FACTORS ASSOCIATED WITH PARENTING STRESS AMONG MOTHERS WITH DOWN SYNDROME CHILDREN IN KOTA BHARU, KELANTAN

BY

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DECLARATION

I certify that this thesis does not incorporate without acknowledgement any material previously submitted for a degree or diploma in any university; and that to the best of my knowledge and belief it does not contain any material previously published or written by another person except where due reference is made in this the text.

CERTIFICATE

This is to certify that the dissertation entitles "Factors Associated with Parenting Stress among Mothers with Down syndrome Children In Kota Bharu, Kelantan" is the bonafide record of research work done by undergraduate nursing student Lee Wai Ling (Matric No: 108643) during the period of September 2013 to June 2014 under my supervision. This thesis submitted in fulfillment for the degree of Bachelor of Health Sciences (Nursing). Every research work and collection of data belongs to Universiti Sains Malaysia.

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LIST OF ABBREVIATION

DS	-	Down syndrome
USM	-	Universiti Sains Malaysia
PSS	-	Parental Stress Scale
PSC	-	Pediatrics Symptoms Checklist
DASS	-	Depression, Anxiety, Stress Scale
COPE	-	Coping Inventory
SPSS	-	Statistical Package Social Science

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ABSTRACT

Through research about predictors of parenting stress among mothers of Down syndrome children, hopefully that some information obtained could be utilized to advocate for mental health services for mothers of young children with intellectual disabilities in Malaysia. Depression, anxiety, parenting stress and others negative impacts were observed among the parents of children with Down syndrome. The aim of this study was to determine the parenting stress level and factors that may associate with parenting stress level among mothers with Down syndrome children in Kota Bharu, Kelantan. After obtaining ethical approval from both hospital and USM ethics commitees, a cross-sectional study was carried out among mothers with Down syndrome children from Pediatrics Clinic Hospital USM and Lion Club's Down syndrome Center in Kota Bharu. Purposive sampling method was used to recruit the sample. There were 30 mothers being involved in this study. Data were collected using a self- administered questionnaire developed by the researcher according to previous literature. The questionnaire was available in two languages (English and Malays) in which included demographic data, parental stress scale, pediatric symptoms checklist, DASS and COPE. Then, data was being analyzed using the Statistical Package Social Science (SPSS) software version 20.0. Descriptive statistics were used to present the demographic data. The results suggested that the parenting stress level could be significantly associated with child behavioral problems, maternal depression and stress as well as maternal coping methods. By using the cut- off point of 28 from Child Behavior Checklist for children aged more than 6 years old and cut- off of 24 for younger children, 12 (40.0%) of the Down syndrome children had reported having behavioral problems. The mean stress score for mothers with a child having behavioral problems (50.5) was higher than that of those who did not report having behavioral problems (37.1), with a p value less than 0.001. The mean parenting stress score of normal, mild and moderate depression score were 39.9, 50.8 and 51.0, with p value 0.023. The mean stress score of mothers that scored normal, mild as

well as moderate stress score were 39.6, 51.4 and 53.5, giving a significant p value of 0.006. The mean COPE score in the study was 79.3 (SD = 9.2), ranging from 66 to 96. The correlation coefficient between mean parenting stress and COPE score was -0.634, with p value <0.001.The parenting stress level among mothers with Down syndrome children was caused by child behavioral problem, then affected by maternal depression and anxiety and lastly buffered by maternal coping methods. Thus, more research should be conducted in order to clarify more about the possible causes of parenting stress level and intervention to alleviate the stress.

Key words: Parenting stress level, mothers, Down syndrome children, child behavioral problems, maternal psychological well- being, maternal coping methods.

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ABSTRAK

Maklumat yang diperolehi melalui penyelidikan tentang faktor andaian tekanan dalam kalangan ibu kanak- kanak Down sindrom diharapkam dapat dimanfaatkan dalam perkhidmatan kesihatan mental untuk para ibu kanak- kanak ketidakupayaan dari segi intelektual di Malaysia. Kebanyakan ibu bapa kanak- kanak Down sindrom mengadu bahawa mereka mengalami depresi, kebimbangan, tekanan dan impak negatif lain- lain (Hedov, Anneran, Wikblad, 2002 b). Menurut Yirmiya & Shaked (2005), ibu bapa kanak- kanak mempunyai ketidakupayaan intelektual seperti Down sindrom atau autisme mengalami tanda- tanda depresi dan kebimbangan. Tujuan penyelidikan ini adalah untuk menentukan tahap tekanan dan factor yang mungkin berkaitan dengan tekanan ibu kanak-kanak Down sindrom di Kota Bharu, Kelantan. Selepas mendapat kelulusan etika daripada hospital dan jawatankuasa etika USM, satu kajian keratin rentas telah dijalankan dalam kalangan ibu kanak- kanak Down sindrom dari Klinik Pediatrik Hospital USM dan Pusat Down sindrom Lion Club di Kota Bharu. Persampelan bertujuan telah dilakukan untuk mengumpul sampel. Terdapat 30 orang ibu menyertai kajian ini. Data telah dikumpulkan dengan menggunakan soal- selidik yang dicipta sendiri berdasarkan kajian sebelum ini. Soal- selidik tersebut adalah dalam dua bahasa (Inggeris dan Melayu) mengandungi ciri- ciri demografi, skala tekanan keibubapaan, senarai kelakuan anak, DASS dan COPE. Kemudian, data tersebut telah dianalisasi dengan perisian "Statistical Package Social Science" (SPSS) versi 20.0. Data demografi dibentangkan dalam bentuk statistik deskriptif. Keputusan menunjukkan tahap tekanan berbeza secara ketara apabila dipengaruhi oleh masalah kelakuan anak, depresi dan tekanan ibu, serta cara ibu menangani tekanan. Berdasarkan panduan senarai kelakuan kanak- kanak, markah pemutus sebanyak 28 bagi kanak- kanak berumur lebih daripada 6 tahun dan markah pemutus 24 bagi kanak- kanak yang lebih muda, terdapat 12 (40.0%) daripada kanak-kanak Down Sindrom didapati mempunyai masalah kelakuan. Skor tekanan min bagi ibu kanak- kanak yang dilaporkan mempunyai masalah kelakuan (50.5) adalah lebih tinggi

daripada ibu kanak- kanak yang tiada masalah kelakuan (37.1), dengan nilai p< 0.001. Skor tekanan keibubapan min dalam kategori depressi normal, sederhana dan moderat ialah 39.9, 50.8, serta 51.0, dengan nilai p 0.023. Selain itu, skor tekanan min ibu dalam kategori normal, sederhana dan moderat ialah 39.6, 51.4, dan 53.5, deng nilai p 0.006. Skor COPE min dalam kajian ini adalah 79.3 (SD= 9.2), dalam lingkungan dari 66 hingga 96. Pemalar korelasi antara skor tekanan keibubapaan min dan skor COPE ialah -0.634, dengan nilai p <0.001. Kesimpulanya, tahap tekanan dalam kalangan ibu kanak-kanak Down sindrom adalah disebabkan oleh masalah kelakuan anak, dan dijejaskan oleh depresi dan tekanan ibu, serta diperbaikkan dengan cara menangani tekanan tersebut. Oleh itu, lebih banyak kajian haruslah dijalankan untuk menjelaskan tentang sebab yang mungkin mengakibatkan tekanan keibubapaan dan intervensi untuk mengurangkan tekanan.

Kata kunci: Tahap tekanan keibubapaan, ibu, kanak- kanak Down sindrom, masalah kelakuan anak, status psikologi ibu, cara menangani tekanan

CHAPTER 1

INTRODUCTION

1.1 Background of The Study

Down syndrome, is the most common cause of genetically based mental retardation where it was associated with chromosomal anomaly which is Trisomy 21. Trisomy 21 could be explained as an extra genetic material exists in chromosome 21 (American National Down Syndrome Society, 2012). This abnormality is caused by a non- disjunction process where the genetic materials unable to separate during the formation of gametes, thus an extra chromosome exist (Roizen and Patterson, 2003). The children with Down syndrome could be recognized through some physical characteristics in them such as flat face, large tongue, slanting eyes, decreased muscle tones and so on.

The prevalence of Down syndrome was observed that it is occurring in a predicted 1 in 1000 live births (Ghosh, Shah, Dhir, and Merchant, 2008). There was no certain cause being proved to be causal factor for Down syndrome. Although there was suggestion on the risk of getting a child with Down syndrome will increase with maternal age, but there was no strong evidence on that. Meanwhile, there was one in every 691 live births in United States in which there are 6000 children born with Down syndrome in United States per year (American National Down Syndrome Society, 2012). On the other hand, based on Universiti Sains Malaysia's Human Genome Centre and Genetic Clinic, the incidence of Down syndrome in Malaysia was one per 950 births (Azman, et. al., 2007).

Unfortunately, many of the children with Down syndrome also afflicted with other medical conditions such as leukemia, cardiovascular disease and even hearing defects. According to Roizen and Patterson (2003), 40– 45 percent of the children with Down syndrome had congenital heart disease. Some infants of Down syndrome were failure to thrive during infancy, in which they were afflicted with heart disease. As

mentioned in the above report, medical conditions such as intestinal abnormalities, eye problems and skeletal problem were occurring in higher frequency in children with Down syndrome as compared to that of normal children. Besides, 60 to 80 percent of children with Down syndrome have hearing deficits (World Health Organizations, 2013). About one percent of newborns with Down syndrome had hypothyroidism because of underdeveloped thyroid gland (Roizen, 2002). As the children grew older, it was being expected they were suffered more in the development process as compared to normal children.

In the early of year 1990's, the life expectation of people with Down syndrome was less than 10 years old. However, the 21st century in which the world had been updated with more advanced medical care and technology, the people with Down syndrome were expected to live until 50 years and more (World Health Organizations, 2013). However, the prognosis of Down syndrome has to depend on the people's medical condition such as congenital heart disease. Since more information could be obtained through research, there were more interventions being carried out in order to improve the Down syndrome people quality of life. Those interventions were mainly focused on meeting their special health needs such as regular check- ups to monitor the physical and mental development, some timely interventions such as counseling or special education (World Health Organizations, 2013). There were some community- based support systems like special school which facilitates their participations in the society.

Most of the families were not exposed to the care of intellectual disabled children until after the children are born. The birth of a Down syndrome child was an unanticipated event for a family and interrupted a family's normal functioning. The parents of those children were reported to suffer from depression, anxiety, parenting stress and a range of negative impacts (Hedov, Anneran, Wikblad, 2002b). According to Yirmiya and Shaked (2005), the parents of children with intellectual disability such as Down syndrome or autism had reported symptoms of depression and anxiety.

As compared to normal children, parents of children with Down syndrome need to pay more attention in the children's growth and development process (Gau, Chiu, Soong, and Lee, 2008). In the development process of child with Down syndrome, there was an anticipated delayed in cognitive, development of thinking, reasoning and understanding in the child. Some children with Down syndrome may exhibit Autism Spectrum Disorder which is having more repetitive and stereotyped pattern of behavior (Ghosh. et. al., 2008,). Therefore, taking care of children with Down syndrome needs undivided attention and patience. In other words, parents will need more time to take care of a child with Down syndrome.

Although both the parents of the Down syndrome were adversely affected, it was observed that mothers of the child suffered from higher level of stress in a Greek study (Hedov, Anneren and Wikblad, 2000a). Traditionally, mothers were taking responsibility of child bearing and therefore they were spending more time with their children (Gau et. al., 2008). This is because mothers were the primary caregiver and spent more time staying with child. Some mothers even have to leave their job and stay at home in order to take care of their children. According to Barnett and Boyce (1995) being cited in Hedov et al. (2002b), mothers of children with Down syndrome had increased time for child care by nine hours a week and decreased their working time by seven hours a week.

Most of the health settings or Down syndrome centers in Malaysia were mostly focus on maximize the children with Down syndrome cognitive, social functioning, but those health facilities seldom pay attention on parents' stress or the support they require. Many studies being carried out in developed countries especially Western countries to measure or compare parenting stress among parents of children with intellectual disability and factors that contributed to parenting stress, but there were limited studies in Malaysia for the same objectives (Chan, Abdullah and Ling, 2013).

Undeniable, the child with Down syndrome created new financial, educational, familial and social relations burden in the family. While considering about the families,

the issues of parenting stress in Down syndrome child bearing actually affected a great population.

1.2 Problem Statements

According to Universiti Sains Malaysia's (USM) Human Genome Centre and Genetic Clinic, the incidence of Down Syndrome in Malaysia is one per 950 births in year 2007 (Azman et al., 2007). There were more research on pathophysiology of Down syndrome emerged but not many research on parents of children with Down syndrome's psychological status carried out. Although there were some studies being done to measure maternal or parental psychological well- being status in the process of rearing a child with Down syndrome, but yet there were limited interventions to increase parents' quality of life.

The parent of children with Down syndrome were having lower levels of stress as compared to that of parents of children with other types of intellectual disabilities such as autism (Griffith, Hastings, Nash and Hill, 2010; Ogston, Mackintosh and Myers, 2011.). The difference in the parenting stress level was explained by Ogston et al. (2011) that children with Down syndrome have less behavior difficulties as compared to children with Autism and behavioral disorders. Many of those researches were carried out in Western countries but only a small proportion of extant studies in Malaysia to evaluate the association between predictors of stress and parents' well- being.

A Swedish study showed that there were difference of psychosocial impacts faced by fathers and mothers of children with Down syndrome. There was a study suggested that the fathers of children with Down syndrome usually reported less stress or worry about the child's problem than that of their mothers (Luoma, Koivisto and Tamminen, 2004). The child's limitation in terms of physical and intellectual capacities could be an extra burden for mothers as main caregivers in addition of lack of husband's involvement in child rearing process. But Ghai (2001) stated that there were limited literature from

economically developing countries supported the common perception that there was stigmatization and burdensome in the families of children with DS. Parents of children with developmental disabilities may face many decades of caregiving responsibility. As part of the responsibility, they encountered various challenges.

Parents of children with Down syndrome need to spend more time and more financial costs because many of children with Down syndrome afflicted with others medical conditions. In Yam et al.'s study (2008), there were various medical issues identified among children and adolescent with Down syndrome such as cardiovascular problem and endocrine problem (refer to Table 1.1 in Appendix 1). As an example stated in Roizen and Patterson's study (2003), there were around 38%- 78% of children with Down syndrome have hearing loss problem which can be sensorineural, conductive or mixed. Therefore, the children with need to undergo medical management to treat the problem (otitis media) or using hearing aids.

Based on Hauster, Warfield and Shonkoff (2001), the major stressors for parents with disabled children were long- term care, additional medical expenses as well as disabled children's behavior problems. However, there were some families able to adapt well with the chronic disabled situation using their own coping styles (Rehm and Bradley, 2005). The mothers of children with Down syndrome's parenting stress levels associated with child behavior problem, burden of care, marital status, economic status, coping styles as well as social support (Norizan and Shamsuddin, 2010). According to Chan, Abdullah and Ling (2013), the geographical characteristics, less developed infrastructure and inaccessibility to service may be the issue of concern for parenting stress in some rural communities.

Parents of children with intellectual disabilities were prone to report depression, anxiety and stress in taking care of their children. There was impact on the child's development when the parent is under depression, anxiety and stress. Parental depression could influence the family interaction which eventually leads to dysfunctional nurturing

of the child (Tan and Rey, 2005). Past researches on parenting stress level of parents with disabled children showed that the parents who denied their children's disability or blamed themselves were tend to report higher stress level than parents who adopted coping strategies characterized by positively reframing the situation (Abbetudo et al., 2004; Dabrowska and Pisula, 2010). Therefore, it was worth to explore the association between maternal factors and parenting stress level.

The choice of predictors was based on Hill's ABC- X model. This model was developed by Reuben Hill in year 1949. Hill's framework for family stress theory focuses on three independent or interrelated variables which are the provoking events and stressors (A factors), the family's strength or resources at the time of event (B factors) and the family's perception or definition on the stressors (C factors) (Boss, 2002). In this study, the impact of child behavior problem (A factor) on parenting stress (X) was explored. Besides, the effects of maternal resources such as maternal coping methods and maternal individual characteristics such as age on the parenting stress level among Kelantan mothers were examine as well. The association between mothers' perception on stressors (C factor) and parenting stress level (X) was explored in this study. The perception of mothers on the stressors was being influenced by maternal psychological status.

1.3 Research Objectives

1.3.1 General Objective

To determine the factors associated with parenting stress level among mothers of Down syndrome children in Kota Bharu, Kelantan.

1.3.2 Specific Objectives

1. To identify the relationship between children behavioral problems and mean parenting stress score among mothers with Down syndrome children.

2. To examine the relationship between psychological well-being status of mothers with Down syndrome children and mean parenting stress level.
3. To determine the maternal factors (age, employment status, marital status and coping method) that associate with the parenting stress among mothers with Down syndrome children.

1.4 Research Questions

1. Is there any association between child behavior problem and parenting stress level of mothers?
2. Is there any relationship between maternal psychological well beings and mothers' stress level?
3. What are the maternal factors that influence the parenting stress of mothers?

1.5 Hypothesis

1.5.1 Ho: There is no significant relationship between the child behavior problems and parenting stress level.
HA: There is a significant relationship between the child behavior problems and parenting stress level. (Ho≠HA)
1.5.2 Ho: There is no significant relationship between psychological well- being and parenting stress level.
HA: There is a significant relationship between psychological well- being and parenting stress level. (Ho≠HA)
1.5.3 Ho: There is no significant association of parenting stress level based on maternal factors.
HA: There is a significant association of parenting stress level based on maternal factors. (Ho≠HA)

1.6 Definition of Operational Terms

Parenting Stress - Parenting stress or the stress generated by parenting process is conceptualize as being comprised of parental characteristics, child characteristics and situational variables directly related to parental role (Sumpter , 2009). In this study, parental stress is defined as stress directly related to a person's role as a parent and parenting a child with disability.

Children - Child/ children is defined as the young human being below the age of puberty or below the age of legal majority (Oxford Dictionaries, 2013). According to Malaysia's Child Act 2001, child is anyone under the age of 18 years old (UNICEF, 2004). In this study, young human beings under 18 years old are defined as child.

1.7 Significance of The Study

In view of incidence of Down syndrome in Malaysia, there was 1 in 1000 live births in year 1989 and increased to 1 in 800-950 live births in year 2007. Since the risk of Down syndrome is associated with advancing maternal age, therefore there will be an expected increase in the incidence rate of Down syndrome in Malaysia. The increase in numbers may due to the women nowadays are getting married in older age and give birth to babies in older age as well.

There was a study conducted in Kinta district (Perak) which showed that even though most of the pregnant women carry out ultrasound examination as a routine for antenatal visit but it is not done as screening test for birth defect (Ho, Thong, and Nurani, 2006). Ho et al. (2006) said that there was also low expertise of prenatal screening for

birth defects in Malaysian population. Therefore, the birth of children with DS in Malaysia is not preventable. At the same time, Kota Bharu in Kelantan is strongly influenced by Islamic background since the Malays population dominates. In Islamic belief, child is the will of God and termination of pregnancy is socially unaccepted (Bryant, Ahmed, Ahmed, Jafri, and Raashid, 2011). In this research, the perception of mothers with Down syndrome in Kota Bharu will be investigated to determine relationship with parenting stress.

In fact, there were lots of studies that focused on the impact of birth of a child with Down syndrome on parent's psychological well- being in developed countries especially Western culture countries (Abbetudo et al., 2004). Most of the families in Western countries adjusted well to a child with DS and often encountered a quality of life similar to that of other normal families (Van Riper, 2007). Through the study, hopefully that some information obtained could be utilized to advocate for mental health services for mothers of young children with intellectual disabilities in Malaysia.

Malaysia is a developing country well known for its diversity of culture. Thus, the diversity in culture, religions may influence the perception and the coping methods of those parents of children with DS. The differences in socioeconomic, cultural and educational background among the population may influence their adaptation strategies handling their children with disabilities (Isa, et al., 2013). Thus, it is vital to explore and identify the factors that alter mothers' parenting stress level so that targeted interventions could be designed besides taking consideration into cultural, educational and socioeconomical aspects in Malaysia. From Ahmed, Bryant, Ahmed, Jafri, and Raashid's study (2013), research that carried out in Taiwan, Pakistan and Britain demonstrated that there were some experiences in common when raising up children with Down syndrome across economically and culturally diverse societies. Yet, lacking from all of these studies is the perspectives of contemporary families who have children with DS in Kota Bharu.

From a study titled "Having a Son or Daughter with Down Syndrome Perspective From Mothers and Fathers" (2011), the researchers had obtained the result that an overwhelming majority of parents who have children with Down syndrome reported that they were proud of their children and their children brought more joy and more caring. In contrast, it was often assumed that the increased stress of raising children with Down syndrome might causes negative consequences for both children and the whole family (Ferguson, 2002). This study aimed to increase attention to change in family demand as the children with Down syndrome grow up in order to find a balance in between negative and positive consequences.

In Malaysia, mothers are the most prominent caregivers for children in a family. Although there were more women starting to be employed, but they still spend more time as compared to men in taking care of children. As mentioned in Boyce and Barnett's studies (1995), mothers of children with Down syndrome spent eighty percent more time in taking care of the children than the fathers (Hedov et al., 2000a). They always know better than the children's father in the ways of take care of the children. Since mothers are the main caregivers in the family, they are responsible for all daily physical care of the disabled children, and therefore very much aware the gap between the disabled child and peers or siblings. There should be more studies carry out to focus on mothers of children with Down syndrome because mothers are the primary caregivers and spending more time to raise the child (Norizan and Shamsuddin, 2010).

The risk of worse parent and family functioning should be viewed as a severe matter because it is not only affect family's quality of life but also success of the children's development and rehabilitation (Isa et al., 2013). Investigations into contributors that cause parenting stress are essential as it draws out a framework in order to identify the key variables that may induce experience of stress. Therefore it is valuable to take a stock of current research on parenting stress focus on families with Down syndrome children.

According to Gupta, Sapra and Kabra (2013), embracing the paradox is a compromise between acceptance and denial. Therefore, it is essential for the psychological well- beings of the parents of children with Down syndrome because embracing the paradox energizes them and allows for hope and optimism, a positive vision of the future and personal growth. It is essential that nurses and other health care professionals understand what it means for the families to embrace the paradox of their child's disability (Van Riper, 2007). Nurses can promote resilience and adaptation in families of children with Down syndrome by helping families to recognize multiple stressors, strains and transitions in their lives. However, nurses need to equip themselves with knowledge such as predictors associated with parenting stress and the maternal factors that may affect children's development prior to promoting resilience.

There were more studies on child behavior problems in Down syndrome during 1990-an but the studies during 2000-an were more focus on comparison of child behavior problem between children with Down syndrome and children with other intellectual disabilities. The findings on predictors of parenting stress among mothers of children with Down syndrome are of concern because distress of mothers will lead to a wide range of negative outcomes towards the children including less than optimal parenting, failure to engage with services, undecided to seek out- of- home care for their disabled children, impeded child development, and higher rate of child antisocial behavior (Llewellyn, McConnell, Thompson and Whybrow, 2005).

CHAPTER 2

LITERATURE REVIEW

2.1 Introduction

Parenting stress is defined as "the aversive psychological reaction to the demand of being a parent" (Yousefia, Far and Abdolahian, 2011). Parents, are the single most important protective role for children in their lives. For the children with disability, it's important for their parent to play an important role in rehabilitation and promoting the maximum potential of children. When parent is at stressed, it becomes more difficult to meet the children's physical, emotional and mental requirements. Children who are not experience positive relationship which is engaging and grow up in stressful environment are more likely to develop learning, behavior and attachment issues that lead to long lasting effect in their later life.

Olsson and Hwang (2001) stated that not all the people will face depression when came across with stressful events but the meaning the individual attached to the stressors will determine its impact to the individual. Lopez, Clifford, Minnes and Ouellette- Kuntz (2008) had pointed out that the experience of stress depends on how the parents perceive their conditions and the coping approach used.

2.2 Review of Literature

2.2.1 Children Behavior

Children with DS usually have well- recognized phenotypes, included external characteristics, specific health problems (such as thyroid dysfunction, congenital heart disease and visual impairments) and intellectual impairments with delayed cognitive and motor development. Average one quarter to one third of the children with DS have significant emotional and behavior problem (van Gameron- Oosterom, et al., 2011). van Gameron- Oosterom et al. (2011) also showed that 8- 23% of the children with DS have significant psychopathology.

Many of previous studies showed that children with DS usually seldom associated with maladaptive behavior in comparison with children with Autism or other behavior disorders (Walz, and Benson, 2002; Griffith et al., 2010). Some mothers in those researches describe their children who have DS as affectionate, sociable, cheerful, outgoing and controllable (Hodapp, Ricci, Ly and Fidler, 2003). Besides that, the mothers of children with DS often experienced lower stress levels than mothers of children with other intellectual disabilities as shown in Ogston's study in year 2011. Hence, the society has comes across with the perception of children with DS are easy to be raised up and brought up less negative impacts than children with other disabilities.

However, a reconsideration of the prominent image of children with DS as being easier to raise up should be called. It should be noted that personality traits also variable among children with DS. As cited in Brian's study, the children with development disabilities may prone to seek attention, wake up at night, difficult to settle down during sleep time, experienced day and night wetting and express fears more frequently than the normal children (Skotko, Levine and Goldstein, 2011). Therefore, the mothers were actually spending more time and attention to take care of their children besides carry out home- based teaching. Delayed in development of cognitive, social skill is an universal feature of children with DS, thus the children with DS will encountered some difficulties in understanding instruction, or performing self- care activities (Walz and Benson, 2002).

Although the issue of child behavior problem was seldom raised up among the parents of children with DS, but there was a study which focused on parents and teachers' rating of children's behavior problem. Based on the Dykens et al.'s study (2002), the children with DS had behavior problem from the aspects of attention deficit, noncompliance, thought disorder, and social withdrawal. Gau et al.'s study (2008) also showed the result that consistent with Dykens's findings that DS children had more severe attention problems, somatic complaints, thought problem, and withdrawal problem. Although there are researches had obtained results that proved children with Down

syndrome having less child behavior problem than other children with intellectual disability such as autism, yet there were limited descriptions of behavioral problem that may exist among children with DS.

As cited in Baker, children with DS were not problem- free, since they were found to show higher level of maladaptive behavior as compared to normal developed peers or siblings (Bakers et al., 2003). Then, what are the effects of child behavior problem on a family's functioning or parental stress? Although the previous researches showed that the maternal stress is significantly associated with child behavior problem, but the role of child behavior problem in eliciting stress is still a puzzle. This is because maternal stress levels of children with DS or other learning difficulties was shown to be associated with other factors such as coping methods or mothers' perception on their children as presented by Norizan and Shamsuddin (2010). Further, prior studies were prone to include the families of children with Down syndrome as a comparison group to families with autism or other psychiatric impairments. Given the extreme behavioral problem in autistic or emotionally impaired children, those studies may have "stacked the deck" in the favor of families of children with Down syndrome (Bakers et al., 2003).

On average, the children with Down syndrome may become less sociable and more withdrawn as their aged older (Hodapp et al., 2003). Hodapp et al. (2003) also reported that the children with Down syndrome have slower rate of cognitive and linguistic development in their school- age as compared to their infant and toddler years. Hence, such slowing developmental with age would make the parents being frustrated, making them feel less reinforced by the children with Down syndrome.

2.2.2 Maternal Stress

According to Raina et al. (2005), "stress can be defined as the balance between external environment demands and the perceived internal ability to respond and may occur when the demands prevent the pursuit of other life objectives". Although the

mothers of children with Down syndrome reported less stress in early childhood as compared to mothers with children of other disabilities, but their stress levels have been shown to increase along with the children's growth (Hauser- Cram et al., 2001). Hauser-Cram et al. (2001) also explained that it is possible that the mothers face difficulty in obtaining services and worried about the child's future as the child enters late childhood and middle adolescent.

Being a mother, most of the women will be overwhelmed by intense joy. However, the mother or the whole family has to face the challenge of reconsidering their role in order to adapt their new lifestyle. If the newborn is born with certain disability, the problems and challenges will multiply in a family. Mothers of children with Down syndrome face various problems in the process of raising their children. In Hauser- Cram (2001), the major stressors for the parent are long term care, additional medical expenses, child behavior problem, less social support as well as parents of a younger age. They are being exposed to heightened stress and emotional problem such as denial, anger, anxiety, disappointment as well as avoid facing external world (Woolfson and Grant, 2006).

In McConkey, Truesdale-Kennedy, Chang, Jarrah and Shukr study (2008), there is an increase of risk for stress, exhaustion and poor health because mothers of children with Down syndrome need to deal with an ongoing, chronic situation in supporting their child's various requirements throughout their life. Therefore, the mother with a disabled child is likely to be exposed to crisis, which leads to stress (Sen and Yurtsever, 2007). As cited in Gau et al. study, the findings of Krauss (1993) and Cheng and Tang (1995) study show that parents of children with Down syndrome may show more apparent maladjustment as compared to that of parents with typically developing children.

Isa et al. study (2013) showed that female caregivers or mothers had poorer functioning based on comparison with male caregivers or fathers. Mothers, who traditionally spent more time in caregiving for their children with disabilities besides doing domestic chores prone to have more physical, psychological and social strains than

the fathers who typically work outside (Raina, et al., 2005) . The previous studies also demonstrated that mothers who were single parents experienced higher stress levels and poorer family functioning (McConkey et al. (2008); Norizan et al., 2010).

Children with DS usually associated with more than one physical disability such as congenital heart problem. Children with complex or multiple disabilities are more physically and emotionally demanding of their parents (Leung and Li- Tsang, 2003). Hu, Wang and Fei's study (2011) presented that the severity of disability and degree of caregiving demands are inversely associated with the caregiver's physical and psychological health and family quality of life. Dykens, Shah, Sagun, Beck and King (2002) had pointed out that children with a particularly genetic disorder are more likely to demonstrate one or more etiology- related behavior including psychopathology maladaptive behavior, personality or specific cognitive, linguistic or adaptive strengths and weakness.

2.2.3 Mother's Psychological Well- being

For mothers of children with disability, the first stressor to be encountered was facing a child who was totally different from their expectations at the moment the baby born. They may experience greater stress and many of them will undergo the grieving process. After the grieving process, they may able to accept the child but there will be impact on the families' psychological well- being (Isa et al., 2013).

Past studies explored into mothers or families' stress levels rather than explored their psychological well- being. As stated in Johnston's study, the relationship between parental stress and psychological well- being (especially depression) could be bidirectional when mothers' existing psychological health could lead to parenting stress, while parenting stress could affect mothers' psychological well- being (Johnston, et al., 2003). If a life- event or stressor threatens upon personal concerns central to the mother or a family's self- perception, then a depressive response may be elicited (Olsson and

Hwang, 2001). Olsson and Hwang (2001) described that the experience of raising a child with intellectual disabilities may provoke the feeling of loss, helplessness (unable to change the situation) and failure (having a child with difficult behavior).

Although there have been progressive shifting in the distribution of parenting responsibilities between mothers and fathers, mothers still carry disproportionate burden in raising a child with DS. In response to heightened stress, mothers of children with delayed development often report depression, anxiety, social isolation, health problem and low self- esteem. Johnston's study suggested that the psychological well- being of mothers with intellectual disability children was significantly associated with parental feeling of isolation. According to Johnston et al. (2003), it can be presumed that a mother may not able to access to adequate resources if she is suffering from significant psychological problem, therefore her competence in parenting skill will be decreased and sense of isolated being elevated. When the mothers gain less coping resources, this will further increase their parenting stress (Lloyd and Hastings, 2008).

In Gallagher et al. study (2008), almost two- thirds of the parents of intellectually disabled children in the current study met conventional criteria for possible clinical depression and three quarters for possible anxiety. Many of past studies on parenting stress among parents of children with disabilities or Down syndrome focuses on parenting stress levels or other predictors of parenting stress whereas the psychological well- being of the parents were seldom being explored. Some of the parents may report low level of anxiety, but there were two- thirds of them met the clinical criteria for depression in an earlier UK studies (White and Hastings, 2004).

2.2.4 Maternal Factors

There were some studies on predictors of parenting stress among mothers of Down syndrome children which highlighted the maternal factors such as mothers' perception towards their child and their coping methods did associated with the parenting

stress (John, 2012; Norizan and Shamsuddin, 2010). In Rao's study (2006), there were eight mothers recognized and accepted their children's disability, they also emphasized their "normality". By labeling their children's impairment as "inconvenience" rather than a disability, the mothers were prone to promote social acceptance as well as inclusion of their children. The children's normality was being constructed in term of fulfilling families' duties and demonstrating socially accepted conducts (John, 2012).

Past studies had reported the parents with children with disability (Down syndrome, autism and Fragile X) who adopted coping strategies characterized by positively reframing the situation or seeking for social support tend to demonstrate lower stress levels as compared to parents that denied their child's disability (Abbeduto, et al., 2004; Glidden et al., 2006). Stoneman, Gravidia- Payne and Floyd (2006) found that personality traits, especially Neroticism, and coping strategies, especially wishful thinking, contributed to predicting parental distress and life satisfaction. They also found that the patterns for coping strategies were different among mothers and fathers. For mothers, practical coping was positively associated with life satisfaction, whereas for fathers coping through passive acceptance was negatively associated with life satisfaction. As cited in Folkman's study (2000), there are two types of coping strategies: problem-focused and emotion- focused. Problem- focused coping strategy involves any efforts to actively control or amend the source of stress, whereas emotion- focused coping strategy involve regulating stressful emotion (Folkman and Moskowitz, 2000). Kim, Greenberg, Seltzer and Krauss's studies (2003) suggested that problem- focused coping strategies are usually accompanied by positive adjustment outcomes while emotional- focused did not. This is due to emotional- focused strategies tend to focus on denial, escape, and avoidance of the stressors and therefore associated with less positive adjustments (Stoneman et al., 2006). Stoneman et al. (2006) also had pointed out that perception-focused coping is used in coping with stress. Perception- focused coping attempts to change the individual's appraisal towards the stressors.

Family adaptation is defined as the outcome of family efforts to bring a new level of balance and functioning to a stressful or crisis situation. As cited in Van Riper's study (2007), McCubbin (1993) has reported that family adaptation in a family dealing with a crisis situation depends on the range and depth of the family's repertoire of problem solving and coping strategies. In Norizan and Shamsuddin's study (2010), most of the mothers preferred to use religious coping as coping styles rather than acceptance, optimist and active coping. In the acceptance of the special child, mothers will prone to seek helps from others. Lam and Mackenzie (2002) had explained that via communication with others or exposed to others with similar situation, mothers may realize that their children's condition was not the worst.

Furthermore, religions have been examined to some extent with respect to parental adaptation. Religion coping could be positive or negative. Positive religious coping is that the parents view their child as a blessing whereas the negative religious coping is viewing the disability is the punishment for the past sin of the child (Tarakeshwar and Pargament, 2001). John's study (2012) has demonstrated when religion is positively used to reframe the child's disability (blessing), it may be adaptive. But when the religion negatively utilized, it perhaps become maladaptive.

Hastings, Allen, McDermott and Still (2002) noted that reframing coping strategies were positively associated with maternal perceptions of the child as a source of happiness and fulfillment and as a source of family strength. There has probably always been resilience in families in families of children with Down syndrome; some have been just too busy searching for dysfunction to notice.

Besides, mothers' demographic factors such as age, employment status were found associated with parenting studies. For instance, there are well- established links between socioeconomic position and both child disability and parental well- being in Emerson, Hatton, Lyewellyn, Blacher and Graham's study (2006).

2.3 Conceptual / Theoretical Framework

The Hill's ABC- X Model of Stress is used to describe the association between the predictors and the parenting stress level. Hill's ABC- X Model was proposed by Reuben Hill in year 1949, as a result of his study on "Family dismemberment" during and after World War II. Hill proposed that there were three interrelated factors which precipitated family crisis when the families on war were separated. The three factors that contributed to family crisis are the stressors and related to hardship (A factor), the families' resource to cope with the stressors (B factor) and the families' definition of stressor (C factor). Not all the families that encountered stressful event will lead to a crisis, but why is it so? According to Hill in his model, there are two protective factors ('B' and 'C' factors) which could buffer the impact of the stressor.

Hill theorized that major stressful events or traumatic events can disrupt family equilibrium. Most of the families will seek to re- establish the equilibrium in order to cope with the stress. In ABC- X Stress Model, the letter 'A' refers to events that disrupt equilibrium. The 'A' factor as a stressor which means that a situation for which the family had little or no prior preparation and must therefore be viewed as problematic. Moreover, Hill also contended that 'A' factor affect a family in different extent based on the hardships they face. Hardship is defined as complications from the stressor that depends on competencies of the family. According to Hill, the crisis precipitating factor (A) is interrelated with the family's acquired resource to cope with the stressors.

The 'B' factor in Hill's ABC- X Model is the family's stressor- meeting resources, which may urge the family into crisis if absent or buffer the family's stress if present. In other words, the resources will determine the family's crisis- proofness or crisis-proneness. 'B' factors include both internal and external family resources and social support through community, religions or other alternatives. Families with strong social ties were proved that able to cope with the sudden onset of the stressful event than the

families with poor social ties. According to Hill (1949), the A factor and the B factor are interacted with C factor (the family's definition of event) to create crisis (X).

A family definition towards a major stressful event is subjective and it is made equaled to interpretation of the event and the hardship of the event in that family. The 'C' factor refers to the family's shared beliefs and perception towards the stressors. Hill suggested that if a family perceived the stressor positively and constructively, the family is better to handle the stress. On the other hand, a family that dwelling on the negative consequences of the stressful event will undergoes a harder time to cope with the stress. The 'X' in the Stress Model is the family crisis. If a family could not deal with the stressor, then everything will end up in a crisis.

The Hill's ABC- X model still used as the basis of family stress theory although there is modification of the model. ABC- X theory is withstood time and the explanation in this theory still relevant to the family stress in current century. Furthermore, the theory is easy to be understood and it did explain all the processes involved to create a family crisis. However, the classic ABC-X model did not consider about the pile- up of stressors over the occurring time. Hence, McCubbin and Patterson (1983) had expanded the ABC-X theory to Double ABC- X theory in taking account into cluster of stressors over a period (Hill, 2005).

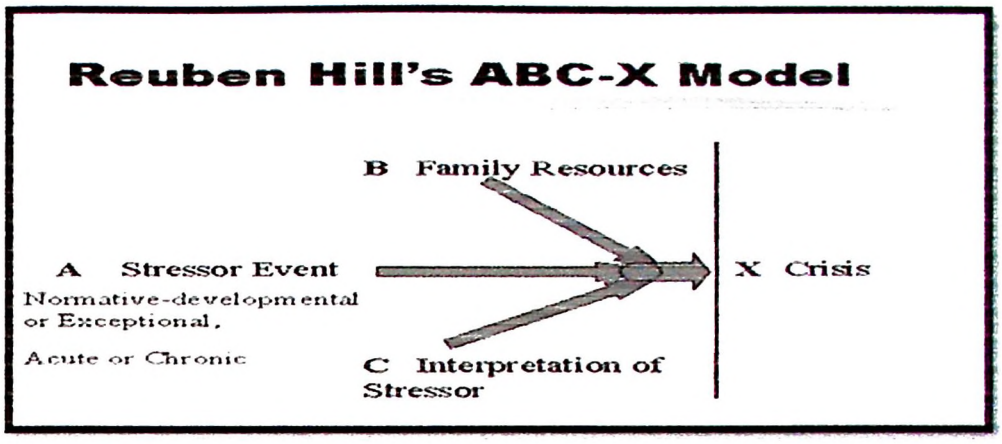

Figure 2.1 Reuben Hill's ABC- X Model. From "Work-Family Facilitation and Conflict, Working Fathers and Mothers, Work-Family Stressors and Support" by Hill, E. J., 2005, Journal of Family Issues, 26(6), 793-819.

CHAPTER 3

RESEARCH METHODOLOGY

3.1 Research Design

This study was a descriptive study with cross- sectional design. The descriptive study was aimed to identify the association between the variables and obtain a description of the individuals or groups. Meanwhile, cross- sectional design was used because this design took shorter time to collect data since the mothers of children with Down syndrome have to answer questionnaire once only.

3.2 Population Setting

Young (2004) defined that population as "all inhabitants of a given country or area considered together". The aim of this study was to assess the parenting stress level of mothers with Down syndrome children and identify factors which may correlates with parenting stress. In this study, the mothers with Down syndrome children who stayed in Kota Bharu were recruited to fulfill the purpose of study. The respondents in the study were recruited from Lion Club Down Syndrome centre Kota Bharu and Pediatric Clinic in Hospital USM.

3.3 Sampling Plan

The samples in this study were mothers of children with Down syndrome from Kota Bharu Lion Club Down syndrome and Pediatric Clinic in Hospital USM, Kelantan.

3.3.1 Sample

When conducting a research, certain inclusion and exclusion criteria were applied.

Inclusion Criteria

- Mothers of children with Down syndrome
- Able to communicate in Bahasa Malaysia or English
- Willing to participate in this study

Exclusion Criteria

- Mothers of children with others disabilities
- Mothers who has difficulty to communicate in Malay or English
- Not willing to participate in this study

3.3.2 Sampling Method

Purposive sampling was used in this study to select sample from a population which contains certain characteristic or criteria. Due to small population of Down syndrome children available in Pediatric Clinic in Hospital USM and Lion Club's Down syndrome center, purposive sampling was used to obtain adequate sample size.

3.3.3 Sampling Size

The researcher found that the population size for mothers of Down syndrome children in Lion Club Down Syndrome Children was around 25 whereas there were around 20 Down syndrome children came for follow- up in Pediatric clinic of Hospital USM.

According to Krejcie and Morgan's sample size table (1970) (refer to Table 3.1 in Appendix 1):

Total number of children with Down syndrome from Pediatric Clinic Hospital USM and Lion Club's Down syndrome Centre was 45. Therefore, the sample size required in this study was 40 participants.