UNIVERSITI PUTRA MALAYSIA

PSYCHOLOGICAL EFFECTS AND THEIR ASSOCIATED FACTORS AMONG CAREGIVERS OF DISABLED CHILDREN IN COMMUNITY BASED REHABILITATION CENTRES IN SELANGOR

GROUP 30

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ABSTRACT

Background: Caregivers of disabled children face various challenges which affect their psychological well-being. Therefore, this study was carried out to determine the factors influencing the psychological effects among caregivers of disabled children below 18 years old in Community-Based Rehabilitation (CBR) Centres in Selangor. **Materials and Methods:** This study was conducted using secondary data. The respondents were re-selected from the existing data by simple random sampling using a table of random numbers. Data that was extracted from the primary data were the psychological effects (depression, anxiety and stress), sociodemographic factors and characteristics of the disabled children. The data were analysed using the standard statistical software package IBM SPSS Statistics V25.0 for Windows. **Result:** Out of 240 respondents, the prevalence of depression was 20.8%, anxiety 34.2% and stress 15.8%. There was significant association between depression and level of education ($\chi 2$ =6.319; df 2; p=0.042) and child receiving other types of education ($\chi 2$=4.412, p=0.036). The analysis also showed that anxiety was significantly associated with caregivers with medical problems ($\chi 2$ =5.668; df 1; p=0.017), child's gender ($\chi 2$=4.154; df 1; p=0.042) and types of disability ($\chi 2$=9.419; df 2; p=0.009). Factors that were significantly associated with stress were monthly income ($\chi 2$ =4.318; df 1; p=0.038), presence of medical problems ($\chi 2$ =8.539; df 1; p=0.003), attainment of education among the children ($\chi 2$ =7.795; df 1; p=0.005) and number of years attending CBR ($\chi 2$ =13.197; df 2; p=0.001). **Conclusion:** The psychological effects and their influencing factors need to be addressed and the caregivers need to be given support to ensure their mental wellbeing.

Keywords: *psychological effects, caregivers, disabled children, community-based rehabilitation centre, depression, anxiety, stress*

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ABSTRAK

Latar belakang: Penjaga kanak-kanak kurang upaya menghadapi pelbagai cabaran yang akan mempengaruhi kesan psikologi. Oleh itu, kajian ini dilakukan untuk menentukan kesan psikologi di kalangan penjaga kanak-kanak kurang upaya di bawah umur 18 tahun di CBR di Selangor. **Metodologi**: Kajian ini dijalankan dengan menggunakan data sekunder. Kajian ini akan menggunakan pensampelan rawak mudah dengan menggunakan Jadual nombor rawak. Data yang diperolehi daripada kajian terdahulu yang merangkumi sumber maklumat mengenai kesan psikologi, sosiodemografi dan ciri-ciri kanak-kanak kurang upaya. Data sekunder akan dianalisis menggunakan pakej perisian statistik standard IBM SPSS Statistik V25.0 untuk Windows. **Keputusan:** Daripada 240 responden, kelaziman kemurungan adalah 20.8%, manakala kebimbangan adalah 34.2% dan tekanan adalah 15.8%. Kemurungan mempunyai perkaitan yang signifikan dengan tahap pendidikan ($\chi2$ =6.319; df 2; p=0.042) dan anak mendapat pendidikan lain ($\chi2$ =4.412; df 1; p=0.036). Analisis itu juga menunjukkan kebimbangan mempunyai perkaitan yang signifikan dengan penjaga dengan sejarah kesihatan ($\chi2$ =5.668; df 1; p=0.017), jantina anak ($\chi2$ =4.154; df 1; p=0.042) dan jenis kecacatan ($\chi2$ =9.419; df 2; p=0.009). Faktor yang mempunyai perkaitan yang signifikan dengan tekanan adalah pendapatan ($\chi2$ =4.318; df 2; p=0.038), sejarah kesihatan ($\chi2$ =8.539; df 1; p=0.003), anak mendapat pendidikan lain ($\chi2$ =7.795; df 1; p=0.005) dan tahun menghadiri CBR ($\chi2$ =13.197; df 2; p=0.001). **Kesimpulan:** Kesan psikologi dan faktor-faktor yang mempengaruhinya perlu diberi perhatian dan penjaga kanak-kanak kurang upaya perlu diberi sokongan untuk memastikan kesihatan mental mereka.

Kata kunci: Kesan psikologi, penjaga, kanak-kanak kurang upaya, pusat pemulihan dalam komuniti, kemurungan, kebimbangan, tekanan

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LIST OF ABBREVIATIONS

ABR	Auditory Brainstem Response
ADHD	Attention Deficit Hyperactivity Disorder
AOR	Adjusted Odds Ratio
ASD	Autism Spectrum Disease
AT	Assistive technology
BAER	Brainstem Auditory Evoked Response
BDI	Beck Depression Inventory
CBR	Community Based Rehabilitation
CDC	Centres for Disease Control and Prevention
CG	Caregiver
CI	Confidence Interval
CRC	UN Committee on the Rights of the Child
CRPD	Convention of the Rights of People with Disabilities
DASE	Denver Articulation Screening Examination
DASS	Depression, Anxiety and Stress
DSM	Diagnostic and Statistical Manual of Mental Disorders
FPL	Federal Poverty Level
GDD	Global Developmental Delay
HADS	Hospital Anxiety Depression Scale
ICF	International Classification of Functioning, Disability and Health
ID	Intellectual disabilities
IPH	Institute for Public Health
ISMI	Internalized Stigma of Mental Illness
JKM	Jabatan Kebajikan Masyarakat Malaysia
n	Number
N	Sample Size

NHMS	National Health and Morbidity Survey
OAE	Otoacoustic Emission
OKU	Orang Kurang Upaya
OR	Odds Ratio
P	Significance Level
PHQ-9	Patient Health Questionnaire
PI	Psychiatric Illness
PWD	Person with Disability
SD	Standard Deviation
SDAC	Survey of Disability, Ageing and Carers
SMD	Standardized Mean Difference
SPSS	Statistical Package for the Social Sciences
UNICEF	United Nations Children's Fund
UPM	Universiti Putra Malaysia
USA	United States of America
WHO	World Health Organization

CHAPTER 1

INTRODUCTION

1.1 Background

The Convention of the Rights of People with Disabilities (CRPD) which was adopted in year 2006 defines disability as “those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.” (World Health Organisation (WHO), 2006). Disabled children are at higher risk of being marginalized than peers without disabilities and confront a wide range of challenges in their daily lives including stigma, discrimination and societal barriers. Poverty exacerbates these vulnerabilities (Child Welfare Information Gateway, 2018). Hence, it is crucial for children to have early intervention in order to significantly increase opportunities and are able to face complex attitudinal, environmental and institutional barriers.

Across the world, approximately 15% of the world’s population lives with some form of disabilities, of whom 2- 4% experience significant functional difficulties (WHO, 2011). In Malaysia, the Department of Social Welfare reported that in 2018 there were 497,390258 persons with disability (PWD) were registered with the department. This figure has increased over the years from 409,269 in 2016. Among them, PWDs in the physically disabled category recorded the highest number, which was 36%, followed by learning disability category (34.2%) and hearing impaired category (9%) (Department of Social Welfare Malaysia, 2018).

There are many challenges faced by disabled children that could leave a large impact on their family. In the aspect of medical issues, disabled children might face severe conditions such as cancer, heart defects, muscle dystrophy and mucosal fibrosis. Indirectly, disabled children may need frequent medical tests, hospital stays, facilities and disability accommodations

(Strizhitskaya et al., 2019). In addition, some disabled children such as Down Syndrome face developmental problems and are removed from the education mainstream (Weis, 2018). This may lead to low self-esteem and behavioural difficulties among disabled children.

Caregivers of disabled children carry the responsibilities to take care and fulfil the needs of disabled children. Caregivers can be defined as a family member or helper who regularly looks after a child or a sick, elderly, or disabled person (Windham, 2015). Most of the disabled children are cared for at home by their parents and families with rehabilitation services inclusive of assistive devices such as walking frames, sticks, wheelchairs and hearing aids (WHO, 2015). Early intervention can greatly increase one's academic achievement as well as overall human development (Abdul Nasir & Erman Efendi, 2016). It helps partners to enhance their services and provide community-based services. The Inclusive Pre-school Programme was established to integrate children with learning difficulties into a normal nursery setting (Sukumaran et al., 2015).

There are various issues faced by caregivers of disabled children, including the cost of raising disabled children, parenting stress and additional time allocation (Child Welfare Information Gateway, 2018). In a recent UNICEF (2016) report, it was stated that financial barriers are one of the major problems faced in caregiving for a child with disabilities (United Nations Children's Fund (UNICEF), 2016). This is largely due to the medical bills, supplements and assistive devices, which are expensive and burdensome to parents.

In the aspect of parenting stress, parents need to allocate extra time in caring, teaching and feeding children with physical disabilities. As a result, caregivers of disabled children are at higher risk to have adverse psychological effects and chronic stress (Child Welfare Information Gateway, 2018). Similarly, parents of young children with developmental deficits report experiencing more stress than parents of children without deficits (Neece et al., 2012). The

stress experience is, however, based on how people perceive their situation, and whether effective coping strategies (such as problem-focused, emotion-focused, and coping with appraisals or perceptions) are used for stress management (Strizhitskaya et al., 2019).

Poverty among caregivers aggravates the challenges faced in taking care of disabled children (Auerbach et al., 2019). They face additional problems such as poor living conditions and poor accessibility to health care. The inability to provide basic needs for the wellbeing of the child increases the psychological impact on the caregivers. (Gupta et al., 2012)

Therefore, greater knowledge regarding ways of caregiver caregiving disabled children enables the improvement of existing services and the development of new strategies to sustain caregivers in their vital roles. (Auerbach et al., 2019).

1.2 Problem statement

Globally, there are more than 1000 million people with disability, which is about 15% of the world's population. Of this number, between 110 million and 190 million adults experience significant difficulties in functioning. It is estimated that some 93 million children or one in 20 of those under 15 years of age live with a moderate or severe disability (WHO, 2014).

The prevalence of overall impairment and disability was 26.9% in the National Health and Morbidity Survey (NHMS) 2015, using the International Classification of Functioning, Disability and Health (ICF) definition (Institute for Public Health [IPH], 2015). In the earlier Malaysian NHMS, different definitions of disability were used. According to The Malaysia Third NHMS in 2006, among all types of disability, the prevalence of difficulty in seeing was highest at 16.8% (95% CI: 15.9, 17.8), followed by difficulty in walking 11.3% (95% CI: 10.6, 12.0), difficulty in remembering 9.4% (95% CI: 8.7, 10.1), difficulty in listening 5.5% (95% CI: 5.0, 6.0), difficulty

in communicating 3.4% (95% CI: 3.1, 3.8) and difficulty in self-care 2.5% (95% CI: 2.2, 2.8) (Ministry of Health Malaysia [MOH], 2015).

The burden of psychological effects among caregivers of disabled children is much higher compared to caregivers of normal children (Auerbach et al., 2019). The birth of a healthy child is eagerly awaited by most parents. Because of this expectation, an early diagnosis of a disability is seen as the breaking of an ideal. Parents and other family members may experience a variety of feelings as they encounter the significant change that comes from someone close to them with a disability. They usually do not have adequate training, preparation or ongoing support (Sukumaran et al., 2015). Caregiving responsibilities, as well as the lack of preparedness, guidance and support, erode their physical and emotional health and their financial resources (Auerbach et al., 2019).

There are fewer studies about psychological effects among caregivers of disabled children in developing countries compared to western countries (Gupta et al., 2012). Similarly, in Malaysia, there are not many studies conducted on psychosocial effects among caregivers of disabled children. Therefore, there is a need to look more in-depth on the psychological effects and their associated factors among caregivers of disabled children.

1.3 Significance of study

This study can help in determining the psychological effects and its associated factors among caregivers of disabled children in Community Based Rehabilitation (CBR's) in Selangor. It can be used to create awareness not only among the caregivers, but also among the community at large. Identifying factors influencing psychological effects is crucial in determining the association between factors and psychological effects. In addition, it is also beneficial in determining means to improve Healthcare in disabled children.

1.4 Research Questions

i. What is the prevalence of psychological effects among caregivers of disabled children?

ii. What are the factors associated with the psychological effects among caregivers of disabled children?

1.5 Objectives

1.5.1 General Objectives

To determine the psychological effects and its associated factors among caregivers of disabled children below 18 years old in Community Based Rehabilitation centres in Selangor.

1.5.2 Specific Objectives

i. To determine the psychological effects (depression, anxiety, stress) among caregivers of disabled children.

ii. To determine the socio demographic factors of caregivers of disabled children

iii. To determine characteristics of the disabled children.

iv. To determine the association between sociodemographic factors of caregivers of disabled children (age, gender, ethnicity, marital status, education level, employment status, monthly income, medical history, relationship with the child attending the CBR) and psychological effects among caregivers of disabled children.

v. To determine the association between characteristics of the disabled children (age, gender, position of the child in the family, type of disability, attainment of other education, duration in the CBR) and psychological effects among caregivers of disabled children.

1.6 Research Hypothesis

H1: There is a significant association between sociodemographic factors and psychological effects among caregivers of disabled children.

H2: There is a significant association between characteristics of the disabled child and psychological effects among caregivers of disabled children.

CHAPTER 2

LITERATURE REVIEW

2.1 Disabled children

According to the Persons with Disabilities Act, 2008, Orang Kurang Upaya (OKU) defined as it includes those who have long term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society (The Commissioner of Law Revision Malaysia, 2018).

Disability can be congenital or acquired disability. Congenital disability is a disability that occurs during intrauterine life and can be detected prenatally, at birth or later in infancy. Congenital or birth defects affect 1 in every 33 babies born in the United State for every year in about 120,000 babies. Birth defects may affect any part of the body such as heart, brain and foot and can be classified from mild to severe. Congenital disability such as hearing loss, heart defect, spina bifida and cerebral palsy. The causes of congenital disability can be due to smoking, drinking alcohol, certain medical conditions such as diabetes, family history and older much above 34 years of age. This can be prevented by taking 400 mcg of folic acid everyday one month before pregnant, controlling medical conditions and asking for advice from health care about before taking medications (Centres for Disease Control and Prevention [CDC], 2019)

Acquired disability defined as disability developed during a person's lifetime due to accident or illness. Accident related disabilities are head trauma, spinal injury, loss of vision, loss of hearing and loss of limb. While illness related disability is post stroke, multiple sclerosis, arthritis, motor neurone disease and mental disability (Employer Disability Information, 2020)

List of types of disability registered under the Social Welfare Department are hearing disability, visual disability, speech disability, physical disability, learning disability, mental disability and multiple disability. Any application for OKU registration may be made at any district of the District Department of Social Welfare Office (Social Welfare Department, 2020). Ministry of Health also classified disability as hearing disability, vision disability, speech disability, physical disability, learning disability, mental disability and multiple disability (MOH, 2014)

In 2017, 453,258 persons registered as Person with Disabilities (PWD) under the Department of Social Welfare in Malaysia. Physical disability has the highest prevalence which is 35.2% followed by learning disability (34.8%), visual disability (8.9%), mental disability (8.3%), hearing disability (7.6%) and lastly multiple disability (4.7%) (Departments of Statistic Malaysia, 2018).

2.1.1 Hearing Disability

According to the Ministry of Health, hearing disability is defined as inability to hear in one or both ears for a person. Hearing disability consists of three types which are conductive hearing loss, sensorineural and mixed hearing loss. Conductive hearing loss is due to external or middle ear disease. While sensorineural hearing loss is due to diseases of the inner ear such as damage to the cochlear nerve that transmits sound to the brain (MOH, 2012)

Centres for Disease Control and Prevention (CDC) stated that all babies should get the screen for hearing loss not more than 1 month of age. All babies also should get the full hearing test if the babies did not pass the screening test. The full hearing test should be conducted less than 3 months of age. While children who are at high risk for congenital or acquired hearing loss, the baby should have at least on hearing loss test by 2 or 2 ½ years of age (CDC, 2019).

Full hearing test also called as audiology evaluation. Some of the tests are the Auditory Brainstem Response (ABR) or Brainstem Auditory Evoked Response (BAER) tests. These tests will check on how the brain responds to the sound and this test does not rely on a person's behaviour. Other than that, Otoacoustic Emission (OAE) test. This test is to check how the inner ear responds to sound. Lastly, Behavioural, Audiometry Evaluation test. This test will check how a person responds to sound overall and check the function of all parts of the ears (CDC, 2019).

Rehabilitation of hearing disability are by using hearing aid and speech therapy also required to improve the condition (MOH, 2012).

2.1.2 Visual Disability

The International Classification of Disease 11 (2018) classifies vision impairment into two groups which is distance and near presenting vision impairment. Distance vision impairment refers to mild which is presenting visual acuity worse than 6/12. Moderate is presenting visual acuity worse than 6/18. Severe is presenting visual acuity worse than 6/60 and blindness is presenting visual acuity worse than 3/60. While near vision impairment Presenting near visual acuity worse than N6 or M.08 with existing correction (WHO, 2014-2019).

It is important to check for children's vision during new-born, infant, preschool a school age to avoid the worsen condition. The test can be performed by a paediatrician and health care professional. In new-born, paediatricians should examine the baby's eye by performing a red reflex test. In preschool years between 3 and 3 ½ year of age, a child's vision should be checked using vision acuity as soon as the child is able to use eye charts for eye examination. If relative errors such as myopia and hyperopia are detected, the child should get a comprehensive exam by an ophthalmologist to begin early treatment (American Academy of Ophthalmology,2020)

Husin (2015) stated that factors that contribute to children's vision problems include squint, amblyopia, ptosis and cataract. Children should get eye screening before 3 years old, take recommended vaccines, healthy and balanced activities and seek for early treatment. Refractive error can be treated through glasses or contact lenses. Cataract through surgery and glaucoma through eye drops.

2.1.3 Speech Disability

Speech disability is an inability to speak that impairs proper communication and cannot be understood by those who interact with the person. The condition is permanent or incurable (Department of Social Welfare, 2016).

Types of speech disability includes Complex Communication Disorders such as paediatric speech and aphasia for adults. Other than that, Motor Speech Disorder such as apraxia and dysarthria. Other types are voice disorder which is dysphonia and resonance disorder such as hypernasality and hyponasality (Department of Social Welfare, 2020).

Children must do assessment on speech examination at five years of age and above (Department of Social Welfare, 2020). Kahn (2019) stated that the test required to diagnose speech disorder are Denver Articulation Screening Examination (DASE) which test the pronunciation of the children within 2-7 years of age, Early Language Milestones Scale 2 that will determine the language development, and lastly is Peabody Picture Vocabulary Test that measure person's vocabulary and ability to speak. The children will listen to words and point out pictures that are the same as the words listened to.

Kahn (2019) also stated that the treatment is different depending on types of speech disorder. Mild speech disorder sometimes does not require treatment, or this can be cured with speech

therapy. In speech therapy, the professionals will guide with exercises that strengthen the muscle of the throat and face. Other than that, a guide to control breathing while speaking. These combinations improve the speech condition.

2.1.4 Learning Disability

Learning disability is defined as intellectual capabilities that do not match with biological age (Department of Social Welfare, 2016).

Types of learning disability, including Global Developmental Delay (GDD) due to delay development in gross motor, speech, cognition and social for the age less than 5 years old. It also can be classified as mild, moderate and severe. Furthermore, Down Syndrome is excessive in chromosome 21 and it is also divided into mild, moderate and severe. Other types are Attention Deficit Hyperactivity Disorder (ADHD), Autism Spectrum Disorder and Specific Learning Disability that can be further classified as dyslexia, dyscalculia and dysgraphia (Department of Social Welfare, 2020).

Full evaluation of diagnosed learning disabilities is by doing medical exams such as neurological exams, reviewing child's development, social and school performance, history taking and psychological testing. Role of speech language pathologist that will evaluate child's learning skills such as reading and writing, understanding direction and manipulate sound (National Institutes of Health, 2018).

Behavioural therapy for learning disabilities to improve the children's performance including, learning better social, emotional and communication skills. This also can improve children's relationships with others. Based on examination, effective treatment is required such as

neurotransmitter therapy, hormonal therapy, epigenetic therapy and AA/EPA/DHA therapy to control learning and emotional balance (International Psychology Centre, 2014).

2.1.5 Physical Disability

Physical disability is defined as permanent inability at the parts of body due to loss, absence or inability of any part of the body that will affect the function fully to carry daily activities such as self-care, movement and change position of the body (Department of Social Welfare, 2020).

Types of physical disabilities include limb defect, spinal cord injury, stroke, traumatic brain injury and cerebral palsy (Department of Social Welfare, 2020).

Physical disability examination includes monitoring the developmental of a child's growth over time by asking parents to watch the child during examination on how the child moves. During developmental screening, a short test is required to detect any developments, delays include motor and movement delay through interviews or questionnaires. All children are recommended to check for their development delay during their visit when the child is 9 months, 18 months and 24 or 30 months. The doctor will evaluate the child's motor skills, muscle tone, reflexes, posture and history of presenting illness such as seizure or hearing and vision problems. Other than that, imaging test also can be used such as brain imaging test, x-ray and genetic testing (CDC, 2019).

Vaccination and medical check-up in the age group and risk situation are recommended. Regular check-up allows early detection and early treatment (Swiss Academy of Medical Sciences, 2017). If there is impairment in mobility, a wheelchair can be used.

2.1.6 Mental disability

In general, mental disorders are characterized by a mixture of dysfunctional thinking, beliefs, emotions, actions and interactions with others. Mental disorder includes depression, bipolar, schizophrenia and other psychoses, dementia and developmental disorder including autism (WHO, 2019).

Types of mental disorder include organic mental disorders such as dementia in Alzheimer's disease, vascular dementia. Other than that, Schizophrenia and Delusional Disorders are also considered mental disorders. Mood disorder such as bipolar affective disorder, recurrent depressive disorder and persistent mood disorder. Lastly, severe anxiety disorder such as panic disorder, Obsessive Compulsive disorder and Phobic Anxiety disorder (Department Social Welfare, 2020).

Simple test called General Health Questionnaire can be used to test for mental health status. If the score is 4 and below, no significant mental health problem. While if the score is 5 and above, the tester does have mental health problems (MOH, 2012). The doctor will do a physical examination by listing out the signs and symptoms, lab test by screening for thyroid hormone function, alcohol and drugs and psychological evaluation. The doctor will ask about the symptom, thoughts, feelings and behaviour pattern by answering a questionnaire (Mayo Clinic, 2019).

Psychotropic drugs must be used according to professional criteria (Swiss Academy of Medical Sciences, 2017). Supportive therapy such as psychotherapy, cognitive therapy, family therapy and psychosocial rehabilitation are all important (MOH, 2012). Treatment includes antidepressants, anti-anxiety medication and antipsychotic drugs (Mayo Clinic, 2019).

2.1.7 Multiple disability

Multiple disabilities is defined as disability with more than one types of disability (Department of Social Welfare, 2020).

Assessment of disabilities are measures to diagnose multiple disabilities includes developmental history, assessment of individual intelligence and achievement, behaviour, motor development, auditory and visual perception (Arkansas Special Education Unit, 2014).

Assistive technology (AT) and alternative communication includes text to speech technologies, hearing aids and sign language can be used to resolve the communication problem. Technology and special education aid can be helpful for people with multiple disabilities (Special Education Guide, 2013-2020).

2.2 Psychological Effects Among Caregivers with Disabled Children

Caregivers with disabled children appear to have higher risk to get depression, stress and anxiety compared to the caregiver with normal children. One of the studies about Psychosocial effects among caregivers of children with autism spectrum disorder in Oman, stated that the equal proportion of caregivers having stress and anxiety is 45.9% while depression is 48.6 (Al-Farsi et al., 2016).

2.2.1 Depression

According to American Psychiatric Association, depression is a common and serious mental illness that will affect how you feel, the way you think and how you act (American Psychiatric Association, 2020).

Symptoms will persist for weeks to months. Symptoms can be classified as psychological symptoms which are moody, feeling hopeless, low self-esteem, anxious and worried, suicidal thoughts. Physical symptoms include chest pain, loss of libido, uncontrolled menstrual cycle, insomnia and lack of energy. While social symptoms are avoided interact with people, bad relationship with family and friends (National Health Service, 2019).

Screening for people considered at high risk to develop depression using Whooley Question and severe depression should be assessed. People who are at high risk are history of depression, obesity, chronic disease, financial constraint, experience major life changes and pregnant or postpartum mother. Tools used in Malaysia for screening are Beck Depression Inventory (BDI), Depression, Anxiety and Stress (DASS), Patient Health Questionnaire (PHQ-9) and Hospital Anxiety Depression Scale (HADS). While the Whooley Questions are the shorter tool. Assessment includes history taking, mental and physical examination and investigations. Some of the history taking are family history, suicide attempts, substance abuse, social and social support history. While mental examination such as presence of psychotic symptoms, risk of harm to others and self and evaluate the severity of depressive symptoms. The severity of depression also can be classified into mild, moderate and severe. To be diagnosed, minimum five depression symptoms are required (Malaysian Health Technology Assessment Section (maHTAS), 2019)

Treatment required varies based on the severity of the depression. Mild to moderate depression, psychosocial intervention and psychotherapy can be offered. Moderate to severe, combination of pharmacotherapy and psychotherapy are required. Psychosocial includes psychoeducation, counselling, peer support, exercise and relaxation. While psychotherapy is cognitive behavioural therapy, interpersonal therapy, marital therapy and problem-solving therapy (maHTAS, 2019).

If depression is not being treated, the severity can get worse. Depression can become a serious condition, not just their own health but it may also affect their physical and other people around them. In worst case, depression can lead to suicide. Close to 800 000 people die due to suicide every year and it is the second leading cause of death in 15 to 29 years old (WHO, 2014). Other complications due to depression are anxiety, family conflicts, work or school problems, alcohol and drug abuse and obesity (Mayo Clinic, 2018).

2.2.2. Anxiety

The American Psychiatric Association stated that anxiety is a normal reaction to stress, and it can be beneficial to others in some situations. While anxiety disorder is different from normal feelings of nervousness or anxiousness, and involve excessive fear or anxiety (American Psychiatric Association, 2017).

The symptoms of anxiety are classified as emotional and physical symptoms. People with anxiety may have one or more anxiety symptoms. Emotional symptoms are feelings of fear and worry, restlessness or irritability, feeling tense and jumpy. Physical symptoms include rapid heart rate, sweating, tremors, headache, fatigue, frequent urination and diarrhoea (National Alliance on Mental Illness, 2017).

Anxiety has various types which are Generalized Anxiety Disorder that produce excessive worry of daily life that lead to less concentrate, Social Anxiety Disorder which is fear of social interaction and more shyness, Panic Disorder by having panic attack and sudden feelings of tremor, Phobias that feel triggered for curtain things such as place, events or objects (National Alliance on Mental Illness, 2017).

After ruling out underlying illness with similar symptoms as anxiety disorder, the doctor will further carry out screening by doing physical examination, interviews and lab examination. Diagnostic and Statistical Manual of Mental Disorders (DSM) is used as a guideline to diagnose a specific type of anxiety (National Alliance on Mental Illness, 2017). When listing differential diagnosis, it is also important for the doctor to exclude disease with similar symptoms as anxiety disorder such as hyperthyroidism, hyperparathyroidism, heart disease and pulmonary disease. Usage of substances that can trigger anxiety such as caffeine, levothyroxine, and ibuterol are also important (Locke et al., 2015).

People with anxiety can reduce the risk by getting help or diagnosed early to get early treatment, stay active by interacting with others, and avoid abusive substances that will cause feelings of anxiety such as alcohol and drugs (Mayo Clinic, 2018).

Anxiety disorder can lead to depression with anxiety, insomnia, digestive problem, headache, suicide, trouble in communication, social isolation and low performance in school and work (Mayo Clinic, 2018). Antianxiety medication, stress and relaxation therapy, psychotherapy also can help patient with anxiety (National Alliance on Mental Illness, 2017).

2.2.3 Stress

Stress can be defined as physical, mental and emotional factors that cause mental or body tension. Stress can be due to external or internal environments. Combination of neurologic and endocrinologic systems due to stress can cause “fight or flight response” (Shiel, 2018).

Sign and symptoms of stress can be classified into physiological, behavioural, mental, emotional and social symptoms. Physiological symptoms include hypertension, muscle tension at the back and shoulder, chest pain and migraines. Behavioural symptoms are less

or excessive eating, smoke and drug abuse, fatigue and loss of libido. Mental symptoms are easily forgotten and confused, loss of interest in work and school, less concentrate and attitude worsen. Emotional symptoms are moody, quiet and feel disappointed. Lastly, social symptoms are poor relationships with friends and family, low self-esteem, interrupt communication with others and prefer to be alone (Huri, 2017).

There are a few tips to reduce stress in a healthy way. Exercise at least 30 minutes every day, eat healthy food, stop abusive substances such as alcohol and drugs, proper sleep schedule, improve communication by taking opportunities to interact with others, breathing exercise and taking proper therapy such as aroma, music, massage and colour therapy (Huri, 2017).

Long term stress may cause severe medical conditions, including hypertension, heart disease, diabetes and anxiety. Obesity and chronic fatigue also can occur due to excessive release of cortisol hormone (Caporuscio, 2020).

2.3 Factors Associated with Psychological Effects Among Caregivers of Disabled Children

2.3.1 Sociodemographic of caregivers

2.3.1.1 Age of caregivers of disabled child

American Baby and Child Law Centre (2018) described the obstacles for grandparents seeking to get their grandchildren cared for as a concern of parental child abuse and neglect and looking for the support in taking care of their disabled grandchildren (American Baby and Child Law Centre, 2018). Another study also found out that the grandparents had total custodial care of their grandchildren because the parents had no active or consistent participation in rearing them (Whitley et al., 2015).

A study in Canada showed the result with regard to demographic and other characteristics, the average age of caregivers was 58.1 years (SD=10.12) with men and 58.08 years (SD=9.25) with women, with no significant difference (p=0.208) evident between women and men (Penning & Wu, 2016).

After accounting for age, multivariate covariance analysis was performed to assess the disparity in psychological status in a study done in India. There was a statistically significant difference amongst the participation of Intellectual disabilities (ID) and psychiatric illness (PI) classes in depression, anxiety and stress Symptoms after age control among the caregiver, F (3, 75) = 5.36, p<0.002, Wilk 's disease = 0.720, 5-02 = 0.823 (Panicker & Ramesh, 2019).

2.3.1.2. Ethnic and cultural

Regarding need, any parent-identified emotional difficulties were positively associated with increased likelihood of care for all races. Specifically, the odds of a mental health visit increased notably when definite/severe problems were reported and were highest for Asian children (OR=33.7), followed by African American children (OR=32.5), White children (OR=22.3), other race children (OR=14.7) and Latino children (OR=7.0) in a study done in United Kingdom (Banta et al., 2013).

The study on culture showing prevalence of reporting 'any' racism experience was higher among native Māori and Asian child caregivers (30.0 per cent for both groups in 2006/2007) compared to European / Other children (14.4 per cent in 2006/2007). Vicarious racism was independently linked to unmet child health care needs (OR=2,30, 95% CI 1.65 to 3,20) and dissatisfaction with their child's medical centre (OR=2.00, 95% CI 1.26 to 3.16). Importantly, there was a dose-response relationship between the number of racism experiences reported

and the use of child health care (e.g., unmet need: 1 racism report, OR=1.89, 95 % CI 1.34 to 2.67; 2 + racism reports, OR=3.06, 95 per cent CI 1.27 to 7.37) (Paine et al., 2018).

2.3.1.3. Paternal / maternal

Parental stress has been described as a significant effect on the psychological well-being of carers and a rise in the risk of involuntarily putting children with disabilities in caring for others (Cramm & Nieboer, 2011).

Parents of children with ASD generally report that they have more mental health problems in themselves than parents of children with intellectual and other developmental disabilities (Kuusikko-Gauffin et al., 2013). Commonly, these parents experience higher stress levels (Hayes & Watson 2013; Lai et al. 2015) and report more depression and anxiety symptoms (Lai et al., 2015).

A study in India showed the mean of parenting distress scores of mothers of children in different groups differ significantly (F= 95.24, df=4,120, P< .01). Post-hoc Duncan"s test revealed that mothers of children without disability scored significantly less (mean= 31.84, SD= 8.93) on parenting distress compared to mothers of children with disability. Mothers of children with both mental and physical disability scored significantly higher (mean = 56.68, SD=1.95) on parenting distress. Mothers of children in other groups did not differ significantly in their scores on parenting distress (Shyam et al., 2014).

Meanwhile, another study found out that mothers are more likely to have poor overall mental health and well-being (standardized mean difference (SMD) −0.38, 95 % CI −0.56 to −0.20),

higher rates of depression (SMD, −0.46; 95 % CI −0.68 to −0.24), stress (SMD, −0.32; 95 % CI −0.46 to −0.19) and anxiety (SMD, −0.30; 95 % CI −0.50 to −0.10) (Dunn et al., 2019).

2.3.1.4. Household Income

Caregivers of children with disability tended to be disproportionately single or divorced, had less than a high school education, and were more likely to have income less than the FPL (less than $22,050 for a family of 4 in 2009) compared to caregivers of typically developing children (all $p<0.05$). Results showing that Caregiver with low income which is less than 100% FPL (32.3%), P=0.001, with highly significant result among low income and caregiver psychological stress (Goudie et al. 2014).

A study in the USA showed the results from the American Community Survey (Americans With Disabilities Act Participatory Action Research, 2014) show significant disparities in the median income for those with and without disabilities. Median income for people with no disability exceeded $30,469, compared to the median income of $20,250 reported for persons with disabilities (U.S. Census Bureau, 2015).

2.3.1.5. Marital status (single/married/divorce)

Families with a disabled child will share much of the same family life pressures and enjoyments as their peers. Any increased risk of separation during the early stages of parenting a disabled child is most likely: this may be linked to parental adaptation issues or access to support issues (Woodman, 2014).

In a study conducted in Japan, almost half (44.4%) of caregivers (CGs) had psychological distress (k6 score; 5 +) nationwide, and 8.9% of CGs might have serious mental illness (K6 score; 13+). After adjusting covariates of child, CG, and household factors, CG having a

current symptom (OR, 95% CI: 3.26, 1.97–5.39), CG's activity restriction (OR, 95% CI: 2.95, 1.38–6.32), low social support (OR, 95%CI: 9.31, 1.85–46.8), three generation family (OR, 95% CI: 0.49, 0.26–0.92), and lower 25% tile group of monthly household expenditure (OR, 95% CI:1.92, 1.05–3.54), were significantly associated with psychological distress of CGs (Yamaoka et al., 2015).

Meanwhile, in a study conducted among Canadian found over two-thirds of the caregivers (67.8%) were married. Male caregivers were more likely than female caregivers to be married or cohabiting, whereas female caregivers were more likely than male caregivers to be either uncoupled (widowed, separated/divorced) or never married. As a result, female caregivers were also more likely to be living alone (16.9%) with p=0.001 (Penning & Wu, 2015)

2.3.1.6. Employment status

The SDAC 2015 recorded data on employment for participants as a caregiver aged 15 years and over. The key outcome of concern in this analysis was the state of employment — whether or not an individual is employed (unemployed or not in the labour force) and the results showing that employment increased 25,000 to 12,419,800, whereas unemployment increased 100 to 715,000 (Australian Bureau of Statistics, 2018). In this study, 33.1% of working-age mental health carers were employed full-time, 24.7% were employed part-time, and 42.3% were unemployed or not in the labour force. Results showing that Employed mental health carers reported a range of working hours, with 17.2% (95% CI: 12.8–22.8) working 1–15 h per week, 25.5% (95% CI: 19.3–33.0) working 16–34 h, 32.9% (95% CI: 26.4–40.2) 35–40 h and 24.3% (95% CI: 19.7–29.6) 41 or more hours compared to employed mental health carers, employed non-carers had significantly lower odds of working fewer than 16 h per week (Diminic et al., 2019).

Apart from working hours, type of works seems to have a significant factor on Psychological effect of caregiver applying for high-level occupational groupings, 36.3% (95% CI: 29.5–43.6) of employed mental health carers worked as a manager or professional; 41.1% (95% CI: 35.0–47.6) in a technical, trade, service, sales or clerical role; and 22.6% (95% CI: 17.5–28.7) as a machinery operator, driver or labourer. Employed non-carers and carers for other cognitive/behavioural conditions had significantly lower odds than employed mental health carers of working as a machinery operator, driver or labourer rather than any other technical or professional role (Diminic et al., 2019).

2.3.1.7. Caregivers education status

Several studies showed significant association between educational level of caregivers and psychological problems among caregivers with children with disabilities. A study in Canada found out that overall score for educational level is 6.08% with SD=2.87 account for both men (6.18%, SD=3.13) and women (6.01%, SD=2.69), with a p=0.344 showing that higher educational level is not significant with parental stress among the participants (Penning & Wu, 2015).

Another study conducted in Turkey on parents' education status, it was found that 3 of the fathers (4.3%) were an alphabet, 3 of the fathers (4.3%) were literate, 17 (24.6%) were elementary school graduates, 12 (17.4%) were secondary school g graduates raduates, 9 (13.0%) were high school graduates and 25 (36.2%) were university graduates. Meanwhile a survey of mothers showed that 12 of the mothers (17.4%) were illiterate, 3 of the mothers (4.3%) were literate, 19 (27.5%) were elementary school graduates, 10 (14.5%) were high school graduates, 11 (15.9%) were high school and 14 (20.3%) were university graduates. Pearson correlation study conducted and found significant difference was detected between mother’s education and ISMI scale total score (r=-0.325**; p= 0.006) (Öz et al., 2020).

2.3.1.8. Number of disabled children

The number of new children with disabilities (CWDs) registrations in Malaysia fluctuates Between 2009 and 2013 this number has increased significantly since 2014 (Department of Social Welfare, 2009, 2015). Social welfare department (2014, 2015) announced that in 2014 11,546 children under the age of 18 had been registered as having a disability. The number of CWDs rapidly surged in 2015 after 105,174 children registered as having a disability.

In a study in Japan**,** results showed that raising a child with a disability was significantly associated with maternal psychological distress (crude odds ratio (OR) 1.78, 95% confidence interval (95%CI) 1.51-2.09 for one child with a disability; OR 2.90, 95%CI 1.47-5.70 for two children with a disability). After controlling for the characteristics of the mother and household, the adjusted OR (AOR) was still significantly associated (AOR 1.72, 95%CI 1.44-2.05 for one child with a disability; AOR 2.85, 95%CI 1.28-6.34 for two children with a disability) (Yamaoka et. al., 2016).

Another result showed that among partnered mothers living without grandparent(s), 446 mothers had one child (2.2%) and 24 mothers had two children with a disability (0.12%). The AOR remained 1.80, with significance (95%CI: 1.47–2.21), for one child, and 2.84 for two children with a disability (95%CI: 1.14–7.07). Among single mothers, 61 mothers had one child with a disability (2.0%), and eight mothers had two children with a disability (0.26%). Raising one or two children with a disability was not significantly associated with psychological distress (AOR, 95%CI: 1.42, 0.81–2.47 for one child; 4.43, 0.51–38.7 for two children with a disability) (Yamaoka. et.al., 2016).

2.3.2 Characteristics of Disabled Child

Characteristics of disabled children were divided into types of disability and its severity. According to article 1, paragraph 2, of the draft convention on the rights of persons with disabilities, “Persons with disabilities include those who have long-term physical, mental, intellectual, or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.” (A/AC.265/2006/4, Annex II).

Paragraph 1 of article 23 was considered as the leading principle for the implementation of the Convention with respect to children with disabilities: the enjoyment of a full and decent life in conditions that ensure dignity, promote self-reliance and facilitate active participation in the community (CRC, 2006).

While the cost of the intensive level of service provided in institutional care settings within countries is expensive, it is offset by the fact that few disabled children require this level of service and most care at home (Mulheirg, 2012). Resources allocated to children with disabilities should be sufficient and earmarked so as not to be used for other purposes; to cover all their needs, including programs established for training professionals working with disabled children such as teachers, physiotherapists and policy makers; education campaigns; financial support for families; income maintenance; social welfare; assistive devices; and related services.

2.3.2.1. Types of disability and its severity

Malaysia was seeing a growing incidence of people with learning disabilities. The number of registered persons with learning disabilities increased from 109, 708 in 2009 to 178, 800 in 2013. The Malaysian Department of Social Welfare reported that in 2013 there were 13,519

newly registered people with learning disabilities including 6,526 children aged 18 and below (JKM 2011, 2014).

Most studies (n=27) were cross-sectional, included a range of Neurodevelopmental Disorder (NDDs) and were of "poor" quality (n=14) or "fair" quality (n=17). Few good quality studies in parents of children with NDDs compared objective measured sleep with parents with typically developing children. Consistently, parents of children with NDDs reported substantially poorer subjective sleep quality and having chronic fatigues despite of caregiving responsibilities (Micsinszki et al., 2018).

There were some variations reported when the parental experience was investigated through diagnoses. It has been found that parents of children with Down syndrome experience less stress (Ricci & Hodapp, 2003) and depression (Abbeduto et al., 2004) than parents of children with children other than autism.

Child carers with severe disability were more likely to experience a higher perceived level of stress and depression (psychological distress) (AlGamal & Long, 2013). Caregivers of shunts patients with spina bifida were seen to be more anxious than those without shunt (Malm-Buatsi et al., 2015).

Child, behavioural problems and parental stress correlated significantly ($r=0.488$, $p=0.001$) (Neece et al, 2012). Importantly, child behaviour problems related to parental stress in children with Down syndrome ($r=0.17$; $p<0.05$) mothers (Norizan & Shamsudin, 2010). The parental burden is related to the actions of children ($r=0.38$, $p<0.0001$) (Whittingham et al., 2013).

2.4 Facilities for Disabled Children

There were government bodies responsible for caring for the welfare of children with disabilities in Malaysia. Multisectoral involvement is performed in Malaysia. For example, the Ministry of Education, Ministry of Health and Ministry of Social Welfare, Ministry of Transport, plays their designated roles. The Ministry of Education has a department of special education which is mainly responsible for providing education to children with disabilities in Malaysia. They are to provide education for these disabled children for children with disabilities who are educable and eligible under the Special Education Regulations.

2.4.1 Health and Medical Care

Health services play a key role in the prevention and early detection of disability and provision of ongoing assistance. Evidence though Suggests Malaysia 's view of affordable, accessibility to healthcare especially for people with disabilities, which is yet the most vulnerable (Lee, 2019). Lack of access to vaccination, nutrition and growth monitoring programmes in the early years can also contribute to the incidence of developmental delay (which can become disability) in young children, since disease and poor nutrition can negatively affect neurological and physical development (Government of Malaysia 2015).

Malaysian Healthcare programmes for Person with Disability (PWD) under Ministry of Health Malaysia can be divided into 3 phases which are the first phase starting from 1996-2010 which mainly focusing on development of programmes and services for PWD, second phase starting from 2011-2020 which mainly focusing on strengthening the services for PWD and the third phase starting from 2021-2025 which mainly focusing on consolidation of programmes and services for PWD (MOH 2014; Abu Bakar, 2014).

Ministry of Health as one of the governmental bodies provide programmes and services such as Provision of and promoting early detection of disabilities; Provision of initial assessment of

children with disabilities; Provision of follow-up treatment of children with disabilities; Provision of primary health care, management and rehabilitation services including speech therapy, hearing therapy / audiology, physiotherapy and activities of daily living in hospitals and health clinics; Provision of immunisation and nutritional guidance; Formulation of healthcare policies and plans for the detection, treatment and rehabilitation of children with disabilities; Development of health education materials focused on specific disabilities; Conduct of national campaigns to increase public awareness on disability detection and prevention; Provision of essential medical examination for students entering the first year of primary level education including physical examination, eye examination and hearing assessment; Conduct of post basic training for health care providers; Provision of technical input and outreach services to some CBR centres (MOH, 2014).

Health clinic rehabilitation also became one of the important services under the Ministry of Health beginning in 1996, when therapists from major hospitals would visit nearby health clinics to provide services. Each year demand for rehabilitation services continues to rise (My Government Information, 2018). Physiotherapists and occupational therapists were put in selected health clinics starting in 2003 until 2018. There are 341 Physiotherapists / Rehabilitation Officers, 260 Occupational Therapists / Occupational Rehabilitation Officers and 2 Speech Rehabilitation Officers in 263 (30 %t) health clinics across Malaysia until 2018 (MOH, 2018). Through outreach programmes, rehabilitation services provided by these officers are extended outside health clinics including Community-Based Rehabilitation Centres (CBR), institutions, schools and homes (Government of Malaysia, 2018).

2.4.2 Education

In Malaysia, primary education is compulsory, and children with Disabilities have the right to get access to education accommodation to suit their needs. However, there is a tiered structure where most disabled children do not understand their right to better, comprehensive education, but rather experience segregated (as in special education) or integrated education systems (Government of Malaysia, 2015; UNICEF, 2019). A 'zero reject' policy stipulates that no child can be turned away from education. Since its implementation, over 10,000 children with disabilities have been enrolled in education (Lee, 2019).

Malaysia Education Blueprint stated that the target should be achieved in the aspect of quality, equity and access in 13 years. The Malaysian special needs education system can be analysed along five dimensions through three waves: first wave within 2013-2015 which is to strengthening the existing foundation, second wave within 2016-2020 which is to scaling up initiative and the third wave within 2021-2025 which is to evaluating and consolidating initiatives (Ministry of Health 2016; Jopri, 2016). Based on the statistic given by the Ministry of Education 2016, the number of Special Education Needs (SEN) in Malaysia increasing from 56,406 (9.60%) in 2013 to 74,131 (25.50%) in 2016 (Jopri, 2016).

Ministry of Education plays their vital role in implementing regulation on the right for the PWD to have an access towards education system in Malaysia under Department of Special Education in 1995 (now known as Special Education Division), a special education chapter has been included in the 1996 Education Act and the 1997 Ministry of Education adopted the Education Rules (Special Education Rules) (Lay & Hui, 2014). There are three special education laws of Education (Special Education) Special school programmes, integrated programs and inclusive programmes (Lay & Hui, 2014). Apart from that, Provision and management of special needs education to certain categories of children with disabilities through special education schools, Special Education Integration Programme (SEIP) and

inclusive education programmes; Formulation of curricula and educational modules for special needs (Ministry of Education 2013: Government of Malaysia, 2015).

2.4.3 Social welfare

Disability has the potential to impact a whole family. This was not unusual for children with disabilities to have their mothers abandoned by their partner, and an extended family. They might experience 'proxy handicaps' which include stigma, isolation, income loss and health problems. A fatality of employment, and/or other disability related costs Can affect siblings upon siblings who may also suffer food insecurity, poor nutrition, or reduced access to services. (UNICEF, 2019).

Department of Social Welfare under Persons with Disabilities Unit offers services such as the registration of disabled individuals, the issuance of a disability card known as a "OKU" card, financial assistance, financial help to receive treatment, white canes and braille machine, work placement, employment protection for disabled workers and the issuance of rehabilitation and training centres. There are few institutions that provide institutional care, such as Taman Sinar Harapan, where people with learning disabilities need care, training, rehabilitation and protection, Bangi Industrial Training and Rehabilitation Centre which provides services to persons with disabilities (PWD) through vocational training and medical rehabilitation, and the Sheltered Workshop is reserved for persons with disabilities who are unable to obtain open market jobs (MFWCD, 2013).

The World Health Organization (WHO) recommended Community Based Rehabilitation (CBR) centres that are established throughout the country by the Department of Social Welfare. A CBR centre is meant to be a one-stop centre for persons with disabilities, and is intended to provide such services as diagnosis, rehabilitation, treatment, special education and vocational training (WHO, 2014-2021). In Malaysia, the understanding of CBR has developed

considerably with many programs organized around CBR matrix such as health, education, livelihood, social and empowerment with as many as 540 CBRs under the management of the Social Welfare Department have been visited. It is estimated that more than 20,000 disabled using the facilities have benefited from the programme (My Healthy CBR Activities, 2012).

2.4.4 Non-governmental Organization

MWFCD lacks the exact number of NGOs and other service providers working with disabled children (MWFCD, 2013). One explanation for this is that there are several facilities that remain unregistered with the MWFCD. The types of services offered by the various NGOs are also inaccessible from the Government. However, NGOs that work with or advocate for the rights of children with disabilities are instrumental in the care and development of children with disabilities (MOH, 2013). Malaysian Care maintains a directory of organisations and agencies that work with and on issues relating to persons with disabilities in Malaysia by providing children services, inclusive pre-school programme, family support and resources services and training and disability awareness (Malaysian Care Service Directory, 2020).

There are also NGOs that play a crucial role in advocating with the government for improvements in early detection mechanisms, health and education services and accessibility for children with disabilities. For example, the National Early Childhood Intervention Council (NECIC) actively campaigns for effective early childhood intervention methods and improving the special needs education system for children with disabilities by creating an awareness programme such as early communication and inclusion workshop (National Early Childhood Intervention Council (NECIC, 2017).

The Malaysian Association for the Protection of Children, Malaysian Care, Asia Community Service, Handicapped Children Centre, Bureau of Learning Difficulties (BOLD), Cheshire

Home, Bethany Home, National Autism Society of Malaysia (NASOM), Down Syndrome Association of Malaysia and Malaysian Federation for the Deaf are some of the example of other NGO involved in helping the children with disabilities (Government of Malaysia, 2015). Kiwanis Centres maintains a directory of organisations and agencies that work with and on issues relating to persons with disabilities in Malaysia. They also provide the children with guidance so they can perform better in the traditional schools (Kiwanis Centre service directory).

2.5 Conceptual Framework

As shown in Figure 2.1, the conceptual framework for psychological effects of caregivers of disabled child factors is portrayed. The dependent variables were psychological effects which are depression, anxiety, and stress. Independent variables are categorized into socio-demographics factors and characteristics of disabled children. A straight line shows the relationship between dependent and independent variables which is being studied.

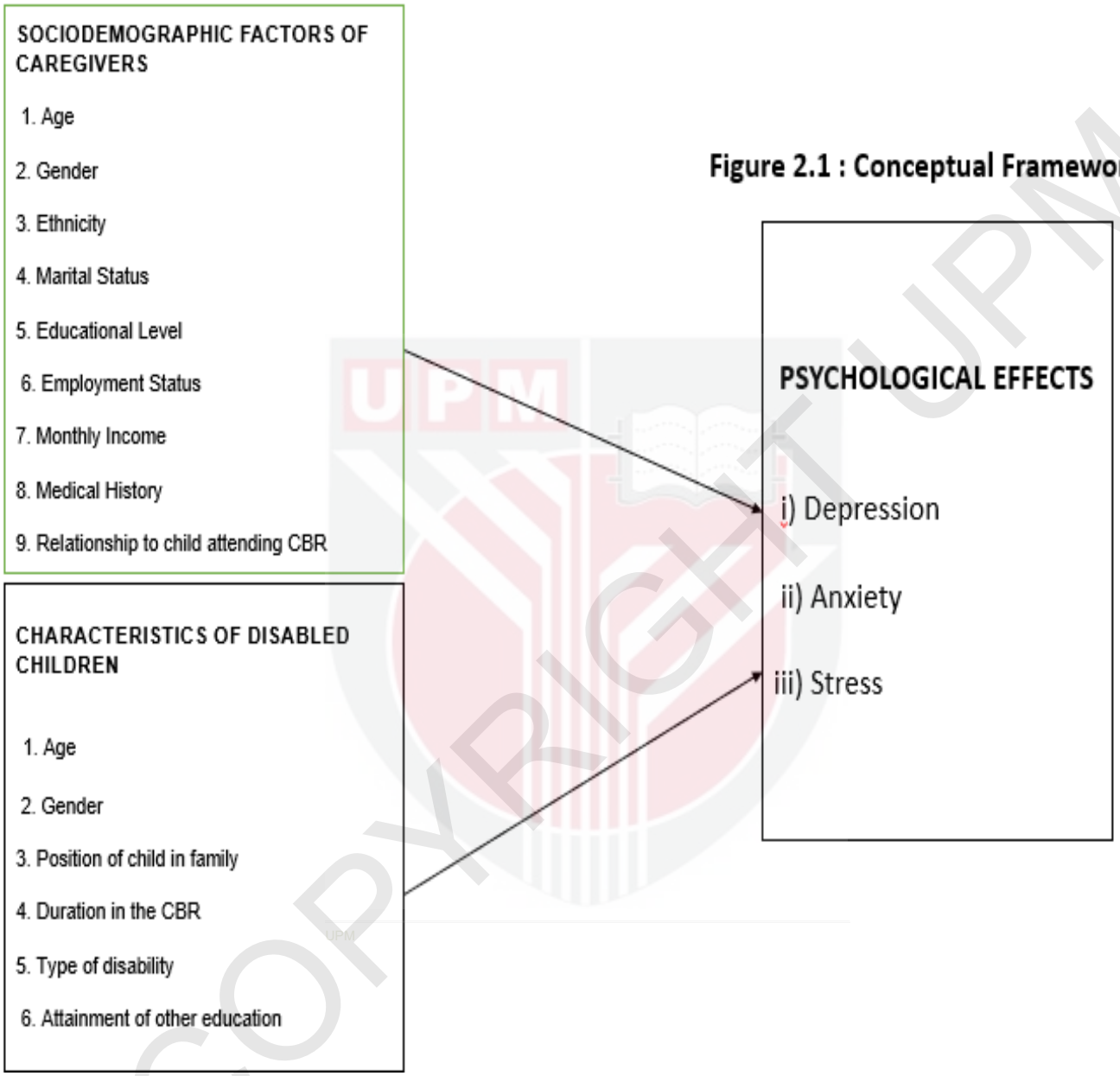

Figure 2.1 : Conceptual Framework

CHAPTER 3

METHODOLOGY

The study used data from a previous study entitled “Psychological Effects and their associated factors among caregivers of disabled children in Community Based Rehabilitation Centre in Selangor ". The study completed in August 2016 by V.C Anuratha Subramaniam among caregivers of disabled children registered with Community Based Rehabilitation Centre (CBR) in a randomly selected district in Selangor. The data obtained from the previous study were the psychological effects of the caregivers, the sociodemographic factors of the caregivers and the characteristics of the disabled children

3.1 Study location

The study location of the previous study was selected in districts in Selangor involving Community Based Rehabilitation centre (CBR). CBRs are coordinated under the Department of Social Welfare with a community integration approach and collaboration with the Ministry of Health Malaysia. At the time that this study was carried out, there were 45 CBR centres in Selangor with 2080 trainees registered (in 2016). The types of disability included mental disability, hearing, speech, physical, learning, visual and multiple. The disabled people registered in CBRs varied from children to adult age.

Health services were provided in CBR to ensure disabled can remain healthy and productive. Multiple disciplinary health personnel provide services within the operation area of a health clinic through My Healthy CBR (*PDK KU SIHAT*) programme. CBRs programme can be divided into 3; home-based, centre-based and centre-home based. Activities which are conducted are mainly based on gross motor skills, fine motor skills, social development,

language development, activities of daily living, vocational training, pre reading and drawing skills. The supervisors or the trainers identify the needs of each child via assessment and reports done based on the child performance. Many CBRs which were visited during this study had incorporated a punch-card system for these disabled children as an attendance proof to the CBRs and for their monthly allowance purposes which was RM 150 per month.

3.2 Study design

The study design of this research was cross sectional study

3.3 Study duration

The duration of our study commenced from 1st of June 2020 until 9th of October 2020.

3.4 Study population

The study population was caregivers of disabled children attending CBRs in Selangor.

3.5 Sampling population

Caregivers of disabled children aged below 18 years old who were enrolled in CBR in selected districts in Selangor. Caregivers included either one of the parents or guardians.

3.6 Selection criteria

3.6.1. Inclusion Criteria

1. Caregivers who enrolled their disabled children in CBR centres.

2. The age of the disabled child below 18 years old.

3. Active participant of CBR with no defaulter records of 2 months /more.

3.6.2. Exclusion criteria

1. Caregivers whom their disabled children were home bound

3.7 Sampling frame

List of respondents from the data of the previous study.

3.8 Sampling unit

A caregiver whose disabled child was enrolled in the CBR and fulfilled the inclusion and exclusion criteria.

3.9 Sample size

The sample size for this study was calculated using the two proportions formula Lwanga and Lomeshow, 1991.

$$N = \frac{[Z1\text{-}(2P\ (1\text{-}P)) + Z1\text{-}\ (P1\ (1\text{-}P1) + P2\ (1\text{-}P2)]2}{(P1\text{-}P2)^{2}}$$

N = Sample size estimate

Z1- = standard error associated with 95% confidence interval = 1.96

Z1-β = standard error associated with 80% power = 0.84

P = (P1+P2) / 2 = 0.50

$$N = \frac{[1.96\ (2(0.50)\ (1\text{-}0.50)) + 0.84\ (0.59(1\text{-}0.59))+(0.41(1\text{-}0.41)]^{2}}{0.0324}$$

n = 120 which is the minimum required a sample size

Calculating for 2 groups; n= 120 x 2 = 240

Total sample size calculated is n= 240 respondents

3.10 Sampling technique

The sampling technique of the previous study was cluster sampling. However, this study used simple random sampling from the list of respondents from the previous study. There were a total 348 respondents from the previous study. A total of 240 respondents were selected for analysis by simple random sampling using a Table of random numbers.

Based on previous study, the calculated sample size was 415. With an average of 124 disabled children in CBRs in each district. As shown in Figure 3.1, four districts were selected randomly among 10 districts in Selangor namely as Klang, Shah Alam, Sepang and Gombak. Caregivers of disabled children in CBRs in the selected district were chosen based on inclusion and exclusion criteria.

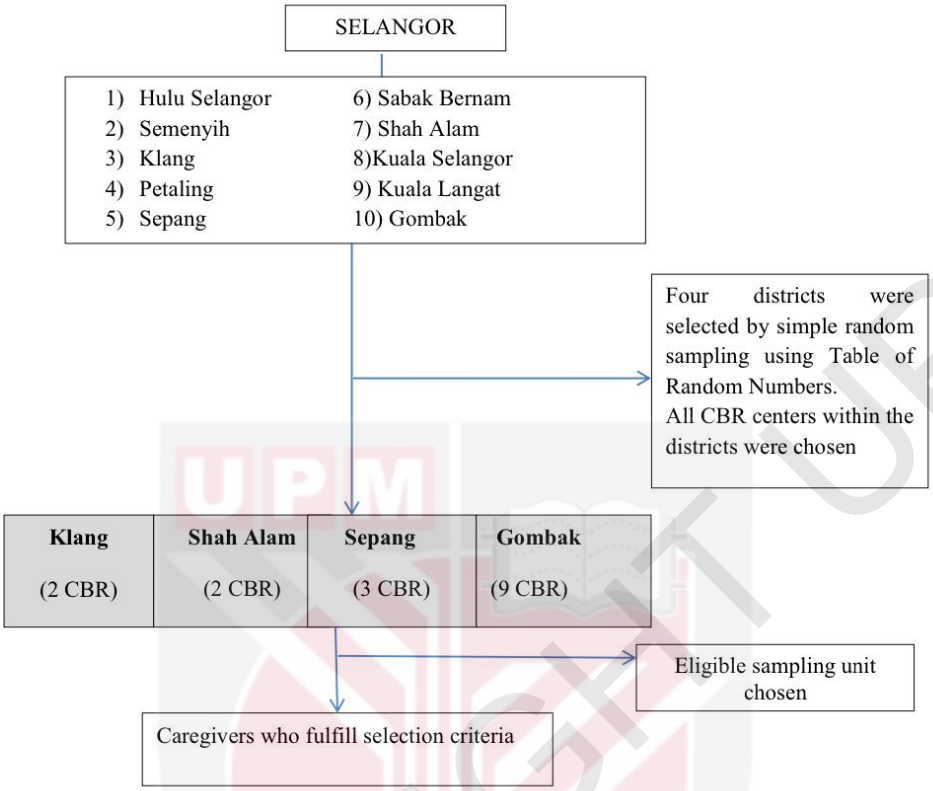

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FIGURE 3.1: Flow Chart of Sampling Method. Sampling Frame obtained from Department of Social Welfare, Selangor.

3.11 Instrument

The previous study used a questionnaire which consisted of six parts. Part A: Sociodemographic Factors, Part B: Characteristic of disabled children, Part C: Family characteristic, Part D: Perceived support or associated received, E: Psychological effect and Part F: Brief cope.

In this current study, section A, B and E was chosen as variables of the study, and rearranged as follows to be consistent with the objectives:

Part A: Psychological effects;

Part B: Sociodemographic factors of caregivers;

Part C: Characteristic of disabled children

Part A: DASS Questionnaire

Depression, Anxiety and Stress Scale (DASS) are designed to measure depression, anxiety and stress. The questionnaire consisted of 3 domains; depression, anxiety and stress. A Likert item was used in the DASS questionnaire with a minimum score of zero for each question (didn't apply to me) and a maximum score of three (very applicable to me) depending on the statement given. To calculate final score, the total DASS-21 score was multiplied by two. The minimum final score was zero and the maximum score was 42. Each condition for depression, anxiety and stress was then further classified into normal, mild, moderate, severe and extremely severe. Table 3.1 indicates the scoring for each category based on the psychological condition.

Table 3.1: DASS-21 Domains and its Scoring

Category	Depression Scale	Anxiety Scale	Stress Scale
Normal	0-9	0-7	0-14
Mild	10-13	8-9	15-18
Moderate	14-20	10-14	19-25
Severe	21-27	15-19	26-33
Extremely severe	28-42	20-42	34-42

Part B: Sociodemographic Factors of Caregivers

This section consisted of questions to collect data on age, gender, ethnicity, marital status, education level, employment status, monthly income, medical history and the relationship of caregiver of the disabled children attending the CBR.

Part C: Characteristic of disabled children

This section was in the list of questions included children's age, gender, position of the disabled child in the family, the number of siblings, year of enrolment in the CBR, period, in years in CBR programme, attainment of other education / programme and type of disability.

3.12 Variables and Operational Definition

3.12.1 Dependent variables

Depression, anxiety and stress were psychological factors. From previous study, these were measured using a questionnaire from DASS-21. For each domain in the total scores was times two. Then, for each depression, anxiety and stress area, they were graded into normal, mild, moderate, severe or extremely severe based on scoring as shown in table 3.1. Normal and mild were classified as "no psychology effects". While moderate, severe and extremely severe were classified as "having psychological effects".

3.12.2 Independent variables

The independent variables were as follows:

3.12.2.1 Sociodemographic Factors

This section consisted of caregiver's age, ethnicity, paternal or maternal, household income, marital status, employment status, education status and number of disabled children

Table 3.2: Sociodemographic Factors and its Operational Definition

Age	The age of the caregivers of disabled children was divided into two; below 40 and above 40.
Gender	The respondents were divided into Male and Female.
Ethnicity	The ethnicity was categorized into Malay and Others.
Marital Status	The respondents were divided into Unmarried, Married, Widow or Divorcee.
Educational Level	The status of education of respondents influences the psychological effects. The respondents were divided into three groups; Primary, Secondary and Tertiary Education Levels.
Employment Status	The employment status of respondents. The respondents were divided into Working and Others.
Monthly Income	The economic status of respondents. The respondents were divided into groups of two; With income and Without income.

Medical History	The medical history of respondents. It was categorized into Present and Absent.
Relationship to child attending CBR	Relationship to child attending CBR of respondents. It was divided into Mother and Others

3.12.2.2 Characteristic of disabled children

This section includes child's age, gender, position of child in family, duration in the CBR, type of disability and attainment of other education.

Table 3.3: Characteristic of Disabled Children and its Operational Definition

Age	The age of disabled children. It was an open-ended question based on birthdate in day/month/years and completed age in years. In this study, it was categorized to 1-6 years, 7- 11 years and 12-17 years old.
Gender	The gender of disabled children. It was divided into Male and Female.
Disabled child's position in family	It was divided into Eldest, Middle or Youngest Child.
Duration in the CBR programme	It was an open-ended question and further divided into less than 5 years, 5-10 years and more than 10 years.
Attainment of other education	This was an open-ended question if the child attended any other education besides attending CBR.
Types of disability	Types of disability was classified as Learning Disability,

	Multiple Disabilities and Others.

3.13 Validity and Reliability of Questionnaire

3.13.1 Face Validity

The pre-test was carried out randomly among 50 caregivers of disabled children selected in CBRs in Kuala Langat district, which was not included in the study. Assessment and amendments were made for the for-face validity from feedback from the respondents upon the pre-test study.

3.13.2 Content Validity

Content validity was discussed with the two experts in the field. Comments were taken and corrections were done accordingly.

3.13.3 Reliability of Questionnaire

The original Brief COPE was translated into the Malay language by Yusoff (2011). This questionnaire consisted of 28 statement items with 14 coping strategies domains. The reliability test of the Malay Brief COPE by Yusoff (2011) scored a total Cronbach's alpha value of 0.83. Most of the coping strategies showed acceptable internal consistency with Cronbach's alpha values of more than 0.5 and the Malay Brief COPE has good psychometric value (Yusoff, 2011).

The Depression Anxiety Stress Scales (DASS) had three main domains namely depression, anxiety, and stress. The depression domain had seven questions, the anxiety domain had seven questions and stress seven questions. The DASS-21 had been translated into Malay

language (Bahasa Malaysia (BM)). In few studies conducted by Musa et al. (2011) in Malaysia, the BM DASS-21 had been proven to have 37 good psychometric properties among clinical and non-clinical populations (Musa et al., 2011). It had good Cronbach's alpha values for depression (0.84 & 0.75), anxiety (0.74 & 0.74) and stress domains (0.79 & 0.79).

Upon pre-test, the Cronbach alpha was used to analyse via SPSS for the questionnaire for reliability in terms of internal consistency. The overall Cronbach alpha value obtained for DASS21 in this study was at 0.86, whereby for depression domain was 0.83, anxiety domain at 0.76 and stress domain at 0.74. Meanwhile for BRIEFCOPE total Cronbach alpha value was 0.912 with 0.87 for adaptive cope domain and 0.81 for maladaptive cope domain. It showed a good internal consistency.

3.14 Data Collection Method

The secondary data obtained from the previous study included psychological effects among the caregivers, sociodemographic factors of the caregivers and characteristics of the disabled children.

3.15 Data Analysis

The secondary data was analysed using the standard statistical software package IBM SPSS Statistics V25.0 for Windows. Normality test was carried out. Descriptive analysis was presented as median, frequency (f) and percentage of all the variables. Chi-Square test for bivariate analysis of categorical data was done. The significant value was set at $p<0.05$.

3.16 Ethical consideration

Ethical approval was obtained from the Ethic Committee for Research (reference number: JKEUPM-2020-243) involving Human Subject University Putra Malaysia (JKEUPM) to carry out the research using secondary data from the previous study.

CHAPTER 4

RESULTS

4.1 Distributions of the factors

4.1.1 Sociodemographic Factor

In this study, the median age of respondents was 43 years old. The mode was 44 years old. The youngest respondent was 23 years old. And the oldest respondent was 74 years old. Female comprised of 73.3% of respondents and male 26.7%. Majority of respondents were Malay (82.9%). Most of the respondents were married (86.3%).

Most of the respondents attained secondary school education (67.5%). Most of the respondents were working (54.6%). Most of the respondents were working received monthly income (61.3%). There were 19.6% of respondents had medical history. Majority of respondents were mothers (70.8%). The results are shown in Table 4.1.

Table 4.1: Distribution of Respondents with Sociodemographic Factors (N=240)

Sociodemographic Factor	Median	(IQR)	n	%
Age Group	43	43		
≤ 40			83	34.6
>40			157	65.4
Gender				
Male			64	26.7
Female			176	73.3
Ethnicity				
Malay			199	82.9
Others			41	17.1
Marital Status				
Married			207	86.3
Unmarried			3	1.3
Widow/Divorcee			30	12.5
Educational Level				
Primary				
Secondary			28	11.7
Tertiary			162	67.5
			50	20.8
Employment Status				
Working			131	54.6
Others			109	45.4
Monthly Income				
With Income				
Without Income			147	61.3
			93	38.8
Medical History				
Present			47	19.6
Absent			193	80.4
Relationship with Child Attending CBR				
Mother			170	70.8
Others			70	29.2

4.1.2 Characteristics of disabled children

In this study, the median age of the disabled children was 9 years old (IQR: 11). The disabled children's age ranged from 1 year to 17 years old. Thirty four percent of the respondent's child's age in this study was in the age-group of 12 to 17 years old.

Most of the disabled children were males (62.5%). The disabled children were commonly in the middle position among their siblings (35.0%). The total numbers of years attending CBR were mostly less than 5 years (65.8 %). Eighty three percent of these respondents' children had no other education attainment. The commonest type of disability was learning difficulties (47.1%) followed by multiple disabilities (35.8%). Multiple disability comprises syndromic children, for example Down syndrome with a physical disability and speech disability. However, all this classification was based on the disability card of the disabled child. The result shown in Table 4.2.

Table 4.2: Distribution of Characteristics of Disabled Children (N=240)

Child characteristic	Median	(IQR)	n	%
Age Group	9	11		
1-6			78	32.5
7-11			79	32.9
12-17			83	34.6
Gender				
Male			150	62.5
Female			90	37.5
Position of child				
Eldest			77	32.1
Middle			84	35.0
Youngest			79	32.9
Attainment of Education				
Yes			39	16.3
No			201	83.7
Years Attending CBR				
<5 years			158	65.8
5-10 years			57	23.8
>10 years			25	10.4
Type of Disability				
others			41	17.1
learning diff			113	47.1
multiple			86	35.8

***p<0.005**

4.1.3 Psychological Effects of Respondents

Psychological aspects of respondents were analysed. Majority of respondents did not either have depression (67.9%), anxiety (56,9%) or stress (72.5%).

Table 4.3: Psychological Effects of Respondents (N=240)

Psychological Effects of Respondents	n	%
Depression		
Normal (0-9)	163	67.9
Mild (10-13)	27	11.3
Moderate (14-20)	37	15.4
Severe (21-27)	9	3.8
Extremely Severe (28-42)	4	1.7
Anxiety		
Normal (0-7)	135	56.9
Mild (8-9)	23	9.6
Moderate (10-14)	48	20.0
Severe (15-19)	20	8.3
Extremely Severe (20-42)	15	5.8
Stress		
Normal (0-14)	174	72.5
Mild (15-18)	28	11.7
Moderate (19-25)	29	12.1
Severe (26-33)	5	2.1
Extremely Severe (34-42)	4	1.7

Distribution of DASS-21 Scoring (N=240)

Table 4.4: Distribution of DASS-21 Scoring (N=240)

Psychological Effects	Yes		No	
	n	%	n	%
Depression	50	20.8	190	79.2
Anxiety	82	34.2	158	65.8
Stress	38	15.8	202	84.2
Depression & Anxiety	16	6.7	224	93.3
Depression & Stress	1	0.4	239	99.6
Anxiety & Stress	6	2.5	234	97.5
Depression & Anxiety & Stress	30	12.5	210	87.5

Scoring of DASS of normal and mild was categorized as no psychological effects meanwhile moderate, severe & extremely severe were categorized as the presence of psychological effects in this study for dichotomous analysis purpose. Prevalence of depression was (20.8%), while anxiety is (34.2%) and stress is (15.8%). There were 6.7% who had both depression and anxiety, 0.4% had depression and stress, 2.5% had both anxiety and stress and finally 12.5% respondents who had all depression, anxiety and stress.

4.2 Association of the Factors

4.2.1 Association between sociodemographic factors and psychological effects among respondents

4.2.1.1 Depression

Based on table 4.5, for sociodemographic factors most respondents did not have depression. In this study, it was found 24.39% respondents of Non-Malay ethnicity were depressed and 20.11% of Malay ethnicity respondents were depressed. However, there was no significant association found between ethnicity and depression(P=0.538). Upon analysis, it was seen 25% of respondents who only had primary school education had depression, 24.07% respondents who only finished secondary school had depression and 8% of respondents with tertiary education had depression. Only level of education had a significant association with depression (χ^2=6.319; df 2; p=0.042). There were no significant associations between other sociodemographic factors and depression found in this study.

Table 4.5: Association between Sociodemographic Factors and Depression (N=240)

Sociodemographic	Depression		χ^2	df	p
	Yes n (%)	No n (%)			
Age group					
≤40 years	19(22.9)	64(77.1)	0.326	1	0.568
>40 years	31(19.8)	126(80.2)			
Gender					
Male	136(77.3)	54(84.4)	1.435	1	0.231
Female	40(80.0)	10(20.0)			
Ethnicity					
Malay	40(20.1)	159(79.9)	0.379	1	0.538
Others	10(24.4)	31(75.6)			
Marital Status					
Married	42(20.3)	165(79.7)	0.270	1	0.604
Others	8(32.0)	25(68.0)			
Level of Education					
Primary	7(25.0)	21(75.0)	6.319	2	**0.042***
Secondary	39(24.1)	123(75.9)			
Tertiary	4(8.0)	46(92.0)			
Employment Status					
Woking	24(18.3)	107(81.7)	1.104	2	0.293
Others	26(23.9)	83(76.1)			
Income					
With Income	28(19.0)	119(81.0)	0.733	1	0.392
Without Income	22(23.7)	71(76.3)			
Medical History					
Present	13(27.7)	34(72.3)	1.651	1	0.199
Absent	37(19.3)	156(80.8)			
Relationship with child attending CBR					
Mother	11(15.7)	59(84.3)	1.570	1	0.210
Others	39(22.9)	131(77.1)			

*p value < 0.05

4.2.1.2 Anxiety

For sociodemographic factors, majority of respondents had no anxiety. Upon gender, 37.50% of female respondents had anxiety compared to 25% of male respondents who had anxiety. Analysis showed that there was no significant association between gender and anxiety (P=0.710). There were 48.94% of the respondents with medical history who had anxiety and 30.57% respondents without medical history who had anxiety. A significant association was found between respondents' medical history and anxiety (χ^2 =5.668; df 1; p=0.017) as shown in Table 4.6. Among mothers 37.65 % were found to have anxiety and 25.71% of other relationships with the child attending CBR were to have anxiety. However, there was no statistical association between relationship with child attending CBR and anxiety (P=0.076).

Table 4.6: Association between Sociodemographic Factors and Anxiety (N=240)

Sociodemographic	Anxiety		χ^2	df	p
	Yes n (%)	No n (%)			
Age group			0.221	1	0.639
≤40 years	30(36.1)	53(63.9)			
>40 years	52(33.1)	105(66.9)			
Gender			3.260	1	0.710
Male	16(25.0)	8(75.0)			
Female	66(37.5)	110(62.5)			
Ethnicity			0.527	1	0.468
Malay	70(35.2)	129(64.8)			
Others	12(29.3)	29(70.7)			
Marital Status			0.465	1	0.495
Married	13(39.4)	20(60.6)			
Others	69(33.3)	138(66.7)			
Level of Education			2.001	2	0.368
Primary	11(39.3)	17(60.7)			
Secondary	58(35.8)	104(64.2)			
Tertiary	13(26.0)	37(74.0)			
Employment Status			0.231	1	0.631
Employed	43(32.8)	88(67.2)			
Others	39(35.8)	70(64.2)			
Income			0.386	1	0.534
With Income	48(32.6)	99(67.4)			
Without Income	34(36.6)	59(63.4)			
Medical History			5.668	1	**0.017***
Present	23(48.9)	24(51.1)			
Absent	59(30.6)	134(69.4)			
Relationship with child attending CBR			3.139	1	0.076
Mother	64(37.7)	106(62.3)			
Others	18(25.7)	52(74.3)			

*p value < 0.05

4.2.1.3 Stress

Table 4.7 depicts the association of sociodemographic factors and stress. Among 15.6% of Malay respondents were stressed and 17.1% of Non-Malay respondents were stressed, but statistically, there was no significant association between ethnic and stress (p=0.811). Monthly income was found to be associated with stress (χ^2 =4.318; df 1; p=0.038) in this study. Respondents without income were found to have stress below than 10% compared to 19.7% respondents who have the monthly income.

It was seen that of the respondents who had a medical history, 29.8% had stress and 12.4% respondents with absence of medical history were stressed. There was a significant association between medical history status and stress (χ^2 =8.539; df 1; p=0.003) noted in this study.

Table 4.7: Association between Sociodemographic Factors and Stress (N=240)

Socio-demographic	Stress		χ^2	df	p
	Yes n (%)	No n (%)			
Age Group			0.003	1	0.958
<40 years	13 (15.7)	70 (84.3)			
≥40 years	25 (15.9)	132 (84.1)			
Gender			1.570	1	0.210
Male	7 (10.9)	57 (89.1)			
Female	31(17.7)	145(82.3)			
Ethnicity			0.057	1	0.811
Malay	31 (15.6)	168 (84.4)			
Others	7 (17.1)	34 (82.9)			
Marital Status			0.831	1	0.362
Married	31 (15.0)	176 (85.0)			
others	7 (21.0)	26 (79.0)			
Level of Education			4.590	2	0.101
Primary	5 (17.9)	23 (82.1)			
Secondary	30 (40.1)	132 (59.5)			
Tertiary	3 (6.0)	47 (94.0)			
Employment Status			3.487	1	0.062
Employed	26 (19.8)	105 (80.2)			
Others	12 (10.0)	97 (90.0)			
Income			4.318	1	**0.038***
Yes	29 (19.7)	118 (80.3)			
No	9 (9.7)	84 (90.3)			
Medical History			8.539	1	**0.003***
Present	14 (29.8)	33 (70.2)			
Absent	24 (12.4)	169 (87.6)			
Relationship with child attending CBR			1.439	1	0.230
Mother	30 (17.6)	40 (82.4)			
Others	8 (11.4)	62 (88.6)			

***p value <0.05**

4.2.2 Association between characteristics of the disabled child and respondents' psychological effects

4.2.2. 1 Depression

For characteristics of disabled children, most of the respondents did not have depression. Analysis showed 21% of the respondents who had either male or female disabled children were depressed. However, there was no significant association between child's gender and depression found (P=0.914). Among 33.3% respondents who had their disabled child attained other education were depressed and 18.41% of respondents who their disabled child did not attain other education were found depressed. There was significant association noted between attainment of other education among disabled children and respondent's depression (χ^2 =4.412, p=0.036). There were no significant associations between other characteristics of disabled children and depression found in this study.

Table 4.8: Association between Characteristics of the Disabled Children and Depression (N=240)

Disabled children characteristic	Depression		χ^2	df	p
	Yes n (%)	No n (%)			
Child's age group					
1-6	15(19.2)	63(80.8)			
7-11	17(21.5)	62(78.5)	0.181	2	0.914
12-17	18(21.7)	65(78.3)			
Child's gender					
Male	29(19.3)	121(80.7)	0.546	1	0.460
Female	21(23.3)	69(76.7)			
Duration in CBR					
<5 years	27(17.1)	131(82.9)			
5-10 years	17(29.8)	40(70.2)	4.289	2	0.117
>10 years	6(24.0)	19(76.0)			
Other Education					
Yes	13(33.3)	26(66.7)	4.412	1	**0.036***
No	37(18.4)	164(81.6)			
Position of child					
Eldest	13(16.9)	64(83.1)			
Middle child	15(17.9)	69(82.1)	3.537	2	0.171
Youngest	22(27.8)	57(72.2)			
Types of Disability					
Learning difficulties	24(21.2)	89(78.8)			
Multiple disability	12(14.0)	74(86.0)	6.885	2	0.32
Others	14(34.1)	27(65.9)			

*p value < 0.05

4.2.2. 2 Anxiety

Table 4.9 depicts 38.55% respondents with disabled children aged 12 to 17 years old had anxiety, compared to 29.11% of respondents with children aged seven to eleven years old and 34.62% of respondents with children aged one to six years old. There was no significant association noted between disabled child's age and anxiety at (χ^2 =1.614; df 2; p=0.446). Analysis showed that 29.33% of respondents with male disabled child had anxiety, while 42.22% of respondents with female disabled child had anxiety. There was statistically significant association between child's gender and anxiety (χ^2 =4.154; df 1; p=0.042).

Analysis showed that 29.11% respondents with disabled child attended CBR for less than 5 years were found to have anxiety, compared to 43.86% of respondents with disabled child attending CBR for five to ten years and 44% respondents who had their disabled child attending CBR for more than ten years. The was no statistically significant association noted between duration in CBR and anxiety (χ^2 =5.249; df 2; p=0.072). In this study, 41.03% of respondents with a disabled child with the attainment of other education had anxiety compared to 32.84% among respondents who their child had no other attainment of other education. There was no statistics significant association between attainment of other education and anxiety (χ^2 =0.974; df 1; p=0.324). The analysis also showed that among 46.34% respondents having a disabled child or other disabilities had anxiety, compared to 38.94% of respondents who had learning difficulties disabled child. There was a significant association between type of disability and anxiety (χ^2 =9.419; df 2; p=0.009).

Table 4.9: Association between Characteristics of the Disabled Children and Anxiety (N=240)

Disabled children characteristic	Anxiety Yes n (%)	No n (%)	χ^2	df	p
Child's age group			1.614	2	0.446
1-6	27(34.62)	51(65.38)			
7-11	23(29.11)	56(70.89)			
12-17	32(38.55)	51(61.45)			
Child's gender			4.154	1	**0.042***
Male	44(29.33)	106(70.67)			
Female	38(42.22)	52(57.78)			
Duration in CBR			5.249	2	0.072
<5 years	46(29.11)	112(70.89)			
5-10 years	25(43.86)	32(56.14)			
>10 years	11(44.00)	14(56.00)			
Other Education			0.974	1	0.324
Yes	16(41.03)	23(58.97)			
No	66(32.84)	135(67.16)			
Position of child			2.416	2	0.299
Eldest	21(27.27)	56(72.73)			
Middle child	31(36.90)	53(63.10)			
Youngest	30(37.97)	49(62.03)			
Types of Disability			9.419	2	**0.009***
Learning difficulties	44(38.94)	69(61.06)			
Multiple disability	19(22.09)	67(77.91)			
Others	19(46.34)	22(53.66)			

*p value < 0.05

4.2.2. 3 Stress

As shown in Table 4.10, it was noted that respondents with a disabled child who had attained education noted to have stress 30.8% compared to respondents with disabled children with no education who were 12.9% stressed. There was also a significant association between attainment of education and stress (χ^2 =7.795; df 1; p=0.005)

There was also a significant association between years of attending CBR and stress (χ^2 =13.197; df 2; p=0.001) from Fisher Exact test. Respondents with a disabled child who attended CBR within five to ten years noted to have stress 31.6% compared to respondents who attended CBR more than ten years 16.0% and less than five years only 10.1%. Among the type of disability of the disabled child, 17.7% of respondents with learning difficulty child was stressed compared to, 12.8% of respondents with multiple disability children and among 17.1% of the respondents with other disabilities in this study. There was no significant association between type of disability of child and stress (p=0.54).

Table 4.10: Association between Characteristics of the Disabled Children and Stress (N=240)

Child characteristic	Respondent stress		χ^2	df	p
	Yes n (%)	No n (%)			
Age Group			3.263	2	0.196
1-6	10 (12.8)	68 (87.2)			
7-11	10 (12.7)	69 (87.3)			
12-17	18 (21.7)	65 (78.3)			
Gender			0.075	1	0.784
Male	23 (15.3)	127 (84.7)			
Female	15 (16.7)	75 (83.3)			
Position of child			2.914	2	0.233
Eldest	8 (10.4)	69 (89.6)			
Middle	14 (16.7)	70 (83.3)			
Youngest	16 (20.3)	63 (79.7)			
Attainment of Education			7.795	1	**0.005***
Yes	12 (30.8)	27 (69.2)			
No	26(12.9)	175(87.1)			
Years Attending CBR			13.197	2	**0.001***
<5 years	16 (10.1)	142 (89.9)			
5-10 years	18 (31.6)	39 (68.4)			
>10 years	4 (16.0)	21 (84.0)			
Type of Disability					
learning	20 (17.7)	93 (82.3)	0.940	2	0.625
difficulties	11 (12.8)	75 (87.2)			
Multiple disability	7(17.1)	34(82.9)			
Others					

***p value < 0.05**

CHAPTER 5

DISCUSSION

5.1 Psychological Effects of Caregivers of Disabled Child

Psychological aspects of caregivers in this study were analysed using the DASS-21 questionnaire. It was found majority caregivers did not have depression, anxiety or stress. Prevalence for anxiety shows the highest, followed by depression and the lowest was stress. This psychological effect was affected predominantly by female caregivers. Parents of children with disabilities may also experience negative attitudes and discrimination, and consequent social isolation, including marital breakdown, which can contribute to poor mental health (Scherer et al., 2019)

In a study done in India, the prevalence of depression was 63% (Dave et al., 2014). In this study, depression was in lower prevalence. However, in one of the studies in a Rural Setting in Kenya, 79% of the caregivers were depressed mostly due to financial lack and loss of close friendship (Mbugua et.al., 2011).

In this study, prevalence of anxiety was the highest compared with other two domain psychological effects. This study was consistent with one of the studies in Oman which was the prevalence of the anxiety was the highest (43%) (Al- Farsi et al., 2016).

As shown in this study stress prevailed lowest compared to the other two psychological effects, depression and anxiety. Contrary to a study done in Brazil, a high proportion of mothers reported experiencing stress (36%), followed by anxiety (27%) and depression (18%). Low social support was linked to higher levels of stress, depression and anxiety (Scherer et al., 2019).

5.2 Distribution of Sociodemographic Factors of Caregivers

Most of the caregivers in this study were aged 40 years old and above. In a study done in Kelantan, the mean (SD) age of caregivers was 38.91 (8.26) years (Nik Adib et al., 2019). Caregivers who participated in this study were mostly female and similar findings were found in a study done by Nik Adib et al. (2019) whereby most of the caregivers of disabled children in Kelantan were female (74.9 %). Most caregivers were Malay in which the finding is a good representative that the major ethnic group in Malaysia is Malays. Most of the caregivers were married in which the findings were consistent with a study showed that majority of caregivers of disabled children were married (88.9%) (Isa et al., 2017).

Most of the caregivers had secondary educational level, followed by tertiary educational level and primary educational level. Contrary to a study done by Dave, most caregivers of disabled children had primary education (58%) (Dave et al., 2014). In the aspect of employment status, majority of the caregivers participated in this study were working and similar findings were found in a study done by Dave, in which 52% of caregivers were working (Dave et al., 2014). It is supported that 45.4% of caregivers were housewives thus had no monthly income.

In this study, majority of caregivers had monthly income and 38.8% of caregivers had no monthly income. A study done by Dave showed similar findings in which 48% of caregivers had no monthly income (Dave et al., 2014). There were 19.6% of caregivers had medical history. This study showed the majority relationship of the caregivers with the child attending CBR were mothers and similar findings were found in a study done by Nik Adib et al., in which 55.9% of caregivers were mothers (Nik Adib et al., 2019).

5.3 Factors associated with psychological effects of caregivers

5.3.1 Sociodemographic factors

5.3.1.1 Age of caregivers

This study showed that age was not significantly associated with depression, anxiety or stress. Similar findings were found in a study by Al Farsi in Oman, in which age was not associated with mental health of caregivers of disabled children (Al- Farsi et al, 2016). Contrary to another study conducted among Japanese parents, age showed significant association. It was negatively correlated with depression ($r=-.30$, $p<.01$) and anxiety ($r=-.36$, $p<.01$) (Kono & Mearns, 2013). A study conducted in India also showed that age of caregiver was significantly associated with high depression score (Dave et al., 2014).

5.3.1.2 Gender

In this study, gender was not significantly associated with depression, anxiety and stress. This was supported by a study in India that showed gender was not associated with a high anxiety score among caregivers (Dave et al., 2014). However, a study conducted by Mcstay (2014) showed that mothers had higher levels of stress than fathers (Mcstay, 2014). This can be explained by a study that showed mother experienced greater parenting stress than father (Tach, 2011). A study in Malawi also showed that gender was not significantly associated with psychological effects (Masulani-Mwale, 2018).

5.3.1.3 Ethnicity

Ethnicity was not significantly associated with psychological effects of depression, anxiety and stress in this study. Similar study showed that gender was not associated with high anxiety score among caregivers (Dave et al., 2014). However, a study showed that non-Malay parents are more stressed than the Malay parents (OR 3.92, 95% CI 1.29–11.94) (Narkunam et al., 2014).

5.3.1.4 Marital Status

In this study, there was no significant association seen between marital status with psychological effects of depression, stress or anxiety. These findings were consistent with a study conducted in India that showed that marital status was not associated with high anxiety score among caregivers (Dave et al., 2014). However, a study showed that there was significant association between marital status and stress (Tach, 2011). Mothers who had previous multi-partnered fertility also reported greater increases in parenting stress (Tach, 2011).

5.3.1.5 Education Level

There was a significant association seen between depression and caregiver's education level in this study whereby caregivers who had secondary school education had 24.1% of depression compared to another level of education. Low education level had a significant association with depressive symptoms (He et al., 2019). Contrary to a study, education level was not found to be statistically significant ($p>0.05$) (Dave et al., 2014). Education level was found not to be significantly associated with anxiety and stress in this study.

5.3.1.6 Employment Status

There was no significant association between anxiety and caregiver's employment status whereby unemployed caregivers had a high percentage of depression compared to employed caregivers. This finding is not consistent with one of the studies whereby employment has a very high correlation with High Zung's anxiety score, which is highly indicative that unemployed or non-earning caregiver has significantly more Zung's anxiety scale while caring for their intellectually disabled child (Dave et al., 2014). Employment status was found not significantly associated with depression and stress.

5.3.1.7 Income

Many studies have identified a low income as a risk factor for mental health problems. In this study, there was no significant association between depression and income status. Contrary to a study, there was a strongly significant association between depression and income status ($p<0.05$) (He et al., 2019)

5.3.1.8 Medical History

There was a significant association between caregivers' presence of medical history with stress. Caregivers who was anxiety with the presence of disabled children was found at 29.8%. These findings were consistent with a study conducted in Kelantan, 27.9% of the caregivers

had a chronic illness such as diabetes mellitus, hypertension or heart diseases. However, a study showed there is no significant association between medical history and stress ($p<0.05$) (Isa et al., 2017)

5.3.1.9 Relationship with child attending CBR

This study found that anxiety and stress were common among mothers of disabled children while depression is less common among mothers of disabled children. However, there is no significant association between depression, anxiety and stress with the relationship of caregivers with disabled children. Meanwhile, for comparisons of fathers with mothers, another study found out that mothers were significantly more likely to have general mental health problems than fathers ($P< 0.01$), this was also the case for depression ($P< 0.001$), stress ($P< 0.001$) and anxiety ($P< 0.001$) (Kirsty et.al.,2019)

5.3.2 Characteristics of disabled child factors

5.3.2.1 Age

In this study, there was no significant association between child's age and stress. Similar findings were found in a study about perceived stress among Malay caregivers of children with learning disabilities in Kelantan in which child's age was not associated with perceived stress ($p<0.05$) (Isa et al., 2017).

5.3.2.2 Gender

There was statistically significant association between child's gender and anxiety. Contrary study as predicted from an ASD study, the ASD group had significantly more males ($\chi 2(2, N=49) =4.6$, $p<.05$) and had significantly more ASD symptomatology ($t (47) =7.02$, $p<.001$) than the other category of developmental disabilities (Teague et al. 2018).

5.3.2.3 Position of child in family

The disabled children were commonly in the middle position among their siblings followed by youngest and eldest from this study. There was no significant association between the position of disabled children and anxiety. Based on a report by Malm et al. (2015), there was no substantial correlation with the child's status and caregivers' mental well-being found in this research as well.

5.3.2.4 Duration in CBR

There was a significant association between years of attending CBR and stress from Fisher Exact test. Respondents with a disabled child who attended CBR within five to ten years noted to have stress 31.6% compared to respondents who attended CBR more than ten years 16.0% and less than five years only 10.1%. This may be due to the belief of parents that disabled children are transferring from CBR to other services or that a disabled child is chronically ill in CBR.

5.3.2.5 Attainment of other education

Most of these disabled children had no other education attainment and only 16.3% had attained other education. An example of other education attainment was integrated classes in conventional schools where some kids were more than 12 years old after Standard six or age, these kids tend to go back to CBR as they were unable to progress to integrated high school programmes. However, in this analysis, this variable was not further explored. Among 33.3% respondents who had their disabled child attained other education were depressed and 18.41% of respondents who their disabled child did not attain other education were found depressed. There was significant association noted between attainment of other education among disabled children and respondent's depression (χ^2 =4.412, p=0.036).

It was also noted that respondents with a disabled child who had attained education noted to have stress 30.8% compared to respondents with disabled children with no education who were 12.9% stressed. There was also a significant association between attainment of education and stress. These findings can be strengthened by a research done by Kilic et al., (2013) that parents had a higher anxiety trait ($F=8.58$, $p<0.001$) and depression ($F=3.521$, $p<0.001$) in Turkey where parents of disabled children without special education or recovery assistance were noted.

5.3.2.6 Types of disability

The finding of this present study showed the caregivers disabled children commonest type of disability were learning difficulties (45.8%), multiple disabilities (37.1%) and physical disability (17.1 %). Upon comparing with national data of children with disability in 2017, the registered Person with Disabilities (PWD) at the Department of Social Welfare, Malaysia in 2017 were 453,258 persons. PWD in the physical category recorded the highest number, which was 35.2 per cent, followed by Learning disability category (34.8%) and Visually impaired category (8.9%). Speech category recorded the lowest registration of 0.5 per cent (Department of Statistics Malaysia, 2018).

There was a significant association between type of disability and anxiety (χ^2 =9.419; df 2; p=0.009) from this study. Another local study also found a significant association between anxiety and type of disability which it was carried out among caregivers in welfare homes in Penang found that their disabled children had learning problems (41.3%), multiple disabilities (27.5%) and physical disabilities (12.5%) with similar results in this survey (Tan, 2015)

CHAPTER 6

CONCLUSION AND RECOMMENDATIONS

6.1 Conclusion

This study showed that there were caregivers who did not experience any mental health problems, there were caregivers who had one or more psychological problems, with highest being anxiety, followed by depression and stress. Caregivers play an important role in ensuring the children develop their full potential and leads a healthy life. Thus, there is a need to address the factors that influence the mental wellbeing of the caregivers to help them to cope with the challenges of caring for a disabled child. Further study is needed to investigate other factors and sources of stress to enable a holistic intervention to be carried out. Community can play an integral part in providing support for the caregivers, either directly or indirectly, to reduce their burden and consequently, will reduce their mental stress. This study also showed that there is a need to provide mental health support for caregivers to promote effective coping mechanisms.

6.2 Limitations

Upon interpretation of this study, it must be done with caution as there are several potential limitations. Firstly, this study was a cross-sectional study whereby it only measures results at a specific point in time. There can be a difference of results if measured at a different period, for instance, psychological effects can differ upon transition of time. Prevalence –incidence bias also is a limitation of this study as it could not predict the overall population of caregivers of a disabled child in Malaysia. Moreover, Self-reported questionnaires as a minor source of information bias could occur. Caregivers' refusal to participate in this study was also a limitation as the population of caregivers of disabled children are not extensively large in number thus a small percentage of non-response rate gives an effect to the study.

6.3 Study Strengths

The strength of this study was to avoid bias in the data by doing the random sampling method in choosing participants of this study. Moreover, this study had a representation of mixed ethnicity and study population geographical location from rural and urban, thus it represented the population of study well in Selangor.

6.4 Recommendations

Recommendation for future studies is government should take action by early diagnosed for any of the caregivers that are suffering with mental health issues for early intervention. Moreover, the government should provide therapy session for the caregivers such as counselling.

In this study was found the education level is an important factor for caregivers to deal with psychological effects. Thus, we suggest that the government considers education for all disabled children at least until secondary school to ensure they reach their maximum potential. Besides education, caregivers also should provide with enough information on how to handle with disabled children since caregivers with low education level were in high percentage with depression, anxiety and stress.

Majority of the caregivers in this study were mothers. Further studies can be carried out to look at the role of fathers in relation to the care of disabled children. This finding raises important questions about whether fathers want to be involved in caring, and if so, then what barriers they experience. Such information could assist policy makers and service providers to improve

services and support for fathers. Therefore, it is important for future research to explore the mental health and wellbeing of the fathers also.

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APPENDICES

APPENDIX A

Variables	**Category**	**Prevalence**	**Sample size**	**Reference**
Age	1=below 40 2=above 40	P1= 0.590 P2=0.410	n= 240	Dave et al. (2014)
Gender	1= Male 2= Female	P1= 0.231 P2= 0.769	n= 26	Rosdinom R, Norzarina MZ, Zanariah MS, Ruzanna ZZ (2011)
Ethnicity	1= Malay 2= Non-Malay	P1= 0.333 P2= 0.667	n= 38	Ivan Vun JS, Cheah WL, Helmy H (2019)
Marital Status	1=Single 2=Married 3=Widow/Divorcee	P1=0.138 P2=0.815 P3=0.046	n=12	Rosdinom R, Norzarina MZ, Zanariah MS, Ruzanna ZZ (2011)

Variables	Category	Prevalence	Sample size	Reference
Educational Level	1=Primary 2=Secondary 3=Tertiary	P1=0.523 P2=0.200 P3=0.031	n=24	Rosdinom R, Norzarina MZ, Zanariah MS, Ruzanna ZZ (2011)
Employment Status	1=Employed 2=Unemployed	P1=0.373 P2=0.626	n=120	Siti NI, Ismarulyusda I, Azriani AR (2017)
Monthly Income	1= with income 2=without income	P1= 0.439 P2= 0.177	n= 96	Kalman R, Steve R. (2009)
Number of disabled children	1=1 disabled child 2=2 disabled children	P1=0.417 P2=0.700	n=96	Mohamed G. (2007)

Types of disability	Category	Prevalence	Sample size (n)	Reference
Physical disability	1: Children with Physical disability 2: Children with no Physical disability	P :0678 P2:0.284	44	United Nations Children's Fund (UNICEF) Malaysia, September 2017
Visual disability	1: Children with Visual disability 2: Children with no Visual disability	P1 :0.9 P: 46.8	20	United Nations Children's Fund (UNICEF) Malaysia, September 2017
Mental disability	1: Children with mental disability 2: Children with no mental disability	P1: 0.162 P2:0.778	14	United Nations Children's Fund (UNICEF) Malaysia, September 2017
Speech disability	1: Children with speech disability 2: Children with no speech	P:0.569 P2: 0.163	38	United Nations Children's Fund (UNICEF) Malaysia, September 2017)

	disability			
Hearing disability	1: Children with hearing disability 2: Children with no disability	P: 0.19 P2: 0.007	240	Banurekha V, Boopathi K, Sanja M (2017)
Multiple disability	1: Children with multiple disability 2: Children with no multiple disability	P1:0.008 P2: 0.24	158	Banurekha V, Boopathi K, Sanja M (2017)
Learning Disability	1: Children with learning disability 2: Children with no learning disability	P1: 0.037 P2: 0.2182	90	Taiseer AB, ali H. AB, Saqib Ali (2011)

Questionnaire

APPENDIX C

BORANG SOAL-SELIDIK
QUESTIONNAIRE

TAJUK KAJIAN:
RESEARCH TITLE

Kesan Psikologi Dan Faktor Berkaitan Di Kalangan Penjaga Kanak-Kanak Kurang Upaya di Pusat Pemulihan Dalam Komuniti (PDK) Di Negeri Selangor
Psychological Effects And Its Associated Factors Among Caregivers Of Disabled Children In Community Based Rehabilitation Centres In Selangor

PENYELIDIK:
V.C.ANURATHA SUBRAMANIAM
SARJANA KESIHATAN AWAM
Jabatan Kesihatan Komuniti
Fakulti Perubatan dan Sains Kesihatan
Universiti Putra Malaysia

PENYELIA:

DR. ANISAH BAHAROM
PROF. MADYA DR. NOR AFIAH MOHD ZULKEFLI
Jabatan Kesihatan Komuniti,
Fakulti Perubatan dan Sains Kesihatan
Universiti Putra Malaysia

Maklumat yang akan ditanya dalam borang soal-selidik ini adalah semata-mata tujuan penyelidik dan identiti anda akan dirahsiakan
(The information asked in this questionnaire is solely for research purpose and your identity will remain confidential)

BAHAGIAN E/ *PART E*: SKALA DASS-21 / DASS-21 SCALE

Sila baca setiap kenyataan di bawah dan bulatkan pada nombor 0,1, 2 atau 3 bagi menggambarkan keadaan anda sepanjang minggu lepas. Tiada jawapan yang betul atau salah. Jangan mengambil masa yang terlalu lama untuk mana- mana kenyataan.

(Please read each statement and circle a number 0, 1, 2 or 3 which indicates how much the statement applied to you over the past week. There are no right or wrong answers. Do not spend too much time on any statement)

0	**Tidak langsung** menggambarkan keadaan saya / ***did not apply*** *to me*
1	**Sedikit atau jarang-jarang** menggambarkan keadaan saya. / ***applied to me to some degree****, or some of the time*
2	**Banyak atau kerap kali** menggambarkan keadaan saya / ***applied to me to a considerable degree****, or a good part of time*
3	**Sangat banyak atau sangat kerap** menggambarkan keadaan saya/ ***applied to me very much****, or most of the time*

No	**Kenyataan / *Statement***	**Skala / scale**			
		Tidak langsung menggambarkan keadaan saya / ***did not apply*** *to me*	**Sedikit atau jarang-jarang** menggambarkan keadaan saya. / ***applied to me to some degree****, or some of the time*	**Banyak atau kerap kali** menggambarkan keadaan saya / ***applied to me to a considerable degree****, or a good part of time*	**Sangat banyak atau sangat kerap** menggambarkan keadaan saya/ ***applied to me very much****, or most of the time*
a	Saya dapati diri saya susah untuk bertenang *I found it hard to wind down*	**0**	**1**	**2**	**3**
b	Saya sedar mulut saya terasa kering *I was aware of dryness of my mouth*	**0**	**1**	**2**	**3**
c	Saya tidak dapat mengalami perasaan positif sama sekali *I couldn't seem to experience any positive feeling at all*	**0**	**1**	**2**	**3**
d	Saya mengalami kesukaran bernafas (contohnya: pernafasan yang laju, tercungap-cungap) walaupun tidak melakukan senaman fizikal *I experienced breathing difficulty (eg, excessively rapidbreathing,breathlessness in the absence of physical exertion*	**0**	**1**	**2**	**3**

		Tidak langsung menggambarkan keadaan saya / ***did not apply to me***	**Sedikit atau jarang-jarang** menggambarkan keadaan saya. / ***applied to me to some degree***, *or some of the time*	**Banyak atau kerap kali** menggambarkan keadaan saya / ***applied to me to a considerable degree***, *or a good part of time*	**Sangat banyak atau sangat kerap** menggambarkan keadaan saya/ ***applied to me very much***, *or most of the time*
e	Saya rasa diri saya semakin gelisah *I found myself getting agitated*	**0**	**1**	**2**	**3**
f	Saya sukar untuk mendapatkan semangat bagi melakukan sesuatu perkara *I found it difficult to work up the initiative to do things*	**0**	**1**	**2**	**3**
g	Saya cenderung untuk bertindak keterlaluan dalam sesuatu keadaan *I tended to over-react to situations*	**0**	**1**	**2**	**3**
h	Saya rasa menggeletar (contohnya pada tangan) *I experienced trembling (e.g. in the hands)*	**0**	**1**	**2**	**3**
i	Saya rasa saya menggunakan banyak tenaga dalam keadaan cemas *I felt I was using a lot of nervous energy*	**0**	**1**	**2**	**3**
j	Saya bimbang keadaan di mana saya mungkin menjadi panik atau cemas dan melakukan perkara yang membodohkan diri sendiri. *I was worried about situations in which I might panic and make a fool of myself.*	**0**	**1**	**2**	**3**
k	Saya rasa saya tidak mempunyai apa-apa untuk diharapkan. *I felt I had nothing to look forward to.*	**0**	**1**	**2**	**3**
l	Saya rasa sukar untuk relaks. *I found it difficult to relax.*	**0**	**1**	**2**	**3**
m	Saya rasa muram dan sedih *I felt down hearted and blue*	**0**	**1**	**2**	**3**

		Tidak langsung menggambarkan keadaan saya / ***did not apply*** *to me*	**Sedikit atau jarang-jarang** menggambarkan keadaan saya. / ***applied to me to some degree***, *or some of the time*	**Banyak atau kerap kali** menggambarkan keadaan saya / ***applied to me to a considerable degree***, *or a good part of time*	**Sangat banyak atau sangat kerap** menggambarkan keadaan saya/ ***applied to me very much***, *or most of the time*
n	Saya tidak dapat menahan sabar dengan perkara yang menghalang saya meneruskan apa yang saya lakukan. *I was intolerant of anything that kept me from getting on with what I was doing.*	**0**	**1**	**2**	**3**
o	Saya rasa hampir-hampir menjadi panik /cemas. *I felt I was close to panic*	**0**	**1**	**2**	**3**
p	Saya tidak bersemangat dengan apa jua yang saya lakukan. *I was unable to become enthusiastic about anything.*	**0**	**1**	**2**	**3**
q	Saya tidak begitu berharga sebagai seorang individu. *I felt I wasn't worth much as a person.*	**0**	**1**	**2**	**3**
r	Saya rasa yang saya mudah tersinggung. *I felt that I was rather touchy.*	**0**	**1**	**2**	**3**
s	Saya sedar tindakbalas jantung saya walaupun tidak melakukan aktiviti fizikal (contohnya kadar denyutan jantung bertambah, atau berkurangan) *I was aware of the action of my heart in the absence of physical exertion (e.g., sense of heart rate increase or heart missing a beat)).*	**0**	**1**	**2**	**3**
t	Saya berasa takut tanpa sebab yang munasabah. *I felt scared without any good reason.*	**0**	**1**	**2**	**3**
u	Saya rasa hidup ini tidak bermakna I felt that life was meaningless.	**0**	**1**	**2**	**3**

ARAHAN / *INSTRUCTIONS* :

Sila jawab semua soalan.
Isi tempat kosong yang disediakan atau tandakan (√) bagi jawapan anda di dalam petak yang berkenaan.
(Please answer all questions. Fill in the space provided or tick (√) your answer in the appropriate box).

BAHAGIAN A / *PART A*: BIODATA RESPONDEN / *RESPONDENT'S BIODATA*

1.	Tarikh lahir / *Date of Birth* : .....hari/bulan/tahun / *day/month/year*
2	Jantina / *Gender :* ☐ Lelaki / *Male* ☐ Perempuan / *Female*
3	Bangsa / *Ethnicity:* ☐ Melayu / *Malay* ☐ Cina / *Chinese* ☐ India / *Indian* ☐ Lain – lain (Sila nyatakan) / *Others (Please specify)* : .....
4	Status perkahwinan / *Marital status:* ☐ Belum Berkahwin / *Unmarried* ☐ Janda/Duda / *Widow or Divorcee* ☐ Berkahwin / *Married*
5	Tahap Pendidikan / *Education Level:* ☐ Sekolah rendah ☐ PMR /SRP ☐ SPM ☐ STPM ☐ Diploma/ *Diploma* ☐ Sarjana Muda/Sarjana/PhD */Bachelor/Masters/PhD*
6	Status Pekerjaan / *Employment Status*: ☐ Bekerja / *Working* (sila nyatakan / *please state* :_____) ☐ Surirumah/ *Housewife* ☐ Pesara / *Retired* ☐ Tidak Bekerja/ *Not working* (sila nyatakan / *please state* :_____)
7	Pendapatan sebulan / *Income per month* : RM_____
8	Sejarah Perubatan diri-sendiri/ Own *Medical history* : ☐ **Ada / *Yes*;** Sila nyatakan penyakit / *Please specify the illness* : _____ ☐ **Tiada / *No***
9	Hubungan anda dengan kanak-kanak yang menghadiri PDK / *Your relationship with the child attending the CBR :* ☐ Ayah / *Father* ☐ Ibu / *Mother* ☐ Nenek/ *Grandmother* ☐ Datuk / *Grandfather* ☐ Penjaga / *Guardian*

Approval Letter

Ref. no: UPM/TNCPI/RMC/JKEUPM/1.4.18.2 (JKEUPM)
Date: 28 July 2020

Dear Prof./Dr./Mr./Ms.,

APPLICATION FOR JKEUPM ETHICAL CLEARANCE: APPROVED

With reference to the above, I am pleased to inform you that your application for ethical clearance for the research project entitled **'Psychological Effects and Their Associated Factors Among Caregivers of Disabled Children in Community Based Rehabilitation Centers in Selangor'** has been approved.

Please note that the official letter of approval will be issued as soon as possible. However, the ethical clearance is considered effective from the date of this email, and you may now proceed with your research.

Kindly remind the ethical approval is required in the case of amendments/ changes to the study documents/ study sites/ study team.

Researchers should also complete a Study Final Report upon study completion. The form can be obtained from the Ethics Committee for Research Involving Human Subjects (JKEUPM) website (http://www.tncpi.upm.edu.my/faildokumen).

If you have any enquiries, please contact Ms. Nurulhasanah Ishak (03-97691605) or Ms. Nor Ellia Abd Ajis (03-97691244).

Note: Please use this reference number for any transaction:- **JKEUPM-2020-243**

Thank you.

Yours faithfully,

Prof. Dr. Zamberi Sekawi
Chair
Ethics Committee for Research Involving Human Subjects
Universiti Putra Malaysia