# ASSOCIATION BETWEEN COPING SKILLS AND PSYCHOLOGICAL DISTRESS IN PARENTS OF CHILDREN WITH LEARNING DISABILITIES REFERRED TO THE PRIMARY SCHOOL OUTREACH PROGRAM IN SELECTED DISTRICTS IN KELANTAN

By:

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## DECLARATION

I hereby declare that the work produced in this thesis is of my own effort except for quotations and summaries which have been duly acknowledged.

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## CERTIFICATION

This is to certify to the best of my knowledge,

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## CONTENTS

# CONTENTS

(4) Brief COPE questionnaire for parents – Malay version

(5) Informed Consent Form

(6) Ethical Approval from Health Campus

## LIST OF TABLES

### Tables

# LIST OF FIGURES

## Figures

# ABBREVIATIONS

| | |
|---|---|
| HUSM | : Hospital Universiti Sains Malaysia |
| SD | : Standard deviation |
| SLR | : Simple Linear Regression |
| MLR | : Multiple Linear Regression |
| DASS | : Depression, Anxiety, Stress Scale |
| COPE | : Coping Orientation for Problem Experience |
| PSI | : Parent Stress Index |
| IQ | : Intellectual quotient |
| ID | : Intellectual disability |
| SFBT | : Seguin Form Board Test |
| BGT | : Bender Gestalt Test |
| WISC | : Wechsler Intelligence Scale for Children |

# GLOSSARY OF TERMS

| | |
|---|---|
| Parents | : Biological parents of the learning disabled children who were referred for screening during the Outreach program. |
| Children | : The word children in this study refer to children between age 7-12 with learning disabilities whom were screened during the Outreach program. |
| Learning disabilities | : In this study learning disabilities refer to children who has intellectual capabilities that do not conform with biological age and this includes late global development, down syndrome and intellectual disability. It also includes those with autism, attention deficit hyperactivity disorder and specific learning difficulties with regard to the Guidelines of Registration of Person with Disabilities Malaysia 2012. |
| Psychological distress | : Unpleasant, harmful stress due to inability to cope with stress. It is the outcome of this study and was measured by using the DASS 21 questionnaire which consists of 21 items (7 items from each domain) from 3 domains of depression, anxiety and stress. The cut off score for depression is 4, 3 for anxiety and 7 for stress. |

| | |
|---|---|
| Coping skills | : An effort by parents to cope with problems as a result of caring for the mentally disabled child. |
| Intellectual disability | : Intellectual disability (ID) refers to children who scored less than 70 in IQ test and it could be classified into mild, moderate, severe and profound. |
| Outreach program | : A screening program conducted by the Child Psychiatry Unit, HUSM in collaboration with Speech therapist, Occupational therapist and Clinical Psychologist done for primary school children who were identified by their teachers to have problems with their learning. This program was conducted at schools assigned by the Education Department of Kelantan which involved students from selected districts in Kelantan. |

## ABSTRAK

**HUBUNG KAIT DI ANTARA KEMAHIRAN MENANGANI MASALAH DAN TEKANAN PSIKOLOGI DI KALANGAN IBU BAPA YANG MEMPUNYAI ANAK-ANAK DENGAN MASALAH PEMBELAJARAN YANG DIRUJUK KEPADA PROGRAM OUTREACH DI SEKOLAH RENDAH DARI DAERAH YANG TERPILIH DI KELANTAN.**

**Latarbelakang:** Kanak-kanak dengan masalah pembelajaran merupakan satu kumpulan minoriti yang berisiko. Mereka terdedah kepada risiko untuk dipulaukan oleh masyarakat dan berkemungkinan dinafikan hak-hak mereka. Sehingga Disember tahun 2012 seramai 359,203 orang kurang upaya telah didaftarkan dengan Jabatan Kebajikan Masyarakat dan daripada jumlah tersebut 117,699 mengalami masalah pembelajaran. Jumlah ini mungkin bukan jumlah sebenar masalah pembelajaran di Malaysia kerana pendaftaran orang kurang upaya tidak diwajibkan dan sebaliknya adalah dibuat secara sukarela (Islam, 2015). Berdasarkan Garis Panduan Pendaftaran Orang Kurang Upaya 2012, masalah pembelajaran didefinisikan sebagai masalah kecerdasan otak yang tidak selaras dengan usia biologikalnya seperti Lewat Perkembangan Global, sindrom down dan kurang upaya intelektual. Ia juga merangkumi masalah seperti autism, attention deficit hyperactivity disorder dan masalah pembelajaran spesifik (2012).

Kajian terdahulu menunjukkan bahawa ibu bapa dengan anak-anak yang mempunyai masalah pembelajaran ini adalah lebih cenderung untuk mendapat tekanan psikologi. Ini berpunca daripada tekanan yang dihadapi oleh mereka dalam menguruskan anak-anak yang bermasalah seperti ini. Walau bagaimanapun setiap ibu bapa mempunyai cara yang berbeza bagi menyelesaikan setiap masalah yang dihadapi dan bukan semua ibu bapa mengalami gangguan psikologi disebabkan keadaan tersebut. Masalah ini kurang diberi perhatian secara amnya kerana kebanyakan ibu bapa tidak pernah mengadu mengenai tekanan yang mereka hadapi sepanjang membesarkan anak-anak dengan masalah ini ataupun sekiranya mereka mengadu tiada langkah sewajarnya diambil bagi menangani masalah tersebut.

**Objektif:** Tujuan kajian ini adalah untuk mengenalpasti sama ada ibu bapa yang mempunyai anak (anak-anak) dengan masalah pembelajaran mengalami tekanan psikologi serta mengenalpasti jika terdapat hubung kait di antara kemahiran menyelesaikan masalah yang digunakan oleh ibu bapa dan tekanan psikologi yang dialami.

**Metodologi:** Kajian ini adalah kajian keratan rentas yang melibatkan 74 orang ibu atau bapa kepada kanak-kanak sekolah yang dirujuk kepada program Outreach di negeri Kelantan, Malaysia. Kajian ini dilakukan pada masa ujian saringan dilakukan di sekolah iaitu 2 kali pada bulan Oktober dan satu saringan dilakukan di HUSM pada bulan November di mana kanak-kanak yang tercicir semasa program saringan dilakukan dinasihatkan supaya dibawa ke Klinik Psikiatri HUSM untuk disaring. Ibu bapa yang mempunyai anak (anak-anak) dengan masalah pembelajaran yang dirujuk kepada Program Outreach adalah dipelawa untuk mengambil bahagian di dalam kajian ini. Walau bagaimanapun ibu bapa yang didiagnos dengan penyakit mental dan tidak dapat berkomunikasi dalam Bahasa Melayu dengan baik akan dikecualikan daripada kajian ini**.** Ibu atau bapa yang dikenalpasti semasa program saringan akan diberikan soal selidik tentang maklumat peribadi dan dua borang soal selidik iaitu Depression, Anxiety and Stress Scale 21 (DASS 21) dan Brief COPE dalam bahasa Melayu.

**Keputusan:** Semua ibu bapa yang terlibat dalam kajian ini didapati menggunakan kombinasi teknik menyelesaikan masalah yang berbeza. Semua ibu bapa menggunakan pendekatan fokus kepada masalah sebagai teknik menyelesaikan masalah, manakala 77.0% lagi menggunakan pendekatan fokus kepada emosi sebagai teknik menyelesaikan masalah. Ibu bapa didapati mengalami tekanan psikologi di mana 29.7% mengalami ejala kemurungan, 44.6% mengalami gejala kerisauan dan 24.3% mengalami stres. Status sosio-ekonomi didapati tidak mempengaruhi tekanan psikologi yang dialami ibu bapa. Tahap IQ anak (anak-anak) dengan masalah pembelajaran juga didapati tidak mempengaruhi tekanan psikologi yang dialami ibu bapa. Walau bagaimanapun teknik penyelesaian masalah pembebasan tingkah laku didapati mempengaruhi ketiga-tiga masalah tekanan psikologi iaitu kemurungan, kerisauan dan stres (nilai signifikan, $p<0.001$, $p<0.001$ dan $p=0.003$). Kumpulan etnik bukan Melayu didapati mempengaruhi tekanan psikologi kerisauan dan stres (nilai signifikan, $p=0.026$ dan $p=0.001$). Faktor lain yang mempengaruhi adalah teknik penyelesaian masalah mengalihkan perhatian (nilai signifikan, $p=0.024$).

**Kesimpulan:** Ibu dan bapa yang mempunyai anak (anak-anak) dengan masalah pembelajaran adalah berisiko untuk mengalami tekanan psikologi seperti kemurungan, kerisauan dan stres. Teknik penyelesaian masalah yang kurang membantu didapati mempengaruhi ibu bapa mengalami tekanan psikologi. Status sosioekonomi dan tahap IQ anak (anak-anak) dengan kecacatan mental didapati tidak mempengaruhi ibu bapa mengalami tekanan psikologi. Kumpulan etnik didapati mempunyai perkaitan dengan tekanan psikologi. Walau bagaimanapun perkaitan ini tidak dapat disahkan dan memerlukan kajian lanjut. Oleh itu adalah disarankan agar setiap ibu bapa yang mempunyai anak (anak-anak) dengan masalah pembelajaran disaring bagi mengesan wujudnya tanda-tanda tekanan psikologi dan mereka juga perlu diberikan panduan mengenai teknik penyelesaian masalah yang betul.

## ABSTRACT

## ASSOCIATION BETWEEN COPING SKILLS AND PSYCHOLOGICAL DISTRESS IN PARENTS OF CHILDREN WITH LEARNING DISABILITIES REFERRED TO PRIMARY SCHOOL OUTREACH PROGRAM IN SELECTED DISTRICTS IN KELANTAN

**Background:** Children with learning disabilities are one of the vulnerable minority populations in Malaysia. They are at risk of social exclusion and could be denied of their rights. By December 2012 there were 359,203 persons with disability were registered with Department of Social Welfare in which 117,699 were having learning disabilities. This number might not reflect the actual number of Person with Disability in Malaysia since the registration is not compulsory but based on voluntary effort (Islam, 2015). According to the Guidelines for Registration of Person with Disability 2012 Learning Disability is defined as intellectual capabilities that do not conform with biological age and this includes late global development, down syndrome and intellectual disability. It also includes those with autism, attention deficit hyperactivity disorder and specific learning difficulties (2012).

From previous studies, parents of children with learning disabilities were more vulnerable to develop psychological distress such as depression, anxiety and stress. This could me due to the stressors they faced in managing their child with disabilities. However, different parents have their own ways of dealing with everyday problems and not all of them will end up having psychological distress. In general, this problem was not addressed adequately as many parents do not report or discuss the difficulties that they experienced when dealing with these problematic child or if they had discussed it with doctors there are no appropriate measures taken to solve their problems.

**Objectives:** The objective of this study is to identify whether parent of children with learning disabilities have psychological distress and to determine whether there is an association between coping skills that they used and psychological distress that they developed.

**Methods:** This is a cross sectional study involving 74 parents (either father or mother) which their child are referred to the Outreach Program in Kelantan, Malaysia. The children who were found to have problems in learning were identified by their teachers and referred to this program for further assessment and evaluation. This study was done in three occasions, 2 screening program done in October and one was done at Psychiatry Clinic HUSM in November for those who missed the program at school were advised to come to clinic for screening. Parents of children with mental disabilities aged 7-12 years old whom were referred to the Outreach program were invited to participate in this study.

However those parents diagnosed to have mental illness and who could not communicate well in Bahasa Melayu were excluded from this study. The parents who were identified during the screening program and agreed to participate in this study were given personal information form and two questionnaires which are Depression, Anxiety and Stress Scale 21 (DASS 21) and Brief COPE in Malay version.

**Results:** All of the parents were found to use different combination of coping skills. All of them were found to use problem focused coping skills and 77.0% used emotion focused coping skills. They were also found to have psychological distress in which 29.7% were having depressive symptoms, 44.6% were having anxiety symptoms and 24.3% were having stress. Socio economic status of the parents and the IQ of the disabled child were not associated with psychological distress. Behavioural disengagement coping skills was found to be associated with depression, anxiety and stress ($p<0.001$, $p<0,001$ and $p=0.003$). Ethnicity was found to be associated with anxiety and stress ($p=0.026$ and $p=0.001$). Stress was found to be associated with coping skills of self-distraction ($p=0.024$).

**Conclusions:** Parents of children with learning disability are at risk of developing psychological distress. Less useful coping skills were associated with psychological distress. Socioeconomic status and IQ level are not associated with psychological distress. Association between ethnicity and psychological distress was unable to be confirmed and needed further research. Therefore it is recommended that all parents of children with learning disabilities should be screened for psychological distress and they are given some guidance to cope effectively with their problems.

# CHAPTER 1

## INTRODUCTION

Disabilities is a term used covering impairments, activity limitations, and participation restrictions; in which impairment is a problem in body function or structure; activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual in involvement in life situations (World Health Organisation). Learning disability by definition from the WHO would be generally covers the old stigmatizing term of 'mental retardation' which is now replaced with the term of 'intellectual disability'. However in Malaysia the Guidelines for Registration of Person with Disabilities 2012 had includes those with Attention Deficit Hyperacticity Disorder, Specific Learning Disability and Autism Spectrum Disorder to be categorized under the term Learning Disability. In Malaysia as for 2012, there were 29 289 children registered with disabilities. Majority of them were having learning disability which account for 19 150 children with 44% were between 7-12 year old (Malaysia, 2014). The number of children with disabilities especially with learning disabilities may not represent the actual number of these children. This is because in Malaysia the registration of children or person with disabilities is not compulsory. We would expect that there are many children with disabilities who are not registered and hence would be denied of their rights to get same treatment as any other normal children. This report was made to make sure that children with disabilities in Malaysia will get the equal rights of getting education, health and access to other services provided by the authorities. To date, services for children with learning disabilities are still very limited. We are aiming to practice inclusive education in which children with any type of disabilities will have the same chance and rights to get education as other normal child. However this would need skillful teachers and the stakeholders to make policies and provide appropriate services to achieve this goal.

Unfortunately, the data collection of children with disabilities is not systematic and many of them were under represented. There is also low detection rate of children with learning disabilities since no specific organization was appointed to deal with this screening program. Although the Literacy and Numeracy Screening (LINUS) was introduced, it missed to detect some form of learning disabilities and the screening tools used may not be appropriate as some students with learning disabilities might pass the test. Furthermore the decision to place a student with learning disabilities lies on the Special Education Coordinator or the School Principal within the school concerned but due to lack of streamlined process of detecting disabilities and choices of placement leading to its misuse. There were reports that children with learning disabilities were placed in special education system to avoid impact on the overall academic performance for public exams. The enrolment of students into Inclusive Education Program also had substantially declined from 6360 in 2010 to 562 in 2012 (Malaysia, 2014). A study done in several schools in Kelantan involving urban and rural schools, teachers were found to have poor knowledge about learning disabilities and about medical and health professions. The teachers also had limited knowledge about classroom management practice. However the special education teachers were found to have better knowledge about learning disabilities and classroom management practice as compared to regular teachers (Rahim, 2011). A survey done in 107 secondary school teachers found that the most commonly observed disorders were difficulty paying attention, difficulty learning a second language, being fidgety and having difficulty sitting still, and having poor comprehension. They also observed that when parents noticed about their child's disability they tend to send the child for lots of tuition, and to be very frustrated with the child. Some parents even neglected their children's learning disorder, and did not seem to realise how serious the problem was. Although generally many schools were having teachers and counselors for children with special needs and having regular talks and workshops, teachers felt that they had lack of support in assisting children with learning disabilities (Teoh *et al.*, 2008).

Children with learning disabilities were also prone to get comorbidities of emotional and behavioral disturbances. For those with intellectual disability they could get depression or anxiety, having low self- esteem and even psychosis. As for Attention Deficit Hyperactive Disorder, 20-30% of them may also have intellectual disabilities as well as depression and anxiety but what is more alarming is they could develop Oppositional Defiant Disorders or Conduct Disorders (Allington-Smith, 2006; Martin, 2013). If this condition could be detected earlier then appropriate management would prevent further damage to the child. In addition to that our social support system for the family with disabled children is still lacking. Our social network is not as good as in the Western countries. A study done at rehabilitation centers in Selangor revealed that many needs of parents who have children with disabilities are still not met. Many of them felt that they need more information regarding their child's condition which was the highest rating of the unmet needs. This is followed by the need for social support, community services, financial support, family functioning and need for explaining to others regarding their child's condition (Sharif *et al.*, 2011).

Another alarming situation of person with disabilities in Malaysia is social exclusion. Although there are laws to protect person with disabilities in Malaysia, the policies seems to make them becoming more dependent instead of becoming independent. The access rights of persons with disabilities are fundamental rights to education, labour and cultural activities (the right to use various modes of public transportation to ensure mobility, the right to use public facilities, the right to access information) with an aim to ensure equal opportunities and active participation in society. Unfortunately the process of social exclusion of disabled people starts from their family, where they live with their parents, sisters/brothers, close relatives, and within family facilities and recreations. In Malaysian society, family is a very important social institution, where a child is born and brought up (Islam, 2015). Parents of disabled child tend to be overprotective towards their child and felt that having them in the family is a burden which further compromised their disabilities.

As for the current situation, we could see that many children with learning disabilities were referred to either special education schools or special education integration program. Hence their percentage in total student population in national school system is low at around 1% (Malaysia, 2014).

This figure shows the process of social exclusion in person with disabilities (Islam, 2015):

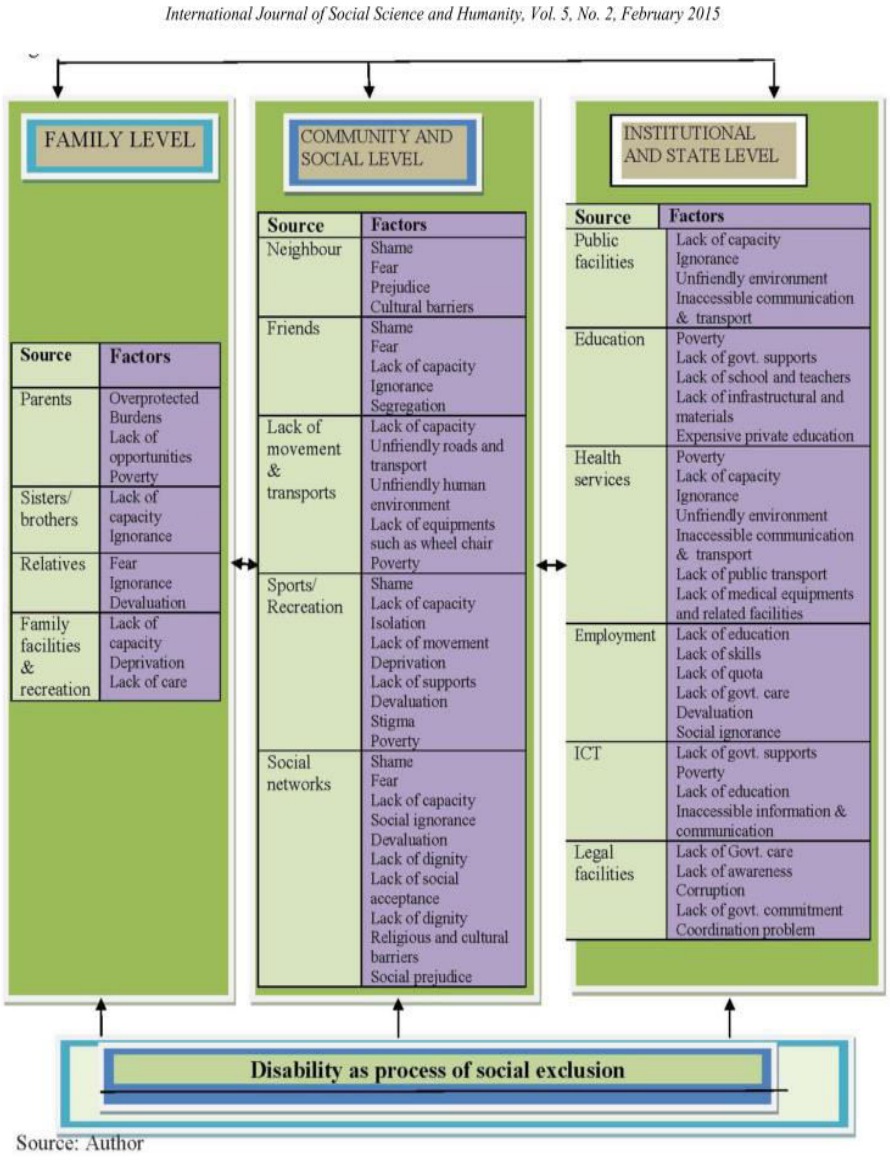



Figure 1.1 The Process of Social Isolation in Person with Disabilities in Malaysia

The term psychological distress is widely used as an indicator of the mental health of the population in public health, in population surveys and in epidemiological studies and, as an outcome, in clinical trials and intervention studies. However the definition of psychological distress is still vague. Scientifically, the expression "psychological distress" is often applied to the undifferentiated combinations of symptoms ranging from depression and general anxiety symptoms to personality traits, functional disabilities and behavioural problems. Psychological distress is largely defined as a state of emotional suffering characterized by symptoms of depression (e.g.,lost of interest; sadness; hopelessness) and anxiety (e.g.,restlessness; feeling tense) (Mirowsky and Ross, 2002). However due to the vagueness of the term others define distress as a consequence of having stressors but depending on the state of coping resources at the time of stressor. It is not at all clear how stressors turn into distress. Some specific problems that people face may not be defined as a problem for them, but this does not mean it will have no impact on their mental health over time only that the person has habituated to them (Wheaton and Montazer, 2009).

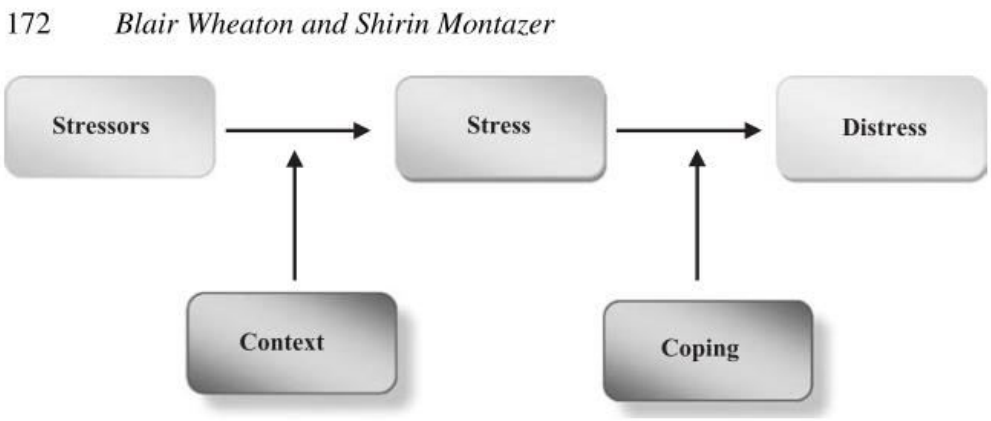



Figure 1.2 Stress, Stressor and Distress

Stressors are defined as conditions of threat, challenge, demands, or structural constraints. This implies that stressors can occur in different ways, representing a type of environmental pressure. Threats involve the possibility or expectation of potential harm. Challenges imply more effort is necessary and that usual response is not enough. Demands involve the load component of stressors, or also commonly referred as "burden" or "overload." Structural constraints stand for reduced opportunities, choices, or rewards resulting from severe or non-self-limiting social disadvantage. There is difference in how a person acknowledges a problem as a stressor. It may not be as threatening to one person as to another because he or she has experienced it before. There are two versions of stress concept :

i. The Biological Stress Model (Selye, 1965) consist of 4 stages

   a. stressors: events and conditions that represent threat or insult

   b. conditioning factors that alter the impact of the stressor on the organism

   c. general adaptation syndrome (GAS), an intervening state of stress in the organism,

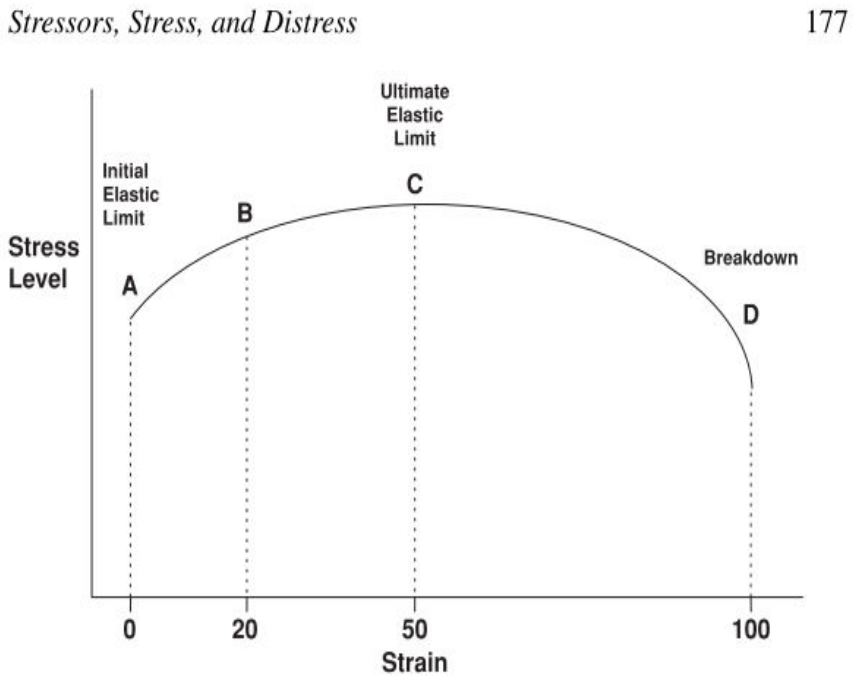
   d. responses, adaptive or maladaptive (distress)

ii. The Engineering Stress Model (Smith, 1987)

   The "original" stress model was formulated to understand the effects of external forces on the integrity of metals. Hence stress is essentially an external force acting against a resisting body. Figure 1.3 below show the curve of relationship between stress and strain according to the engineering model. In the engineering model, strain is the response state of the material (distress). The level of stress is shown on the Y axis, the level of strain on the X axis. As long as the stress applied does not exceed point A, it will not

exceed its elastic limit, and it will return to its original shape after the stress is removed. The model does allow for changes in the elastic limit and when stress exceeds A, to level B, the material is able to adjust by elongation or compression (coping) and, in the process, achieve a new, greater elastic limit thus became stronger. However at some point the individual's ability to respond with adjustments that enhance strength will no longer be possible. If stress is applied beyond point C it will lead to point D, known as fracture or breakdown (Wheaton and Montazer, 2009).

Figure 1.3 The stress versus strain curve in the engineering stress model



Many studies showed that parents of children with learning disabilities had some degree of psychological distress. Parents with autistic children have high prevalence of stress and psychological disturbances. They experience periods of disbelief, deep sadness and depression and self-blame and guilt whereas others experience helplessness, feelings of inadequacy, anger, shock and guilt. (Nikmat *et al.*, 2008; Bashir *et al.*, 2014). Significantly high proportion of parents of children with intellectual disability has psychiatric diagnosis of anxiety, depression or both and the psychiatric diagnosis is associated with gender of parent; and,severity of disability. Mothers reported higher levels of stress and depression as compared to fathers (Mbugua *et al.*, 2011; Azeem *et al.*, 2013a; Kawa and Shafi, 2013). In general, mothers of children with intellectual disabilities report greater parenting demands, increased stress levels and poorer physical and psychological health as compared to fathers as they typically report lower levels of psychological distress than their spouses (IASSIDD, 2014). There is higher parenting stress in parents of children with ADHD and was associated with severity of ADHD symptoms, cooccurring conduct problems and internalizing symptoms.Mothers of ADHD children are more psychologically distressed which was contributed mainly by severity of symptoms of their ADHD children, non-Malay parents more stressed than the Malay parents (Musa and Shafiee, 2007; Neelaveni Narkunam *et al.*, 2012; Theule *et al.*, 2013).

Factors that could lead a person to have psychological distress include age, gender, income, education, employment, household size and ethnicity. Many studies had been done to show the association between socioeconomic status and psychological distress (Weich and Lewis, 1998; Baum *et al.*, 2000; Muntaner *et al.*, 2004; Hammen, 2005; Skapinakis *et al.*, 2006). Studies had proven that many major mental illnesses were related to the socioeconomic status of a person. Those who belong to the lower socioeconomic status were at higher risk of getting major mental illnesses due to the greater risk of exposure to stress as compared to those in the higher socioeconomic status. Those who were in the low socioeconomic status group are also having less chances of getting a good health services. Ethnicity also play some role in which those who belong the minority group also having disadvantaged in term of getting good health services and other social services in a country.

As mentioned above having a stressor or many stressors do not necessarily cause distress because it depends on the coping resources available at that time. Coping is a term that we used to indicate how people overcome a stressful situation. It does not matter whether the strategy that was chosen is successful or not but the process of trying to find the solution that matters most. It is different from each individual depending on their personality and how they were brought up. It is gain through learning from what others do to handle difficult situations or from our own past experiences. Besides that our way of appraising a situation also will determine our coping strategies. A person may appraise a situation as threatening and stressful whereas the other person may not view it as threatening or a stressful encounter. Majority of people tend to use a combination of coping strategies rather that one single strategy in dealing with a demanding situation. Furthermore, there is no evidence to prove that one specific strategy is working in a certain situation. We learn how to cope by trial and error, using a strategy and change to another one if it is not successful. Each and every one of us should be having a reservoir of coping skills by the time we reach adulthood. These important skills can be used interchangeably depending on the situations and what we have learned from the past. Although it is good to have skills in coping with problems, not all coping skills are good. Several coping skills may be immature and will not be effective in solving problems and in fact it may worsen it.

According to Lazarus & Folkman, coping is defined as a constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands which are viewed as taxing and exceeding the person's resources (Lazarus and Folkman, 1984). This definition shows that coping is a process oriented as reflected by the phrase constantly changing and specific demands. It is not an automatized adaptive behavior which is effortless, whereas it needed some efforts to come out with a coping strategy. It is not equal to outcome as coping could be anything that a person does or thinks whether it gives a good or bad result. Finally, coping is not mastery but it is a skill that we use to manage challenging situations by minimizing, avoiding, tolerating or accepting the stressful condition.

Coping has several features including observations and assessments which refer to what actually a person does or thinks rather that what the person usually do, will do or should do. The observations and assessments are then examined within a specific context and usually directed towards a particular condition. Coping is subjected to change according to the changes in the person- environment relationships. The dynamics and change that characterize coping process are not random but they are actually a continuous appraisals and reappraisals of the shifting person-environmental relationships. Coping functions as regulating emotions and altering the troubled situation faced by a person. It is a process and it depends on the cognitive appraisal of the individuals involved. There are several key features in defining coping, first it is process oriented, in which it focused on what a person actually thinks and do in a specific stressful situation. Second, it is contextual, in which combination of the person's appraisal and the situation triggers the coping effort. Lastly, coping is simply a person's effort to manage demands whether the effort is successful or not (Folkman *et al.*, 1986).

The major functions of coping skills are to regulate stressful emotions and altering the troubled person-environment relation causing distress (Folkman *et al.*, 1986; Carver *et al.*, 1989). Thus coping skills can be generally classified into emotion-focused coping, problem-focused coping and appraisal-focused coping. As mentioned above, coping is a process in which it consists of:

i) Primary appraisal - perceiving a threat to oneself

ii) Secondary appraisal - bringing to mind potential response to the threat

iii) Coping - executing the response

Emotion-focused coping involves trying to reduce the negative emotional responses associated with stress such as embarrassment, fear, anxiety, depression, excitement and frustration. It is usually used when it is the only realistic option when the source of stress is out of the person's control. On the other hand problem-focused coping targets the causes of stress in practical ways which tackles the problem or stressful situation that is causing stress, directly reducing the stress (McLeod, 2010). Coping can also be adaptive (positive

reframing, planning, active coping, acceptance, seeking instrumental support) and maladaptive (mental and behavioral disengagement, denial, venting on emotion, substance abuse).

There are not many studies done to examine relationship between psychological distress and coping in parents of children with disabilities in Malaysia. A study done in 2004 at a rehabilitation center on mothers of children with chronic disabilities found that the mothers were using a mixture of coping strategies. However, they scored more in the task-oriented and emotion-oriented coping styles. Single mothers and those with low educational level tend to use emotion-oriented coping strategies while mothers with younger children (< 5 years old) used more avoidance coping strategies. However there were no significant difference of coping styles in association with the mothers' age, ethnicity, duration of marriage, number of siblings, child's birth order or gender (A H Nor Zaidah *et al.*, 2004). In a study on parents of ADHD children, coping by more use of positive reframing (thinking about problems as challenges that might be overcome) was associated with higher role satisfaction for both mothers and fathers and community supports were associated with higher distress for mothers only(Podolski and Nigg, 2001). .One study found that generally, mothers of children with autism who use avoidant coping (distraction and disengagement) was found to be associated with increased levels of maternal depression and anger, while use of cognitive reframing was associated with higher levels of maternal well-being (Benson, 2010). Another study in parents of children with intellectual disability found that psychological stress and coping were inversely related to each other. Gender of the parents did not have any impact over psychological stress and coping scores, however higher educational level was associated with lower psychological stress and higher coping strategies (Venkatesh Kumar, 2008).

Based on studies done previously that having children with learning disabilities could expose parents to significant stress therefore study to examine the relationship between psychological distress and coping is needed to look into the ways that these parents could be helped to cope with their problems effectively.

In this study we will be looking into depressive symptoms, anxiety symptoms and stress as the psychological distress outcome in these parents. It will be measured objectively by using the validated questionnaire of DASS 21.In this study parents with children who had learning disabilities were chosen as participants. It was not uncommon for these parents to have psychological distress looking at the stressor that they had to face. However there might be parents who were not as affected as the others. Probably this could also be related to their socioeconomic status. The children in this study were having learning disabilities such as attention deficit hyperactive disorder, intellectual disability and others. The severity of disability was also different between each other. This could be other factors that might influence the outcome of psychological distress in these parents.

# LITERATURE REVIEW

## 1.1.1 Learning disabilities in Malaysia

Learning disability by definition from World Health Organization (WHO) refers to mental retardation or the new term introduced intellectual disability which is less stigmatizing. Learning disability could be categorized into different categories based on intelligent quotient assessment namely, mild, moderate, severe or profound. However in Malaysia learning disabilities by definition from Welfare Department includes learning disorders, attention deficit hyperactivity disorder, autism spectrum disorder, specific learning disorders (2012). By year 2012, there were 29,289 children with disabilities were registered and majority of them, 19,150, were having learning disabilities. Children aged 7-12 year old represent 44% of children with learning disabilities. This number could be under represented as many children were still not registered. UNICEF representatives had produced a report in order to get equal rights for children with disabilities especially the rights to get education without being discriminated. Therefore the need for inclusive education system is crucial. Many children with disabilities were referred to Special Needs Education or Special Education Integration Program. This further compromised their ability to learn as many of them were actually educable (Malaysia, 2014). Children with disabilities were also vulnerable to social exclusion. This process of social exclusion started at home within the child's own family. The parents will be overprotective towards their disabled child and with poor socioeconomic status and low education level the parents may not realized the problems faced by their child (Islam, 2015). Therefore it is important to be able to detect these children so that the rehabilitation process could be started early.

### 1.1.2 Psychological distress in parents of children with learning disabilities

It is not uncommon for parents of children with learning disabilities to develop psychological distress due to their children's condition. As we know that the disability may require more attention and time from their parents in order to care and nurture them. This could be due to the rehabilitation program and special classes that they may have to attend. Literature had shown that parents of children with learning disabilities were affected by psychological distress of depression, anxiety and stress (Kashdan *et al.*, 2004; R. Hassall *et al.*, 2005; Khamis, 2007; Musa and Shafiee, 2007; Nikmat *et al.*, 2008; Mbugua *et al.*, 2011; ShakilaYousefia *et al.*, 2011a; ShakilaYousefia *et al.*, 2011b; Kobayashi *et al.*, 2012; Theule *et al.*, 2013).

All the studies were done in children with specific learning disabilities such as ADHD, intellectual disability (previously known as mental retardation) and autism spectrum disorder. Researchers also use the term of developmental delay for those children with learning disabilities. However many of the studies were done in mothers as compared to fathers or both parents. This could be due to the mother's role as the primary care giver of the children as compared to fathers. It could also be due to the higher risk of mothers to develop psychological distress as compared to fathers. The studies mentioned above used PSI and DASS 21 as the scale to measure psychological distress in the affected parents.

Psychological distress in these parents is important to be identified as it would affect the dynamics of the family. It could cause marital disharmony as well as poor relationship with other children who were normal. The other children would feel distant from the parents as they were not given similar amount of attention as the disabled child. The relationship between siblings would also be affected.

### 1.1.3 Coping skills in parents of children with learning disabilities

Coping skills is essential for life. All of us will face a great deal of stress throughout our lives. Coping skill is an acquired skill which helps reduce the stress whether it is successful or not. Coping skills are used whether or not it can resolve a problem. More often than not it will only resolve the emotional disturbance arose from the demanding situation. Ideally adapting a problem focused coping skills is a preferred ways of coping. However not every one of us will use the effective ways of coping.

Literature found that majority of parents with learning disabled child were adapting problem focused coping as their ways of coping as well as emotion focused coping especially in mothers (Miller *et al.*, 1992; Nigg, 2001a; Matud, 2004; Hastings *et al.*, 2005; Lopez *et al.*, 2008; Roy McConkeya *et al.*, 2008; Venkatesh Kumar, 2008). The coping skills however very much determined on several other factors. A few studies found that age, gender, educational status as well as personality of the parents are some factors that determined the coping skills they used in rearing children with mental disabilities while other studies did not find these factors significant (Heiman, 2002; Glidden *et al.*, 2006; Gray, 2006; Lopez *et al.*, 2008; Venkatesh Kumar, 2008).

Identifying coping skill is important as emotion focused coping skills would expose parents to a greater risk of psychological distress. Emotion focused coping will not solve the problems but it will give a temporary relief for the emotional disturbance hence one of coping skills function as regulating emotion. The selection of coping skills also depends on how the parents perceived the problems, whether something can be done or nothing can be done to solve it.

### 1.1.4 Socio-demographic factors, children's characteristics and coping skills as contributing factors for psychological distress in parents of children with learning disabilities

Psychological distress in parents of children with learning disabilities varies. Rearing disabled child not uncommonly exposed the parents to develop a great deal of stressful situation. This is due to the extra care and effort needed by these children in order to make sure that they could live as a normal child. However not many parents are able or motivated in doing this. This may have been determined by several factors such as socioeconomic status, personality and the coping skills applied by these parents.

Literature had done studies to compare several factors such as gender, age, severity of disability, age of disabled child, educational level, personality of the parents, diagnosis of the disabled child and coping style which they assume would cause the parents suffered from psychological distress. In a study done in India in normal parents of mentally retarded children, they found that educational level of the parents was a significant factor in relation to psychological distress and coping scores. Those parents with low educational level scored high in psychological distress and scored low in coping scores. However gender did not show to have significant effect (Venkatesh Kumar, 2008).

Other study showed that as parents aged they tend to switch from problem focused coping towards emotion focused coping (Gray, 2006). In this study Dr David E. Gray found that parents with autistic child switched their ways of coping after 8 to 10 years from problem focused coping such as seeking instrumental and emotional support towards emotion focused coping such as turn into religion and acceptance.

Personality of the parents also plays an important role in determining whether they are at higher risk of getting psychological distress (Glidden *et al.*, 2006). In this study, adoptive and biological parents of children with developmental disability were compared with regards to their personality and coping styles. Both adoptive

and biological parents used more of problem focused coping styles as compared to emotion focused coping style. Neuroticism was found to predict coping of escape avoidance which result into higher depression score and lower subjective well-being score as compared to those with positive reappraisal (Glidden *et al.*, 2006)

Other factors studied were socio demographic factors of the parents such as employment status, low income, marital status, gender and educational level. These factors were found to be associated with psychological distress in parents with mentally disabled child (Khamis, 2007; Nikmat *et al.*, 2008; Roy McConkeya *et al.*, 2008; Mbugua *et al.*, 2011). The study by Mbugua (2011) even found that being married was a significant factor associated with increased risk of depression in rural part of Kenya. Gender was associated with increased risk of psychological distress probably due to the difference in women's appraisal of a problem.

Severity of symptoms of the disabled child was also found to be associated with psychological distress in parents. Behavioural symptoms in children with mental disability were not uncommon. Several studies found that the greater the disability or symptoms there was higher risk of getting psychological distress (Nigg, 2001b; Kashdan *et al.*, 2004; R. Hassall *et al.*, 2005; Khamis, 2007; Musa and Shafiee, 2007; Lopez *et al.*, 2008; Theule *et al.*, 2013).

Children's characteristics were also an important factor that was found to be associated with higher risk of psychological distress in parents. Children with younger age were associated with higher risk of psychological distress (Khamis, 2007; Mancil *et al.*, 2009; Azeem *et al.*, 2013a). Disabled child with comorbid chronic illness and care for more than one disabled child were also associated with higher risk of psychological distress (Azeem *et al.*, 2013a).

Other factors associated with psychological distress were family environment, difficulty finding accurate diagnosis, difficulty assessing social support, social isolation and disruption in informal support (Khamis, 2007; Mancil *et al.*, 2009). Study by Khamis (2007) found that achievement-oriented family was associated with higher risk of psychological distress in parents.

### 1.1.5 Intellectual quotient as a factor associated with psychological distress in parents of children with learning disabilities

Learning disabled child is not always associated with low intellectual quotient (IQ). Many of them are having normal IQ especially those with attention deficit hyperactive disorder (ADHD) or learning disability. However a few of them may have underlying intellectual disability which is not detected during the earlier childhood life until they started schooling. Intellectual disability (ID, previously known as mental retardation) is more associated with lower IQ level which has different level of severity namely mild, moderate, severe and profound.

Mild, moderate, severe and profound ID was all associated with depression and anxiety in their parents (Upadhyaya and Havalappanavar, 2008; Karasavvidis *et al.*, 2011; Azeem *et al.*, 2013a; Kawa and Shafi, 2013; Bashir *et al.*, 2014). Having low IQ does not mean that the child could not be trained at all. For those with mild to moderate ID, they could be trained to be independent of activities of daily living. However academically, they may not be able to achieve the level of child with normal IQ especially those having comorbidity with ADHD.

The ideal instrument for assessment of IQ will be the Wechsler Intelligence Scale for Children (WISC). However this scale is a lengthy assessment and requires substantial amount of time. For this study only screening assessment will be used, the Seguin Form Board Test (SFBT) and Bender Gestalt Test (BGT). Identification of intellectual disability in these children hopefully not to label or discriminate them but it is for justification that they are not suitable to be in the main stream education which would not give them any benefit. If they are place in the special education school then they will be taught on domestic skills that are essential for them to be independent in their basic ADL.

# CHAPTER 2

## OBJECTIVES AND HYPOTHESIS

### 2.1 General objective

To determine the association between coping skills and psychological distress in parents of children with learning disabilities.

### 2.2 Specific objectives

2.2.1 To determine the psychological distress (anxiety, depression and stress) among parents of children with learning disabilities.

2.2.2 To determine the pattern of coping style among parents of children with learning disabilities.

2.2.3 To examine the association between socio-demographic factors and the psychological distress (anxiety, depression and stress) among parents of children with learning disabilities from primary school in selected districts in Kelantan.

2.2.4 To examine the association between children's characteristics and the psychological distress among parents of children with learning disabilities from primary schools in selected districts in Kelantan.

2.2.5 To examine the association between coping skills and the psychological distress among parents of children with learning disabilities from primary schools in selected districts in Kelantan.

2.2.6 To examine the association between intelligent quotient of children and psychological distress among parents of children with learning disabilities from primary schools in selected districts in Kelantan.

2.2.7 To examine the association between socio-demographic factors, children's characteristics and coping skills as contributing factors to the psychological distress among parents of children with learning disabilities from primary schools in selected districts in Kelantan..

## 2.3 Research questions

2.3.1 What is the psychological distress commonly affects parents of children with learning disabilities?

2.3.2 What are the common coping skills used by parents of children with learning disabilities to cope with stress?

2.3.3 What is the association between socio-demographic factors and psychological distress (anxiety, depression and stress) among parents of children with learning disabilities from primary school in selected districts in Kelantan?

2.3.4 What is the association between children's characteristics and the psychological distress among parents of children with learning disabilities from primary schools in selected districts in Kelantan?

2.3.5 What is the association between coping skills and the psychological distress among parents of children with learning disabilities from primary schools in selected districts in Kelantan?

2.3.6 What is the association between intelligent quotient of children and psychological distress among parents of children with learning disabilities from primary schools in selected districts in Kelantan?

2.3.7 What is the association between socio-demographic factors, children's characteristics and coping skills as contributing factors to the psychological distress among parents of children with learning disabilities from primary schools in selected districts in Kelantan?

## 2.4 Research Hypothesis

2.4.1 The psychological distress commonly affect parents of children with mental disabilities are depression, anxiety and stress.

2.4.2 The common coping skills used by parents of children with mental disabilities are combination of various coping skills.

2.4.3 There is no association between socio-demographic factors and psychological distress in parents of children with learning disabilities from selected districts in Kelantan.

2.4.4 There is no association between children's characteristics and psychological distress in parents of children with learning disabilities from selected districts in Kelantan.

2.4.5 There is no association between coping skills and psychological distress in parents of children with learning disabilities from selected districts in Kelantan.

2.4.6 There is no association between intelligent quotient and psychological distress in parents of children with learning disabilities from selected districts in Kelantan.

2.4.7 There are no association between socio-demographic factors, children's characteristics and coping skills as contributing factors to the psychological distress in parents of children with learning disabilities from selected districts in Kelantan.

# CHAPTER 3

# METHODOLOGY

## 3.1 Research design

The study was a cross sectional study.

## 3.2 Study setting/ location

This study was done on 3 occasions in October and November 2014. The first location was at SK Seri Bemban, Kota Bharu, the second location was at Dewan Orang Ramai, Gua Musang and the third location was at Psychiatry Clinic HUSM. During every screening program, the same setting was used. The children was screened at five different stations namely vision test, hearing test, speech therapist, occupational therapist and IQ test before referred to Child Psychiatrist or Medical Officer to certify whether they were having learning disabilities or not. While these children were screened their parents were approached to participate in this study.

## 3.3 Population and sample

### 3.3.1 Reference population

Parents of children who are having learning disabilities in Kelantan.

### 3.3.2 Source population

Parents of children with learning disabilities whom their children attended primary school in Kelantan.

## 3.4 Sampling frame

Parents of children with learning disabilities whom their child attended primary school and were referred to the Outreach program.

## 3.5 Inclusion and exclusion criteria

The participants in this study were selected according to the following criteria:

### 3.5.1 Inclusion criteria

i) Parents of children with learning disabilities aged 7-12 year old whom their children were referred to the Outreach program. (Learning disabilities are diagnosed by Child Psychiatrist or Medical Officer MMed students in Psychiatry after the child completed all screening at various stations as mentioned before, also based on the Vanderbilt Assessment Scale for parents and teachers and clinical assessment by the specialist or medical officers).