



Faculty of Cognitive Sciences and Human Development

**COUNSELING INTERVENTION FOR NATIVE MOTHERS OF
AUTISM SPECTRUM DISORDER (ASD) CHILDREN**

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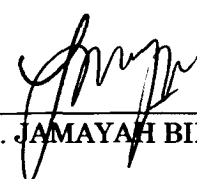


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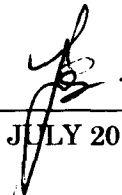
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**COUNSELING INTERVENTION FOR NATIVE MOTHERS OF AUTISM
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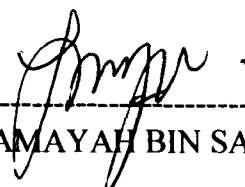
CHAN WEI SIAN

**This project is submitted
in partial fulfillment of the requirements for a
Bachelor of Sciences with Honours
(Counselling)**

**Faculty of Cognitive Sciences and Human Development
UNIVERSITI MALAYSIA SARAWAK
(2018)**

The project entitled 'Counseling Intervention for Native Mothers of Autism Spectrum Disorder (ASD) Children ' was prepared by Chan Wei Sian and submitted to the Faculty of Cognitive Sciences and Human Development in partial fulfillment of the requirements for a Bachelor of Science with Honours (Counselling).

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<p>Gred A -</p>

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ABSTRACT

COUNSELING INTERVENTION FOR NATIVE MOTHERS WITH AUTISM SPECTRUM DISORDER (ASD) CHILDREN

Chan Wei Sian

The purpose of this study was aim to explore about the experiences of native mothers with autistic children in Kuching, Sarawak. This research focused on exploration about the challenged faced by native mothers with autistic children, their coping strategies, and participation in counseling intervention. The research design of this study is qualitative approach and employed face-to-face interview session with participant. Interview session took time for 30 minutes until 45 minutes and semi-structured interview session was used to collect data. Three native mothers with autistic child involved in the interview session while one native mother with autistic child participated in pilot study. Four major themes and nine sub-themes have been identified based on interview result. Four major themes consist of experiences of native mothers, challenges faced by native mothers, coping strategies, and participation in counseling intervention. Nine sub-themes include children's condition, family's acceptance, lack of autism-related resources and support, low awareness of society, self-commitment, assistance from family and agencies, and mother's experiences and expectation. The result of this research is quite interesting because native mothers with autistic child experienced low level of stress in the process of raising up an autistic child and it is contradict with the result of previous research. However, there is some limitations in this research and future work is needed in order to improve this research by involve various population such as Sarawakian and Sabahan, involvement of fathers of autistic children, and mixed-method approach can be applied in further research in order to get more precise information.

Keywords: counseling intervention, native mothers, Autism Spectrum Disorder (ASD) children

CHAPTER ONE

INTRODUCTION

1.0 Introduction

This chapter discussed the background of study, problem statement, research objective, research question, research framework, significance of study, limitation of study, definitions, and the summary of the chapter. These sub-topics could provide brief explanation about the research and discuss about the problem that relate with the research topic.

1.1 Background of Study

Children with Autism Spectrum Disorder (ASD) faced difficulties in social interaction and sensory processing. Autistic children are unable to use verbal and non-verbal communication effectively (American Psychiatric Association, 2013). They failed to match their body language such as facial expression, body movement, and gesture to represent their wants and needs (Autism Spectrum Australia, 2008). Failure of communication leads to frustration and inappropriate behavior among autistic children such as screaming or grabbing. Thus, they are more likely to isolate themselves from social interaction and causes social withdraw since society tends to categorize their unacceptable reaction as behavioral problem (Ventola, Lei, Paisley, Lebowitz, & Silverman, 2017). Impairment of ability to communicate and lack of ability to developing and maintaining a two way conversation leads to functional limitation in effective communication, social participants, social relationship, academic achievement, and occupational performance.

Impairment of brain development leads to sensory of autistic children hyperactive to environment especially sound and touch (Tordjman, Davlantis, Georgieff, Geoffray, Speranza, Anderson, 2015). As the result, they usually overwhelmed with overload information from sensory system. Therefore, they prefer repetitive patterns of behavior instead of behave in new ways to limit the input from environment (Marco, Hinkley, Hill, & Nagarajan, 2011). For example, repeat turn on and off the light, observe the movement of fan, jumping and so on. They feel peace and calm through repetitive behavior. Children with autism required excessive care and patient of parents compared with typically developing children in their development stage.

Statistics showed that it is estimated that one out of every 600 children in Malaysia is born with autism (Lee, 2016). Mothers faced different challenges and experiences the other way in raising up child with autism compared with typically developing children. Special support system need by mothers of autistic child is higher than mothers of typical developing children. Therefore, this research focused on exploration about the challenges faced by mothers of autistic children, their coping strategies, and to suggest appropriate counseling intervention for counselors in helping mothers of autistic children to cope with those challenges.

1.2 Problem Statement

Cases of autism is increasing and numerous research has been conducted to study about autism in many countries including Malaysia. However, most of the previous research employed quantitative approach by using questionnaires and instruments in the research (Davis, & Carter, 2008; Maljaars, Boonen, Lambrechts, Leeuwen, & Noens, 2014; Ventola et.al., 2017). In Malaysia, researchers used quantitative approach to conduct autism research too (Asyikin, Paulraj, Vetrayam, 2016; Lee, Ong, Lee, & Fairuz, 2017). However, qualitative approach has been employed in this research because researcher would like to hear the mother's voice regarding their experiences in raising up an autistic child (Clauser, 2015). Secondly, research related with autism in Malaysia only focused on participants in East Malaysia. For example, Ilias, Liaw, Cornish, Park, & Golden (2017) studies about parenting stress among parents of ASD child at Tangkak Hospital, NASOM in Muar and Segamat. In addition, Illias et al studies about the wellbeing of mothers of children with autism at Klang Valley, urban or suburban region including Kuala Lumpur and surrounding area. Thus, participants of this research focused on native mothers who have autistic children in Kuching, Sarawak. Besides, a lot of interventions provided to autism children instead of mothers (Sze & Wood, 2007). Therefore, counseling intervention is suggested in this research to help mothers in raising up an autistic child.

1.3 Research Objective

This research conducted based on the following objectives:

- 1) To explore the challenges faced by native mothers in dealing with Autism Spectrum Disorder children.
- 2) To explore their coping strategies in raising up Autism Spectrum Disorder children.
- 3) To suggest appropriate counseling interventions to assists mothers in raising up Autism Spectrum Disorder children.

1.4 Research Question

Research question play an important role as a guideline in this research. This research explored about following research questions:

- 1) What are the challenges faced by mothers in dealing with Autism Spectrum Disorder children?
- 2) What are the coping strategies applied by mothers in coping with those challenges?
- 3) What are the appropriate counseling interventions for mothers in raising up Autism Spectrum Disorder children?

1.5 Research Framework

Figure 1 showed the research framework that work as guidelines in conducting this research. This research focused on the experiences of native mothers in raising up an autistic child. Besides, issues discussed in this research are challenges faced by native mothers of autistic child, their coping strategies, and suggest appropriate interventions for counselors to help native mothers in raising up an autistic child. In data collection, semi-structured interview sessions were employed since this is qualitative approach research. Furthermore, this research conducted at Kuching area, Sarawak. Purposive sampling was employed in this research because there are certain criteria that must be fulfill in select participants who are native mothers who have autistic child. Three mothers involved in interview sessions and one mother participated in pilot study. In data analysis, researcher used thematic analysis as the tool to identifying, analyzing, and reporting collected information.

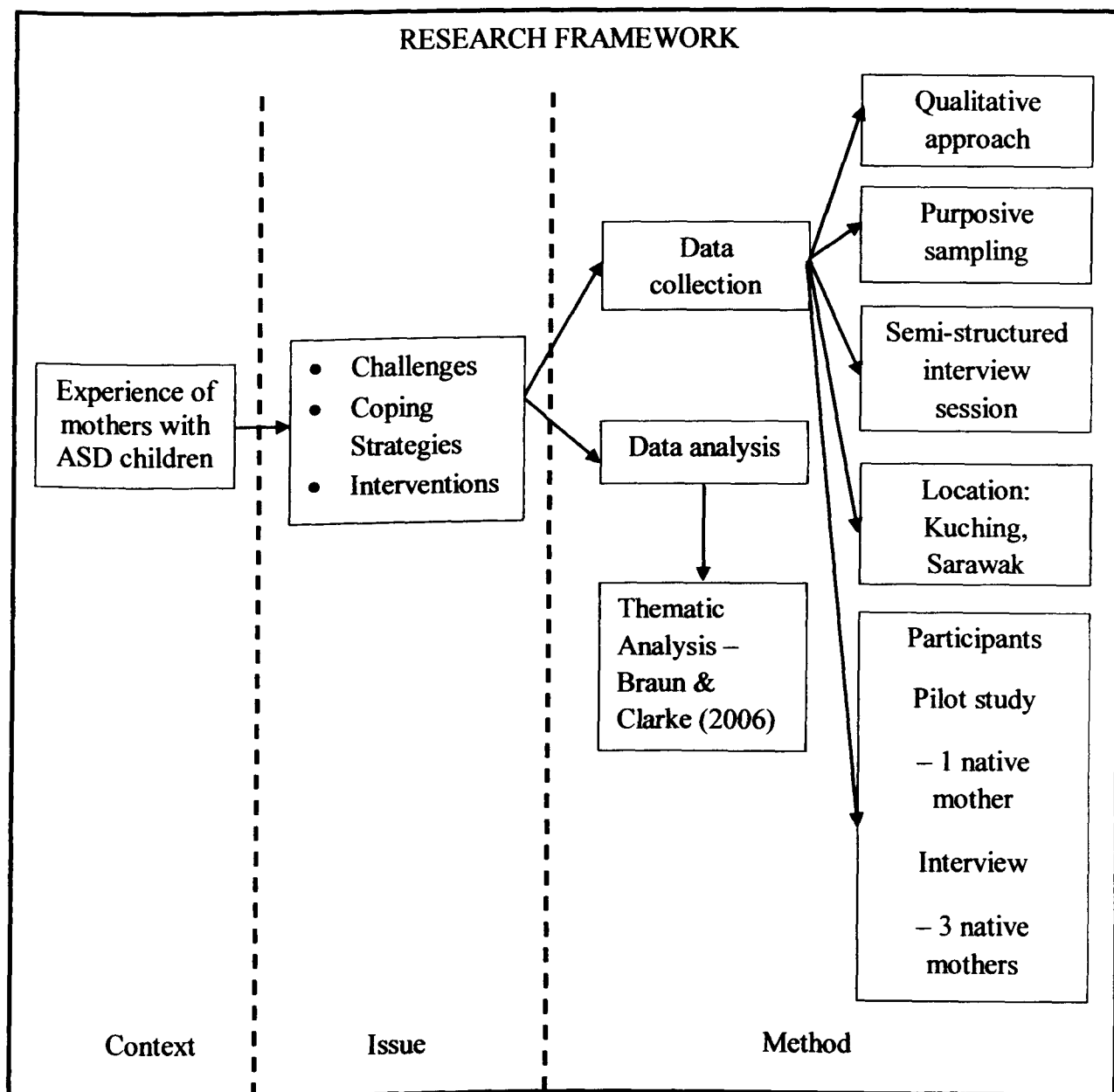


Figure 1.5.1. Research Framework

1.6 Significance of Study

The results of this research are significant to following authorities:

- 1) Researcher. The outcome of this research can be fundamental or references for other researchers in further research.
- 2) Counselor. Collected information can provide deeper understanding about experiences, challenges, and coping strategies of native mothers in raising up an

autism child. Thus, counselors are able to design and develop suitable intervention for mothers in dealing with those challenges.

- 3) Mothers. Mothers of autism child have the opportunity to explore and learn new coping strategies or modify existing strategies in dealing with autism child.
- 4) Society. Increasing awareness among society toward wellbeing of mothers who have autism child. Therefore, it can avoid bias or judgmental of society toward autism children and their family members.

1.7 Limitation of Study

There are some limitations faced by researcher in conducting this research. Firstly, limited participant involved in this research. This is because participant of this research is assigned by Kuching Autistic Association (KAA) since this is a qualitative-based research that involves sharing of real life experiences of native mothers with autistic children. They had carried out screening and asked for permission of participants in joining this research. At the beginning, five native mothers were selected as the participants of this research, but two native mothers with autistic child have withdrawn from this research. Therefore, researcher proceeded the interview session with three native mothers with autistic children. Besides that, variety of participants is limited because participants of this research focus on native mothers meaning who are *Sarawakian* and involve mothers of autistic children only. Based on the interview sessions, the perception of father toward the journey of raising up an autistic child is different with mother. However, this research only focused on the experiences of mothers in the process of raising up an autistic child. Therefore, research about experiences of father in raising up an autistic child could be done by other researcher in further study. Although participants had shared about their experiences, researcher did not explore about the stress level of native mothers. Therefore, mixed-method can be applied in future research to obtain information regarding the experiences of native mothers in the process of raising up an autistic child precisely.

1.8 Definitions of Terms

1.8.1 Native

According to Cambridge Dictionary, native means “relating to or describing someone’s country or place of birth or someone who was born in a particular country or place.” Native refers to describes the location of birth of an individual or the place they growth up. For example, a person is categorizing as native Borneo citizen if the person is born and grow up in Kuching, Sarawak. They can be the *Iban*, *Bidayuh*, *Kayan*, *Kenyah*, *Orang Ulu*, and so on.

1.8.2 Mother

Cambridge Dictionary stated that mother means female parents. Besides, a married or unmarried female individual considered as mother when she given birth to baby.

1.8.3 Autism Spectrum Disorder (ASD)

According to DSM-V, an individual is diagnosed as Autism Spectrum Disorder (ASD) when the person meets certain criteria. For instance, they might have persistent deficit in social communication and social interaction; they prefer repetitive behavior patterns, interest, or activities; symptoms of ASD must be present in early childhood which is approximately age 8 or younger; and impairment of daily functioning among people suffer from ASD (American Psychiatric Association, 2013). Individual with autism has difficulties to understand their needs and others’ needs. Thus, they might be unable to carry out daily activities by themselves and required excessive care from others such as family members or therapist in order to function effectively in their daily life.

1.9 Summary

As a conclusion, this chapter discussed the background of study related to Autism Spectrum Disorder (ASD). Besides that, some previous research stated in problem statement worked as a part of the references for this research. Research framework (Figure 1.5.1) describes briefly about the main context, issues, and methodology and it works as guideline to achieve research objectives and answer all research questions at the end of research. In addition, result of this research is significant to counseling field in Malaysia especially for counselors and other helping profession. However, there are some limitations interfered the process of data collection.

CHAPTER TWO
LITERATURE REVIEW

2.0 Introduction

This chapter discussed the literature review that consists of the trend of Autism Spectrum Disorder (ASD), differences between autistic children and typically developing children, challenges of parents of autistic children, and the implication of counseling in order to help parents to deal with autistic child.

2.1 Trend of Autism Spectrum Disorder (ASD)

Autism society of America described autism spectrum disorder as “a complex development disability that signs typically appears during early childhood and affects a person’s ability to communicate, and interact with others.” (Joanna, 2015, p 6). Autism spectrum disorder is increasing and become more common in today’s society. There is approximately 14.7 per 1, 000 or one in 68 children suffer from autism spectrum disorder in year 2010 (Baio, 2014). Wee (2017) stated that autism cases occur with 10,000 children as standard at several countries and found that ten countries have highest rates of autism.

Table 2.1.1
Rates of Autism Case Per 10,000 Children In Ten Countries

Rating	Country	Rates of autism case per 10,000 children
1	Japan	161
2	United Kingdom	94
3	Sweden	72
4	Denmark	68
5	United States of America	66
6	Canada	65
7	Australia	45
8	Brazil	27
9	Hong Kong	17
10	Portugal	9.2

Note. From “Countries With The Highest Rates Autism”, by Wee, R.Y, 2017. Retrieved from:
www.worldatlas.com/articles/countries-with-the-highest-rates-of-autism.html

2.2 Trend of Autism Spectrum Disorder (ASD) in Malaysia

Statistic of Ministry of Health on children showed that 1.6 in 1,000 children or one out of 625 children in Malaysia suffer from autism (Lim, 2015). According to Department of Statistic, assumed that 853 autism children were born since 511, 865 births occur in years 2014 (Chiam, 2016).

According to Lai (2014), autism occurs in one out of 500 children and boys were four times more likely to be affected by autism in Malaysia. Lai interviewed with Dr Yao, president of Kuching Autism Association (KAA) and found 19 out of 100 children might suffer from autism especially children who are less than age of 14 years with multiple disabilities. However, low awareness and social support are provided to autistic children and their family. Dabrowska (2010) supported that social support should be given to caregivers of autistic children because they usually bond with overload duties that lead to negative psychology development such as stress. Therefore, this research aimed to explore the experiences of mothers in raising up an autistic child and suggest appropriate counseling intervention for them in dealing with autistic child.

2.3 Differences between ASD children and typically development children

2.3.1 Mental

At the early childhood stage, children experienced rapid brain development in terms of thinking, language, and spatial relation. Piaget's theory stated that there are four stages of cognitive development of children during early childhood which are sensorimotor, pre-operational, concrete operational, and formal operational stage. Firstly, children acquired information and interact with their environment with sensory at the sensorimotor stage. They used particular behavior to represent their needs and wants since they are unable to speak. For example, crying is the way baby communicate with their parents when they is hungry. Next, children are able to think symbolically and make something, word, or object stand for something other than itself during the pre-operational stage. For example, they use broom to represent a guitar when they are playing. Then, they experienced a turning point and started to develop operational thought at the age range from seven until eleven years old. They are able to work things out internally in their mind rather than physically try the things out in the real world. Besides, they started to understanding something stay in the same quantity even though its appearance is changed. For example, 400ml of a water bottle remain same quantity

even though it pours into a bowl. Last but not least, they began to develop ability to think and understand abstract object, concept, and test hypothesis logically during formal operational stage (Enose, 2010).

Mostly typically developing children undergo the Piaget's Development Theory. However, ASD children unable to perform cognitive task same as typically developing children. Vikram, Nameera, and Jacob (2016) found that typically developing children performed better compared with children with autism in reasoning about the social world but the reasoning ability of autistic child influence by some aspects such as level of understanding, motivation, history in testing situation, and the relationship with the questioner. However, cognitive ability of autistic children could not be examined by using an intelligence test because impairment of brain in children with autism did not affect their cognitive ability, but it impacts their ability in social interaction and behavioral. Therefore, autistic child usually categorized as intellectual disability group due to their social, communication, and behavioral problems (Marina, 2015). On the other hand, the cognitive ability of children may influence by other factors instead of autism spectrum disorder such as brain size, growth, connectivity and so on (Bernard, 2016).

2.3.2 Psychological

Glasser (1998) believed that all human's behavior is purposeful. An individual would strive to achieve their wants and basic needs such as survival, power, fun, freedom, and love and belonging are unfulfilled. Based on the example of sensorimotor stage in Piaget's Theory, crying is the symbolic behavior used by baby when their survival needs (hungry) is unfulfilled. However, Glasser (1998) stated that love and belonging is the most important basic needs of human. Lacking of love and care may cause the feelings of frustration and problem in one's daily life. Therefore, typically developing children like to develop an intimacy relationship with their parents by sharing their emotion with parents (Tordjman et al., 2015).

For typically developing children, quality of social interaction depends on active dialogue between their parents and the children (Tordjman et al., 2015). However, autistic children tend to withdraw from social interaction compared with typically developing children because they faced difficulties in maintaining a face-to-face communication (American Psychiatric Association, 2013). Limitation of understanding verbal and non-verbal communication such as eye contact and facial expression cause they are unable to develop a

relationship with others such as family members, friends, teachers, and so on (Autism Spectrum Australia, 2008). Some of the parents are unable to understand the needs of autistic child because they cannot express their needs and wants by using words and sentences.

In addition, autistic child dislikes sharing their interest and enjoyment with others since they more prefer restricted interest. However, typically developing children learned to share their happiness or interest with other in order to develop and maintain a positive relationship. Autistic children are interest in particular object or activities such as puzzle, letters, numbers, films, animal, and so on for a very long time compared with typically developing children. Moreover, autistic children often show high intensity of interest on a particular part of an object such as wheels of a toy car compared with typically developing children (Autism Spectrum Australia, 2008). On the other hand, typically developing children are interest with parts that are able to attract their interest and attention such as beautiful design of a toy car.

2.3.3 Biological

Children experienced changes in biological during every development stage. At the age of six years, development of motor skills such as gross and fine motor skills occurred. Gross motor skills refer to the physical activities that involve large muscle groups such as jumping and running while fine motor skills refer to activities that required used of small-muscle coordination and used of eye-hand. Biological development between autistic child and typically developing children cannot be differentiate by external biological characteristic, but internal biological development causes autistic child different with typically developing children (Papalia, Olds, & Feldman, 2009).

Difference in biological development between autistic children and typically developing children is autistic child has abnormalities in circadian rhythm (Tordjman, Najjar, Bellissant, Anderson, Barburoth, & Cohen, 2013). According to Stedman's Medical Dictionary (2002, 2001, 1995), circadian rhythm is "a daily rhythmic activity cycle based on 24-hour intervals that is exhibited by many organisms." It also as known as biological clock which is a 24-hour internal clock that is running in human's brain and define the cycle of sleep and awake at a consistent period of time. Tordjman et al. (2013) found that abnormalities of circadian rhythm causes autistic child face difficulties in adapting with the internal or external environment changes. Therefore, autistic children feel comfortable with repetitive behavior because they are unable to adapt to new changes or environment.

Impairment of brain causes malfunction of sensory system among autistic children. They are hypersensitive to light and sound so they usually suffer from sleeping problem compared with typically developing children (Tordjman et al., 2013). Stein, Polido, Najera, & Cermak (2013) supported that autistic children were over-sensitive to light and feel highly anxious and showed negative response when disclose to bright light. One of the reasons of autistic child prefers repetitive behavior is lacking of the ability to adapt and adopt with new changes or environment. Absence of filter in sensory system causes autistic children usually overwhelm with overload sensory information from their environment (Tordjman et al., 2013). Therefore, they feel comfortable with repetitive behavior and restricted interest in order to minimize the amount of input from sensory system. Furthermore, repetitive movements such as flapping hands and swinging could calm their emotions.

2.4 Challenges faced by mother in raising up an ASD child

Parenting style plays a fundamental role in defining the dynamic of parent-child interaction. However, parenting style of parents with ASD child might different with parents of typically developing children. Children with ASD required excessive care due to impairment in social interaction, behavioral problem, and self-care duties.

According to Hoefman, Payakachat, Exel, Kuhlthau, Kovacs, & Pyne (2014), they did a study regarding the quality of life of parents who have autistic child in Arkansas and found that challenges faced by mothers in raising up an autistic child included overload care duties, financial problem, and negative psychological. Myers, Mackintosh, & Goin-Kochel (2009) supported that rigid family schedules, social isolation, burdened with demanding child care duties, and financial problems are challenges faced by mothers with autistic child. In addition, lacking of support system from society also is one of the challenges faced by mothers in raising up a child with autism. Divan, Vajaratkar, Desai, Strik-Lievers, & Patel (2012) conducted a research to study about the challenges, coping strategies, and unmet needs of families with autistic child in Gao, India. Divan et al. (2012) found that withdraw from social networks, negative experiences due to discrimination, lack of social support network and health care providers, and low awareness of professionals are challenges faced by families of autistic child in the research. In Malaysia context showed that more than half or 53.8% of parents of autistic child experienced disturbance in psychological wellbeing (Nikmat, Ahmad, Oon, & Razali, 2008).

In addition, limitations in raising up an autistic child lead to negative impact toward parents' psychology development such as parenting stress. Maintenance of psychological well-being is considered as one of the challenges faced by mothers in raising up an autistic child. Bluth, Roberson, Billen, & Sams (2013) found that parents of ASD children have greater risk to suffer from chronic stress compared with parents of children with other disabilities or typically developing children. Besides, lacking of social support system causes mothers of autistic children could not seek for assistance for protect their psychological health.

2.4.1 Parenting stress

Davis and Carter (2008) stated that mothers and fathers experienced parenting stress in caring of ASD child, but the level of parenting stress and depression score of mother were uniformly higher than father. This is because the involvement of father in raising up autistic child is lower than mothers. Besides, parents with autistic child experienced higher parenting stress compared with parents of typically developing children. Lee et al. (2017) found that parenting stress among parents with autistic child is higher than parents of typically developing children. Limitation in emotion management and impairment of social interaction as well as behavior problem among autistic children causes parents stick to demanding care duties and affect parent's mental and psychological well-being.

2.4.2 Parent-child relationship

Challenges and negative psychology development of parents affect their behavior and interaction patterns with their children. Beurkens (2010) found that relationship between severity of autism symptoms and parent-child relationship is highly associated in West Michigan. The result showed that the scores of parent-child interaction decrease when the scores of autism symptoms was increasing. It proved that child functioning could be influenced by the patterns of parent-child relationship and parenting behavior. It means that positive parenting patterns and relationship between parent and children promote positive changes among autistic children. It can be proved by active interaction between parents and children could encourage positive development among autistic children (Webster, 2011).