of aggressive behaviour, decreased sibling intimacy, and social and emotional difficulties. These attributes were supported by the findings of Angell, Meadan and Stoner (2012). In qualitative research of Angell et al. (2012), they explored experiences of six brothers and six sisters living with a young person with ASD through semi-structured interviews. The findings revealed the overall theme was contradiction. Participants recognized challenges such as resulting embarrassment or frustration when their ASD siblings did unusual things in public places, social isolation, decreased recreational times with families and positive aspects such as loved and appreciated the ASD siblings, less frequent of quarrelling, develop sense of responsibility regarding safety and care of ASD siblings.

Petalas, Hastings, Nash, Reilly and Dowey (2012) also found the mixed findings. They reported that being the sibling of child with ASD can be an overwhelming task, yet the feelings of empathy and compassion are present. The participants have emotional conflict when they were frustrated regarding the aggressive behaviours of their ASD siblings but still had the feelings of empathy and understanding toward their siblings. In the study of experiences of Australian siblings of ASD individual, Bitsika, Sharpley and Mailli (2015) found the differences in terms of age and genders for issues like time spent with their siblings and the access to their parents. Participants reported that there was a lower level of confidence in being to live in their wished lives associated with having a younger sibling with ASD in their family. Female participants who have siblings with ASD reported that their lives were more affected than male participants. In addition, Gour and Pandey (2016) further explained the female elder sibling would take on a maternal role in taking care of the child with ASD and male elder sibling would less delegation of responsibilities for the ASD child by the parents.

### (c) Teacher

Numerous researchers found that children with ASD are increasingly being placed within mainstream settings (Busby, Ingram, Bowron, Oliver, & Lyons, 2012; Edward, 2015; Lindsay, Proulx, Thomson, & Scott, 2013; Majoko, 2015; Soto-Chodiman, Pooley, Cohen, & Taylor, 2012). However, educating children with ASD in the mainstream setting can be challenging for teachers (Lindsay et al., 2013). When dealing with children with ASD, teachers are expected to deal with some atypical behaviors like poor social communication or interaction, repetitive and restricted behaviors (APA, 2013). In the study conducted by Majoko (2015), teachers reported that the children with ASD would disrupt the routine of the classroom by manifesting the repetitive behaviors such as rocking or sucking, obsessive behaviors, routines and rituals. This is consistent with past research showing that teachers have difficulty in understanding and managing the behavior of children with ASD (Lindsay et al., 2013). Soto-Chodiman et al. (2012) also revealed that the interactional behavioral problem between children with ASD and their classmates always occurred in mainstream setting. They further explained that the problems related to stereotypic utterances and physical mobility that always displayed by children with ASD and other classmates found irritating especially during quiet times.

Some studies found that teachers faced challenge to include the children with ASD in their classrooms due to lack of the basic knowledge and skills (Busby et al., 2012). In consensus with the finding of Busby et al. (2012), Edward (2015) found that teachers had low knowledge about children with ASD due to the lack of in-service training and lack of workshops. Besides of the knowledge and skills, teachers also found difficulties in preparing the teaching materials and the lack of resources for equipment due to the lack of funding for education assistants (Lindsay et al., 2013). The collaboration among other teachers or parents with ASD can also be one of the challenges for teachers. In the study of Busby et al. (2012), the teachers reported that the collaboration between parents of ASD or other teachers are difficult and time-consuming. Although the partnership between parents was viewed as important to help children with ASD, yet they found difficulties to make it due to the time-consuming. However, there is another study showed different perspective regarding the collaboration. Lindsay et al. (2013) found that teachers encountered difficulties in creating an inclusive environment due to the lack of awareness and understanding the disorder of ASD among other teachers or parents with ASD. They further illustrated that other teachers found hard to understand the behavior of the ASD child and may be nervous or have misperceptions about the children with ASD. Teachers also found hard to engage in open communication system due to some parents of ASD chose not to disclose or identify their child's condition.

### Parents' coping mechanism

The coping mechanisms that being used by parents on the Kenyan coast comprise problem-focused mechanisms that involve management and respite care while the emotion-focused mechanisms include the beliefs in supernatural powers, prayers and spiritual healing (Gona et al., 2016). Dardas (2014) also reported that the coping strategy that most commonly used by Jordanian parents of children with ASD was positive reappraisal. The use of positive reappraisal may be explained by the Jordanian culture where the need to believe in God's will and pray to bring calm. Besides of the spiritual methods like reading scriptures, Gour and Pandey (2016) also found that acceptance of diagnosis and general optimism were found to be most effective coping mechanisms in the India families. However, the degree of optimism also depend on the severity of the ASD, the optimism was inherent in the parents' characteristics.

Another study found that problem-focused strategies such as invest in the child and emotional-focused strategies such as reflected positive thinking can help to decrease in maternal stress level. They further reported that the three coping strategies were not helpful in dealing challenges as follows: eating, get angry and explain the family situation to others (Kiami & Goodgold, 2017). In the study of Padden and James (2017), they reported that parents of ASD were used a number of adaptive coping strategies (e.g., emotional support) compared to parents of typically developing children.  In consistent with previous studies, both parents of ASD emphasized the importance of accessing support. However, mothers always reported they need friends, family and professional agencies for emotional and practical support (Pepperell et al., 2016). Luque Salas et al. (2017) also found that mothers use more emotional-focused strategies such as social support and expressing emotion while fathers use more problem-focused strategies due to the level of satisfaction.

In Malaysia, one of coping strategies that being used by participants is to find the meaning and a sense of purpose through the role of mother to a child with ASD. Other coping strategies include developing proactive mindset, progressed toward acceptance and readjusting their expectations about their ASD child's life achievement. Besides that, they also reported that they received many supports from religious institutions or ASD parent support network (Illias et al., 2018). Despite of the types of coping mechanism, the main purpose of using coping mechanisms is to reduce the stress level of affected people. ASD is a lifelong disability that can affect different aspect of the caregivers. Understand the challenges and difficulties that being experienced can help to provide direction for developing coping strategies to reduce the stress level of caregivers and improve the quality life of the caregivers.

### Treatment and Interventions

According to CDC (2018), there are many types of treatment available for autism such as behavior and communication approaches, dietary approaches, medication and complementary and alternative medicine. For behavior and communication approaches, Applied Behavior Analysis (ABA) is a notable treatment approach for people with ASD. ABA used to improve positive behaviors and reduce negative behaviors. There are different types of ABA such as Discrete Trial Training (DTT), Early Intensive Behavioral Intervention (EIBI), Pivotal Response Training (PRT) and Verbal Behavior Intervention (VBI). Besides ABA, other therapies include occupational therapy, sensory integration therapy, speech therapy also can be part of treatment program for a child with ASD.

Similarly, there are many types of intervention that used in Malaysia. According to Ministry of Health (2014), non-pharmacological treatments in ASD include Applied Behavior Analysis (ABA) that used in managing the behavior and learning skill of children with ASD, speech, language and communication intervention that used to help children in ASD to improve their language skill, social story that used to help children in ASD to improve the social skills and appropriate social behaviors for effective and appropriate interaction, occupational therapy that helps children with ASD to maximize activities of daily living. For dietary approaches, there is a call for changes in diet. The changes include remove certain types of foods from a child's diet or using some vitamin and mineral supplements. The concept of dietary approaches is based on the idea that food allergies or lack of vitamin that cause symptoms of ASD. However, this approach does not have the scientific support (CDC, 2018).

Next, there are no medications can be used to treat ASD or even treat the main symptoms. However, there are medications that can help to manage the high energy levels, unable to focus, seizures or depressions (CDC, 2018). In Malaysia, there is a pharmacological therapy refers to the use of medication in the treatment of co-morbid disorders in ASD. The medications included atypical antipsychotics (AAP) that used to reduce the propensity to cause extrapyramidal symptoms, antidepressants like Selective Serotonin Reuptake Inhibitors (SSRIs) and others like Melatonin that used for insomnia in children (Ministry of Health, 2014). Lastly, there are some treatments that are not typically recommended by pediatrician but still using by parents in order to reduce the symptoms of ASD. These treatments are known as complementary and alternative treatments (CAM) which include the special diets, chelation (treatment that used to remove heavy metals like lead from body), body-based systems like deep pressure and biologicals (CDC, 2018).

In summary, there is no one best and standard treatment for ASD because the symptoms of disorder are so different. However, there are many treatments that can to minimize the symptoms and maximize the abilities of children with ASD. According to Ministry of Health (2014), parental involvement and participation in therapy are the most important element of the interaction to ensure the continuity of intervention and provide the best support to the children. In addition, parents are most effective at advocating their child because they are emotionally attached with their child and appeared constantly in the child's life.

## Research Methodology

### Sampling

The qualitative and narrative designs were used to explore the perceptions of the parents towards problem of early detection, life challenges and life coping mechanism in their life with ASD child. The study focused on the purposive sampling because it is a non-probability sampling that can choose the sample who is able to commit the time and provide the related information to achieve the goals of the study based on the judgment of researcher. (Gona et al., 2016; Kumar, 2011). The criteria of selecting a sample also important to ensure the participant meet the requirement of the study. The important criteria of the study are: (1) parent must has at least one child with ASD; and (2) the age of diagnose for ASD children must be between the age of three to five; and (3) parent who are aged between 30-45 years old; and (4) stay in Malaysia. Five parents were selected to participate in the study and the location in Klang valley such as Kepong (Jinjang), Kepong, Kota Damansara, Bandar Sri Damansara and Gombak. The recruitment was made by a special education coordinator who provides home-based intervention for ASD child.

The interviews were used an in-depth and semi-structured format to explore the perceptions of parents on raising and caring their ASD child. Prior to the interviews, participants will be initially approached by phone or mail in order to get their permission to participate the study. Then, the informed consent was obtained from each participant. Demographic information was also collected including the age of diagnose for ASD child, age of parent and the ASD child, occupations, living places , parent's gender, ethnicity and marital status. During the interview, the audio-recorder will be used to record the process of interview with the permission of participant. The interviews were recorded and transcribed into verbatim. The data analysis were started with researcher to read through each transcription several times and noting the key emergence themes. Codes with similar meanings will be developed and structured. Quotes that are reflective of each theme were selected to illustrate the results.

## Results and Findings

There are about 20 themes were generated through coding for (1) perception of parents on the problems in identifying the early detection of their ASD child, and (2) the personal coping mechanism that are used by parents living with ASD child.

Findings showed that Malaysian parents' perception on the factors of diagnostic delay included parental negligence, parents' lack of knowledge and awareness, ASD complex problem, societal judgment, parental problems in familial-relation, ASD child's symptoms and less family interaction. The findings also reported that challenges of parents in living with ASD child included child's cognitive ability, child's social ability, child's emotional expression, child's sensibility, child's self-concept, parenting skill and knowledge and parents' feeling and sensibility. Last, the findings showed that Malaysian parents tend to use the personal coping mechanisms like practice positive mindset, self-encouragement, gaining the family support and social support, sought for treatment and services as well as the school placement for their ASD child. Past research supported the findings of current research where diagnostic delay of ASD caused by many factors such as parental negligence and societal judgment result in the child to miss the opportunity to have early detection and effective intervention. As a result, parents tend to have challenges in living with their ASD child. For example, past research found that parents felt extremely burdened by their child's incapacity to get into routines of everyday life (Van Tongerloo et al., 2014). Another past research also found that parents of ASD children reported that they have higher levels of depression, anxiety and mental health issues (Weiss et al., 2014). Therefore, it is important for parents to use personal coping mechanism to deal with the challenges and emotional difficulties when living with ASD child. According to Salas et al. (2017), functional coping mechanisms have a greater relationship with parents' life satisfaction. Table 1 below showed the generated themes from the research question one.

**Table 1: Themes Generated from Research Question 1**

| Open Coding | Axial Coding | Themes |
|---|---|---|
| • Disbelief<br>• Family past experiences<br>• Relatives have same experience<br>• Late in speech is normal<br>• People around do not have this kind of problem<br>• New parent<br>• No knowledge and experience<br>• Hard to identify the issues due to complex problems<br>• No idea about ASD<br>• Old people said child will speak when they grow up<br>• Doctor's sharing: normal to speak late<br>• less interaction<br>• less family interaction<br>• less attention for the child<br>• No response when playing or calling | • Disbelief tendency (1) (2)<br>• Family past experiences (2)<br>• Living apart for problem detection (1)<br>• Genetic belief (2)<br>• Lack of knowledge and awareness (2)<br>• New parent (1)<br>• Complex problem of ASD (3)<br>• Doctor's normal diagnose (3) (4)<br>• Societal common mind-set (4)<br>• less interaction (5)<br>• -less bonding (5)<br>• -lack of communication skill (5) (6)<br>• -less attention (5)<br>• -No interaction with old people (6)<br>• -Less interaction with others (6)<br>• stereotype behaviors (7) | 1. Parental negligence<br>2. Parents' lack of knowledge and awareness<br>3. ASD complex problem<br>4. Societal judgment<br>5. Parental problems in familial-relation<br>6. Less family interaction<br>7. ASD child's symptoms |

| | |
|---|---|
| • less father bonding<br>• isolated<br>• hard to communicate<br>• arrange the things on her own<br>• Always play alone<br>• Use repetitive words, less verbal<br>• No responsive and lack of awareness to environment and people around<br>• Hand flapping, parrot talk | • -lack of social skills (7)<br>• -lack of eye contact (7)<br>• -able to request with body gesture (7)<br>• -play alone (7)<br>• Able to utter few words without meaning (7)<br>• Lack of expression and talk (7 |

Source: Findings of Research Question One with coding

For first research question, the study aims to explore the perceptions of parent on the problems in identifying early detection of the ASD child. There were seven themes were identified for this research question.

### (a) Parental negligence

Two out of five respondents reported that they did not believe their children have problem because they never meet this kind of children in their lives.

> *We have no experience and people around us do not have this kind of child. So who can we ask? I also don't know. (Parent 1)*

> *Yes. Because he is still young and we think is normal if he is late. (Parent 5)*

> *Parent 1: Ya…don't have knowledge. How can I have the knowledge about this kind of child? I just have 2 children who just 1 year difference. Who knows my children will have this kind of problem?*

> *Parent 4: I don't really know because she is my first child and I don't think any problem will happen on her. If I have experience, I would not drag until now.*

### (b) Parents' lack of knowledge and awareness

Nearly all respondents felt that they have little knowledge about ASD and lack of awareness in their community. They said they knew little or nothing about ASD before their children's diagnosis. One respondent stated that she thought it is a kind of family genetic instead of ASD:

> *Because they keep telling me about their family history and genetic problem. Many of their family members also have same kind of problem. (Parent 1)*

> *Lack of awareness among the people around me and myself. (Parent 2)*

> *We don't know what actually happen to him. (Parent 5)*

### (c) ASD complex problem

The complexity of ASD symptoms may confuse parents and make them to have late diagnosed for their children. Some respondent reported that they find hard to identify the problem because it is a complex disorder.

> *It was very hard for me to fully identify the issue at the beginning because the problems are complex. (Parent 2)*

### (d) Societal judgment

All respondent felt that the judgments from people or specialists are also one of the major causes of diagnostic delay. They stated that many people commented it is normal to speak late for young child because they can develop their language skill when they grew up.

> *Because there are many old people said she cannot talk at this age but sooner or later she can speak automatically (Parent 3)*
> *Parent 4: Because many people said she might not have problem, it is just late. Because you know many old people like to say who and who also late but end up can speak like normal.*
>
> *It is normal if 2 or 3 years old children who cannot speak because he meet those children who can only speak at 5 or even 7 years old. So children can speak when they grew up. (Parent 1)*
> *Yes, but he only said my child's problem due to over screening time. There is no any big issue if we cut down the screening time. He said since my child can speak then there is no big issue. (Parent 5)*
>
> *Nope, I am the one who ask school teacher whether they notice something and they told me she looks ok and seem like no problem and maybe she is late. They even told me majority kids are late as well. (Parent 4)*
>
> *Actually the VE teacher told me that it is not necessary for diagnose and the most important is therapy. Even you go for diagnose, end up you still need to go for therapy. (Parent 3)*

### (e) Parental problems in familial-relation

Some respondents reported that they are lacking of communication and attention to the children. They found that they have less bonding with their children because they are not the main caregiver when their children were born. This may cause them to discover the children's problems late and have diagnostic delay as well. Many respondents commented as below:

> *I have but not much (interaction) because her papa always outstation and I stayed together with my mom (Parent 1)*
> *The biggest issue was our great distance because my child was took care by my mother in law since born and we hardly meet each other. Due to this reason, chances of early detection were very less (Parent 2)*

> *Because she was taken care by my mother, so I don't really know what she did and notice anything (Parent 4)*
>
> *My mother in law helped me to take care of him because I need to work. I only bring him back after work time (Parent 5)*

**(f) ASD child's symptoms**

Two out of five respondents felt that their children can speak with one or two words at the early age so they think their children only have speech delay.

> *Actually I can't remember much but I know she can talk in few words like papa or mama when she was 2 years old. Unlike other special kids who cannot talk even 3 years old. So I thought maybe she was late and many people also said that my daughter is late in her speech (Parent 4)*
>
> *I think he can understand us although he seldom to talk. I think he imitates some characters in cartoon which did not talk at all. He learned their silent mode as well. When I asked him to take something, he can understand. But comes to verbal skill, I am not sure whether he follows the cartoon or he really cannot speak. (Parent 5)*
>
> *I had no idea about what are the symptoms and characteristics may appear in an ASD child however majority of children with ASD shows developmental concern before 3 years old. (Parent 2)*

**(g) Less family interaction**

Some respondents felt that the lack of family interaction can also be one of the factors of diagnostic delay. They found hard to notice and aware of the child's problems as if the child has less interaction with other family members. The ignorance would take place when there is no interaction at all.

> *I think she has no interaction with other family members and always play alone. She has no response when people calling her. (Parent 4)*
>
> *Very less. Because he prefers to play phone or watch TV. He can just focus on TV and ignore people around him. He never initiates talk or play with them. (Parent 5)*

Furthermore, for third research question, the study aims to investigate the personal coping mechanisms that are used by parents living with ASD child. There were six themes were identified for this research question.

**(a) Positive mindset**

Two out of five respondents reported that they like to practice positive mindset as their personal coping mechanisms in handling the challenges. One of the respondents reported that she would stop herself from thinking too much:

> *I don't want to think others although I know there are many things are not finished yet. (Parent 1)*
>
> *Like fostering connection, coaching and not controlling. Quite often this method I use to deal with my son's behavior. Coaching, encouragement and rewards to*

> *shape his behaviors. Think positively before taken action always ends a good result to me. (Parent 2)*

### (b) Self-encouragement

Three out of five parents chose to play games on phone as their coping mechanisms because they felt relieved when playing the phone. They tend to play phone to avoid the stress temporarily.

> *I just played FB when all the children were slept. I don't want to do anything and just played my phone or FB (Parent 1)*

> *Talk to friends or play phone (Parent 3)*

> *Sometimes I will enjoy playing phone when I am alone. I can forget everything when I played the phone (Parent 5)*

Four out of five parents prefer to choose sharing or travelling as their coping mechanisms when dealing with stressful events. They like to talk to their family members, friends or travelling everywhere to release their stress.

> *I like to read books, articles, online, parents- sharing or community sharing. I will go for vacation as well no matter with or without family members. Travel has made me a better person, be more initiative to gain my experience well in my life (Parent 2)*

> *I like travel and also like to talk with people. Talking can also help me to release my stress. I like to talk to my mother and my husband (Parent 4)*

### (c) Family support

Majority of respondents reported that they receive support from family members like husband, parents and parents in law. Most of them receive the financial and emotional support from husband. The parents would also help to take care of the children when they are not around.

> *Among my family members, my parents and my husband are the people who always make effort for to spend time with me. They helped and supported me in different ways. Like my husband has always become my financial supporter since I gave up my career many years ago. Of course, his is also my perfect listener and sometimes a good advisor too (Parent 2)*

> *My husband and his parents. My parents as well. Because my mother always take care of her and she found she has a bit different. So she keeps encouraging me to bring her to see doctor (Parent 4)*

> *My husband and parents in law also helped me a lot as in financial and support me all the time (Parent 3)*

However, there is a respondent felt that she received little support from family members especially her husband.

> *He ah…only helped a little bit lo…Maybe financial support…sometimes he invited me to go for trip but end up doing nothing.(Parent 1)*

### (d) Social support

There is only one respondent receive the support from government like enjoying the benefit of OKU card.

> *OKU card…OKU card helped me to settle some medical fee and also provide the incentive RM150 every month in government school. (Parent 1)*

Another two respondents reported that they only receive the support from community group.

> *I always grateful because the communities are so supportive and willing to share ideas broadly. Their contributions have made me a better parent and understand the value of life. From time to time, I learn from parents who share their valuable experiences with me and I always love to meet new special parents on social media, special event or workshop (Parent 2)*

> *I just joined family support group in facebook. And I don't think I get anything from government temporarily (Parent 3)*

Another two respondents reported that they did not receive any social support from government or community group.

> *Nope… I think I have no idea where to get all these supports. (Parent 5)*

### (e) Treatment ad services

All the respondents reported that they seek for therapy services like occupational therapy or home-based intervention programs can help them in dealing some of their children's behavioral and emotional issues. Indirectly, it also can help them to reduce their stress level. One of the respondents described the process of getting diagnose and therapy in details as below:

> *So in my early detection, my son was only 3 years old, I took him for a diagnostic assessment at Nasom Kiwanis Center. 2 therapists and a psychologist did a screening, evaluation, consultation and of course they provide me information and referrals for further information. Before I take any actions, I raise my concern with my friend who has a special child and she has recommended me to an occupational therapist in Seremban. I see improvement which my son's eye contact has improved, together with speech and fine motor as well. After a year, the kindy principal recommended me another occupational therapist cum brain gym instructor to me for further treatment. At the mean time, my son took art lesson in Da Vincci for 7 months. I know he loves art and art therapy is one effective way for stimulation and benefit ASD child. Another way, he will use PECS to communicate during young age. (Parent 2)*

### (f) School Placement

Majority of respondents felt that it is very important to send their children to a suitable school together with some experienced teachers can also help them to cope with stress in their lives.

*I will advice them to find a proper place for the kid and also look for experienced teachers who can handle this kind of child. (Parent 4)*

**Table 2: Themes Generated from Research Question 2**

| Open Coding | Axial Coding | Themes |
|---|---|---|
| • like to play phone during night time<br>• Talk to family or friends<br>• Reading<br>• Sleeping when I feel stress<br>• Shopping<br>• Traveling with kids<br>• Don't think too much<br>• think positively<br>• Parents in law (take care and cook when parents work)<br>• Parents ( go for trip or take care the child)<br>• husband (financial and emotional support)<br>• OKU card<br>• workshop, meet parents in social media<br>• Send to hospital for therapy<br>• Hire private tutor for the child<br>• Occupational therapy<br>• Send to private center for therapy<br>• Choose the suitable school<br>• Experienced and qualified therapist is important | • Think positively (1)<br>• be optimism (1)<br>• -stop over thinking (1)<br>• Phone Playing (2)<br>• Reading (1) (2)<br>• Sharing (2)<br>• Me-Time (2)<br>• shopping (2)<br>• Sleeping (2)<br>• Travel (2)<br>• Parents in law (3)<br>• Mother (3)<br>• Husband (3)<br>• School Teachers (4)<br>• Therapists (4)<br>• Government (4)<br>• Community group (4)<br>• Parents' support group (social media) (4)<br>• Occupational Therapy (5)<br>• 1 to 1 home- based program (5)<br>• Speech Therapy (5)<br>• Neuroscience program (5)<br>• Find suitable school (6)<br>• Find experienced and qualified teachers (6)<br>• | 1. Positive mindset<br>2. Self-encouragement<br>3. Family support<br>4. Social support<br>5. Treatment and services<br>6. School placement (ASD) |

Source: Findings of Research Question Two with coding

## Discussion

### Research Question One

#### (a) Parental negligence

In current study, parents mentioned that they did not believe their children have problems because they never meet this kind of children in their lives. This finding was consistent with the study of Zuckerman et al. (2014) where Latino parents also felt that they knew little information about ASD because the symptoms of ASD " do not exist" in their community. They reported that some children in Mexico may behave differently but they would not be labeled with any medical condition. Therefore, many ASD children were under diagnosed.

Besides that, the finding of the current research also showed that parents found their children have some abnormal behaviors but they tend to ignore the problems and believed their condition would change better when they grew up. It aligns with past research showing that parents may observe unusual development early in their child's life but they may wait and see if more developmental progress is made with time also can be contribute to diagnostic delay (Brett et al., 2016). Crane et al. (2016) also reported that parents normally waited one year from when they first detect of the signs before sought for professional help.

#### (b) Parents' lack of knowledge and awareness

In current study, the finding showed that parents have little knowledge about ASD and lack of awareness in their community. Some of them also reported that they knew little or nothing about ASD before their children's diagnose. The finding was supported by the study of Ilias et al. (2017) where the limited awareness of ASD in Malaysia society. According to Zuckerman et al. (2014), parents have many difficulties in ASD diagnostic process due to little information about ASD and lack of awareness to receive the care.

#### (c) ASD complex problem

The finding of current research showed that parents were not able to identify the symptoms of ASD due to its complexity. It is consistent with Van Tongerloo et al. (2014) where parents were unable to interpret such abnormal behavior or thought it was not serious enough to consider for further diagnosis. Even the health care provider may be adopting a "wait and see" approach and not referring the child to professionals for further evaluation due to uncertain about the complex symptoms of ASD (Daniels and Mandell, 2014).

#### (d) Societal judgment

The finding of the current research was consistent with the study of Zuckerman et al. (2014) where providers sometimes dismissed the parents' concerns that led many parents normalize their child's early sign and reject that a problem existed. Another study also supported that less proactive health care provider responses were associated with delays in diagnosing ASD (Zuckerman et al., 2015). According to Daniels and Mandell (2014), efforts to enhance health care provider knowledge about ASD based on the parental concerns and screening programs may reduce the chances of diagnostic delay and has the potential to result in earlier age at diagnosis. Therefore, the importance of health care providers' responses should be highlighted.

Besides of the medical team, the finding of current research also found that school teachers were lacked of knowledge about ASD and did not notice the abnormal behaviors of the child. The finding was supported by the study of Illias et al. (2017) where teachers have problems in understanding ASD. According to Edward (2015), he found that teachers had low knowledge about children with ASD due to the lack of in-service training and lack of workshops. Therefore, the judgment of school teachers can also be one of the factors of diagnostic delays in Malaysia.

### (e) Parental problems in familial-relation

In current research, the finding revealed that parents have less attention and communication with their ASD children because some of them might put attention on other children in the family. In this situation, it caused the parents to overlook their ASD child's early signs. The finding was supported by Bickel et al. (2015) where the limited parental attention for many children in one family would lead to potential delays. Besides that, Gour and Pandey (2016) also reported that the parental relationship also affected at the helm of the normal developing siblings. They reported that a parent who always put too much tension on the siblings might cause the distress among the whole family. According to Kalash and Olson (2012), they reported that parents have difficulty to divide their time among ASD child, other children, family members and friends. They were struggled with finding a balance for their ASD child and others.

### (f) ASD child's symptoms

The current research's finding showed that parents were thought their children only have speech delay because they able to speak with one or two words as well as able to understand the instructions. This situation may lead them to have diagnostic delay for their children. The finding was supported by Brett et al. (2016) where children who displayed language regression normally on average at 3 years 5 months so some children would not be diagnosed with ASD for first 3 years.

### (g) Less family interaction

The finding of current research showed that lack of family interaction can also be one of the factors of diagnostic delay. Parents found hard to know about the child's problem as if the child has no interaction with others and always engage in solitary play. Some of the family members would not understand the child's situation due the lack of family interaction as well. For example, grandparents would regard the child's behavior as a response to bad parenting due to the lack of understanding and interaction with the child (Ludlow et al. 2012). Divan et al. (2012) also highlighted the difference it makes to a special need child when there was enough attention from other family members in the house as if the parents may need to work.

## Research Question Two

### (a) Positive mindset

According to a study of Gour and Pandey (2016), acceptance of diagnosis and general optimism were found to be the most effective coping mechanisms for parents. They also reported that parents who had general optimistic viewpoint tend to cope easily and better for the relationship between family members. This was supported by the finding of this current research where parents found practice positive mindset is always ends a good result. In addition, the finding of current research also reported that parents like to stay creative and focus more on encouragement as their personal coping mechanisms. It is consistent with the study of Dardas (2014) where positive reappraisal was the most commonly coping mechanism among the parents.

### (b) Self-encouragement

In current research, the finding showed that parents tend to use self-encouragement like reading, travelling or sharing as their personal coping mechanisms. According to Depape and Lindsay (2015), some parents decided to learn all they could by reading, advocate for their child and challenged the information they gained from others if they thought their child's benefit were compromised. According to Salas et al. (2017), functional coping mechanisms have a greater relationship with parents' life satisfaction. Besides that, Kiami and Goodgold (2017) also supported that increase in helpful coping mechanisms were associated to reduce the maternal stress level. They reported that adaptive coping mechanism -problem focused like investing the child and believe the child will get better can help to reduce the stress level while maladaptive coping mechanisms like eating, throwing tantrum or explaining the family situation to others are not helpful at all.

In current research, the finding also reported that many parents chose to play phone as their coping mechanism. They felt that playing phone can helped them to avoid from thinking too much and escaped from the stress. According to Dardas (2014), the statements like "don't think too much" or "tried to forget everything" are the examples of distancing responses. Therefore, some parents of current study used the distancing coping to cope with their challenges. However, Holahan, Moos and Bonin (2004) reported that distancing coping mechanism is a kind of escape avoidance that might help in the short term but developed more negative impacts on the mental health of parents when used on the long run when raising a child with lifelong disability (as cited in Dardas, 2014).

### (c) Family support

In current study, most of the parents receive greater support from family members especially their partner in the aspect of financial and emotional support. It is consistent with the finding of Illias et al. (2017) where fathers provided financial support and extended family members provided emotional and physical support like taking care of the child or helping with cooking. In short, parents who were coping better when they had support from extended families or relatives (Gour & Pandey, 2016; Ludlow et al., 2012).

### (d) Social support

The finding of current research showed that some parent receives support from therapist and school teachers as well. According to Divan et al. (2012), some parents had positive experiences of mentorship from professionals like special educators were the primary advocates for most of the families in giving educational inputs and emotional help. In consensus with the finding of Divan et al. (2012), Pepperell et al. (2016) reported that mothers reported greater use of family, friends and professional therapists for practical and emotional support.

In addition, Ludlow et al. (2012) also reported that contact with other parents of ASD can be another important source of social support. They described that parents could compare with the experiences of other parents and learn from their success. The contact also allowed them to have the chance to compare their child with other child and it might make downward comparison that make them feel more better It was consistent with current research's finding where some of the parents were benefited from joining the parent support groups or meet new parents of ASD in different kind of workshops. They are not even share the knowledge and skills among the parents, but also provide support to each other.

### (d) Treatment and services

The finding of current research showed that parents sought therapy services for their ASD children in order to help them to overcome some behavioral and emotional difficulties of the children. The therapy not only helps the children but also helps to reduce the stress of the parents. According to Bonis (2016), earlier diagnosis and access to services could lead to improve outcomes for the child, decrease in monetary costs and enhance stress management for parents. In the consensus with Bonis (2016), Koegel et al. (2014) also highlighted the early intervention could increase the possibilities of improved long term outcomes.

### (e) School Placement (ASD)

The finding of current research showed that parents sent their children to school also helped them in reducing stress and their children can get better assistance as well. This is consistent with the study of Divan et al. (2012) where school became a vital support for parents because of the benefits of respite provided by the school setting.

## Research Implications

The findings of the study have several important implications. First, the current research findings might help to develop different modules for training both parents and teachers more on ASD. For example, the finding can help to develop the module for enhancing the interaction skills with ASD children. This can help both parents and teachers to learn how to communicate and interact effectively with the children with ASD. Second, the current research finding might also help to raise the awareness in different setting such as at home, school and community in contributing in making optimal treatment choices for ASD children as well as providing community services by non-government organization for parents, educators and others.

Third, the current research finding might also help the development of knowledge in coping mechanisms for parents, practitioners, educators and other. For example, parents might develop more appropriate strategies by seeking more knowledge. Lastly, the finding might also help to develop the appropriate treatment plan or intervention plan for parents and children with ASD. For example, parents might develop some intervention programs that tailored to their children’s need.

## Conclusion

Some implications of the study were discussed. First, the current research finding might help develop modules for training both parents and teachers. Next, the development of treatment plan for parents and child with ASD by using current research’s findings. The limitations and recommendations of the study were discussed as well. First, the findings of current research cannot be generalized due to small sample size and the location only focused in Klang valley so the finding cannot conclusively describe the life experiences of child with ASD in other geographical locations. Second, the participants were only limited to Chinese mothers so it cannot represent the parents with other races. Therefore, the future research is suggested to use the participants from whole country with different ethnic groups and focus the sample of fathers, siblings, extended family members or educators. In conclusion, all children deserve early and accurate diagnosis as well as appropriate treatment services. Therefore, the government should take action to make more care about the well beings of ASD children and those parents who living with them.

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