SUBJECTIVE HAPPINESS AND QUALITY OF LIFE (QOL) IN PARENTS OF CHILDREN WITH AUTISM SPECTRUM DISORDERS (ASD) IN HOSPITAL UNIVERSITI SAINS MALAYSIA, KUBANG KERIAN, KELANTAN

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LIST OF ABBREVIATIONS AND NOMENCLATURES

ASD	Autism Spectrum Disorder
HUSM	Hospital Universiti Sains Malaysia
QOL	Quality of Life
SHS	Subjective Happiness Scale
SPSS	Statistical Package for Social Sciences
SWB	Subjective well-being
USM	Universiti Sains Malaysia

ABSTRAK

Pendahuluan: Kajian ini bertujuan untuk mengenal pasti tahap kebahagiaan subjektif dan kualiti hidup (QOL) dalam kalangan ibu bapa yang mempunyai kanak-kanak gangguan spectrum autisme (ASD) serta faktor-faktor yang berkaitan. **Metodologi:** Kajian keratan rentas ini dijalankan ke atas 187 ibu bapa kanak-kanak ASD di Hospital Universiti Sains Malaysia (HUSM), Kubang Kerian, dari Disember 2019 hingga Februari 2020. Borang soal selidik merangkumi maklumat sosio-demografik, *World Health Organization Quality of Life-Brief version* (WHOQOL-BREF) (versi Bahasa Melayu), *Subjective Happiness Scale* (SHS) dan *General Health Questionnaire-12 items* (GHQ-12). Tahap ASD ditentukan oleh penyelidik menggunakan *Childhood Autism Rating Scale* (CARS). Analisis deskriptif dijalankan untuk data sosiodemografik, manakala analisis regresi linear mudah dan berganda dijalankan untuk menentukan faktor-faktor yang berkaitan dengan SHS dan QOL. Hubung kait antara SHS dan QOL ditentukan dengan menggunakan *Pearson's correlation test*. **Keputusan:** Purata markah SHS ialah 4.92±0.87. SHS didapati berkait rapat dengan etnik penjaga berbangsa Cina (*b*:-1.62, 95% CI:-2.63, -0.61), tekanan psikologi yang tinggi dalam kalangan ibu bapa (*b*:-0.04, 95% CI:-0.06, -0.01), tidak mempunyai anak dengan ketidakupayaan intelek (*b*:0.491, 95% CI:0.21, 0.77) dan markah CARS (*b*:-0.03, 95% CI:-0.04,-0.01). Purata untuk jumlah markah QOL adalah 94.56±10.42. Purata markah untuk domain persekitaran, fizikal, psikologi dan sosial adalah 68.9±12.42, 69.3±13.50, 70.5±12.61, dan 70.7±16.45. Terdapat hubung kait yang sederhana antara semua domain QOL dan SHS (*r*=0.35-0.49). **Kesimpulan:** Markah SHS dalam kalangan ibu bapa kanak-kanak ASD didapati lebih rendah daripada populasi umum, manakala markah QOL pula masih berada dalam julat normal. Oleh itu, intervensi bersasar dan sokongan persekitaran adalah perlu untuk kualiti hidup dan

subjektif kegembiraan yang lebih baik di kalangan ibu bapa.

Kata kunci: *Gangguan spektrum autisme, kegembiraan, kualiti hidup, ibubapa.*

ABSTRACT

Background: This study aims to determine the level of subjective happiness and quality of life (QOL) among caregivers of children with autism spectrum disorder (ASD) and the associated factors. **Methods:** This cross-sectional study was conducted among 187 caregivers of children with ASD in Hospital Universiti Sains Malaysia (HUSM), Kubang Kerian, from December 2019 to February 2020. Distributed self-administered questionnaires include socio-demographic survey, World Health Organization Quality of Life-Brief version (WHOQOL-BREF) (Malay version), Subjective Happiness Scale (SHS), and the General Health Questionnaire-12 items (GHQ-12). The severity of ASD was determined by the researcher using Childhood Autism Rating Scale (CARS). Descriptive analysis was performed for the sociodemographic data, while simple and multiple linear regression analysis was performed to determine the associated factors related to SHS and QOL. The correlation between SHS and QOL was determined using Pearson's correlation test. **Results:** The mean SHS score was 4.92±0.87. SHS was found to be associated with Chinese ethnicity of caregivers (*b*:-1.62, 95% CI:-2.63, -0.61), higher psychological distress of caregivers (*b*:-0.04, 95% CI:-0.06, -0.01), absence of children with intellectual disability (*b*:0.491, 95% CI:0.21, 0.77) and CARS score (*b*:-0.03, 95% CI:-0.04,-0.01). The mean score for total QOL was 94.56±10.42. The mean score for the environment, physical, psychological, and social domain was 68.9±12.42, 69.3±13.50, 70.5±12.61, and 70.7±16.45 respectively. There was a moderate correlation between all domains of QOL and SHS (*r*=0.35-0.49). **Conclusion:** SHS scores among caregivers of children with ASD was relatively lower than general population, while QOL scores were still within the global normative range. Therefore, targeted intervention and supportive milieu are needed for better QOL and subjective happiness

of the caregivers.

. **Key words:** *autism spectrum disorder, quality of life, happiness, caregivers, Malaysia*.

CHAPTER 1: INTRODUCTION

1.1 Subjective happiness and quality of life of caregivers of ASD children

Evaluation of subjective happiness and quality of life (QOL) in a specific population has been garnering interests among psychologists and researchers in the field of social science as both are intricately intertwined. Happiness can be defined as "good or pleasant emotions ranging from contentment to great delight" (Wolfram Alpha, 2009). QOL is described by the World Health Organization (WHO, 1997) as “an individual's view of their place in life in relation to their objectives, expectations, standards, and concerns in the context of the culture and value system in which they live.”

Autism spectrum disorder (ASD) is a lifelong neurodevelopmental illness that appears to be on the global rise, with 1 in every 44 people affected (Maenner et al., 2018). In comparison to raising healthy children, caregivers of disabled children have reported poorer general and mental health and may suffer from chronic health conditions, activity constraints, heightened depressive symptoms, having more somatic symptoms, and higher stress levels (Guillamón et al., 2013; Gallagher & Hannigan, 2014). A study in Malaysia showed that four out of every five parents of children with ASD in Malaysia reported significantly high levels of stress (Xin Lee, 2017).

Qualitative research also showed that raising a kid with disability had an impact on the parents' physical health, social well-being, freedom and independence, family well-being, professional lives, marital stability, and financial stability (Nimbalkar et al., 2014). More than half of families reported that a parent needs to cut back on work or stop working because of the care needed by the child (Child and Adolescent Health Measurement Initiative., 2013).

1.2 Factors associated with subjective happiness and QOL of caregivers of ASD children

Researchers study parental well-being in the context of three central domains: (1) individual characteristics of both parent and child, including psychological variables, (2) social/environmental characteristics, including family resources, financial barriers, support systems, and (3) subjective appraisals, including perceptions of the meaning and influence of the disability on family life and concerns for the future (Resch et al., 2010; Resch et al., 2012; Cantwell, Muldoon, & Gallagher, 2014).

Previous Malaysian study showed that the factors affecting QOL of caregivers include socio-demographic factors, child disability-related factors, types of disability, child functioning, and psychosocial factors, including coping strategies, social support, parental stress, self-efficacy, and self-esteem (Isa et. al., 2016). There are significant interactions between coping styles and child maladaptive behaviour in determining maternal depression, anger, and well-being (Benson, 2010). Malaysia is a multiracial country with culture-specific definition of subjective happiness and quality of life (Veenhoven, 2012). Hence, this relates to culture-specific coping behaviours, particularly in Asian society whereby parents of children with ASD were observed to engage in more maladaptive or emotion-focused coping such as active avoidance coping, than parents of normally developing children (Lai et al, 2015).

A comprehensive review of the literature revealed that caregivers may have trouble caring for their ASD children due to certain characteristics of the child and the severity of the ASD, such as frequent behaviour problems, hyperactivity, and sleep disorders (McStay et al., 2014; Ilias et al., 2017). ASD may place an additional stress on parents (Hayes & Watson, 2013) due to behaviour problem (Estes et al., 2009), such as

hyperactivity and demandingness (Rao & Beidel, 2009), emotional issue (Giovagnoli et al., 2015) and limitation in communication (Schieve et al., 2011).

Each person with ASD experiences the condition differently, which means that each person's strengths, problems, and treatment requirements are varied (Hyman, Levy, Myers, & AAP Council on Children with Disabilities, 2020). The pharmacologic treatment is often targeted at problems other than the core symptoms of the disorder (Siegel & Beaulieu, 2012). There is no medication that can cure the core symptoms of ASD, although there are interventions that may be effective to lessen the symptoms that affect the child's everyday life and QOL (Medavarapu, Marella, Sangem, & Kairam, 2019; Hyman, Levy, Myers, & AAP Council on Children with Disabilities, 2020). It is important to understand the associated factors because the parents who are experiencing a lot of negative emotions will have a negative impact on their treatment engagement, hence positive attitudes and psychological well-being of parents play a crucial role in the development of children with developmental disabilities (Shobana & Saravanan, 2014).

1.3 Justification of the study

Raising a child with chronic and long-lasting health and mental condition such as ASD has a negative impact on parental or caregivers' psychological, physical, social, and environmental well-being (Falk, Norris & Quinn, 2014). However, this observation contrasted with that of Manning, Wainwright, & Bennett (2011) who found that families of children with ASD can show positive adaptation and wellbeing. However, both studies highlight that family and social support are the factors that contribute to better well-being (Lira Rodríguez et al., 2022). Hence by studying the socio-demographic data and the associated factors in this population, this will give added

information to improve wellbeing and QOL of parents with ASD children.

Many research studies in Malaysia (Lee, Ong, Lee, Fairuz Nazri, 2017; Rahman & Jermadi, 2021) and even in southeast Asia (Ilias, Cornish, Kummar, Park, & Golden, 2018) focused on the stress in parents of children with ASD. There are some Malaysian studies focused on the well-being among parents of children with ASD (Lai et al, 2015; Isa, et al., 2016; Ilias, et al., 2017), however limited research available focused on holistic aspect of QOL and the subjective happiness among parents of ASD. Even a recent Malaysian study on determining the QOL level, perception of the child's autism-specific difficulties level, and their associated factors among the main caregivers who send their children to the largest local NGO-based autism training centers also mention that the subject related to factors associated with QOL among caregivers with children with ASD remains understudied in Malaysia (Asahar, Malek, & Isa, 2021). To the best of our knowledge, this is the first paper of its kind studying on subjective happiness and its associated factors among parents of ASD children in the local Malaysian population. Hence, it is justifiable to utilize the Subjective Happiness Scale (SHS) as a tool to assess the subjective happiness of parents of children with ASD and its interplay with QOL. Identifying the factors that may associate with the caregivers' positive emotions and well-being, might provide the higher authority with a guide that is planning in ensuring targeted intervention to provide a better quality of care for ASD children.

1.4 Study objectives

1.4.1 General objective

To explore the factors affecting the subjective happiness and quality of life (QOL) of parents of children with autism spectrum disorders and its associated factors in Hospital USM Kubang Kerian, Kelantan.

1.4.2 Specific objectives

I. To determine the level of subjective happiness and quality of life (QOL) among caregivers of children with ASD.

II. To determine the correlation between subjective happiness and quality of life (QOL) in caregivers with ASD children.

III. To determine the factors associated with subjective happiness and quality of life (QOL) among caregivers of ASD children based on caregivers'-related factors (race, gender of the caregivers, caregiver's status, socioeconomic status, education level of caregivers, number of children with disability) and child's-related factors (duration of diagnosis, duration of treatment, child's disability, medical illness and severity of ASD).

1.5 Methodology

This was a cross-sectional study conducted among caregivers of children with ASD attending the Child Psychiatric Clinic and Child Occupational Therapy unit in Hospital Universiti Sains Malaysia (HUSM), Kubang Kerian, Kelantan from December 2019 to February 2020. Inclusion criteria were caregivers to children under the age of 18, diagnosed with ASD according to the Diagnostic and Statistical Manual for Mental Disorder, 5th edition (DSM-5), who was able to read/write and communicate in Malay language and voluntarily agreed to participate in this study. Parents who are illiterate were excluded in this study.

A total of 187 participants were selected through convenience sampling. Each caregiver answered four sets of self-administered questionnaires including (socio-demographic data, the Subjective Happiness Scale (SHS), World Health Organization

Quality of Life-Brief version questionnaire (WHOQOL-BREF) (Malay version), and the General Health Questionnaire-12 items (GHQ-12). The level of ASD was assessed by the researcher using Childhood Autism Rating Scale (CARS).

The research subject was explained about the study and informed consent was taken before answering the questionnaire. The data entry and analysis were performed by using Statistical Package for Social Study (SPSS) Statistics Version 26. Data were analyzed with descriptive and logistic regression analysis.

1.6 Dissertation organization

This dissertation is arranged according to Format B Manuscript Ready format according to the guideline by the Postgraduate Office, School of Medical Sciences (2019). It is mainly divided into three chapters. Chapter one is the introduction which outlines the research literature and the rationale of this study. Chapter two is the study protocol that has been submitted and received ethical approval. Chapter three is the manuscript that is ready for submission for the journal *The Malaysian Journal of Medical Sciences* with the author's guidelines. The appendices contain validated questionnaires and relevant supplementary materials. The raw data is included in the attached CD.

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CHAPTER 2: STUDY PROTOCOL

2.1 Introduction

Lately, Subjective Happiness and Quality of Life (QOL) have been the topics of interest among researchers. Both subjects are indeed inter-related (Graham, 2014). Happiness is a mental or emotional state of well-being which can be defined as 'positive or pleasant emotions ranging from contentment to intense joy' (Wolfram Alpha, 2009). During the past two decades, the field of positive psychology has expanded drastically in terms of scientific publications, and researchers have produced different views on causes of happiness, and on factors that correlate with happiness (Claudia, 2005).

Subjective happiness or Subjective well-being (SWB) is defined as 'a person's cognitive and affective evaluations of his or her life' (Diener, Lucas, & Oshi, 2002). Seligman (2011) offered a new theory of wellbeing, describing wellbeing as flourishing and as a construct with five measurable elements with the acronym "PERMA," namely, positive emotion, engagement, relationships, meaning and purpose, and accomplishment.

Likewise, QOL is the general well-being which includes life satisfaction, physical health, family, education, employment, wealth, safety and security to freedom, religious beliefs and the environment (Barcaccia, 2013). World Health Organization (WHO, 1997) defined Quality of Life as an individuals' perception of their position in life in the context of the culture and value system in which they live and are related to their goals, expectations, standards and concerns.

Autism spectrum disorder (ASD) is a lifelong neurodevelopmental disorder characterised by impairments in social interaction, verbal and nonverbal communication, and a restricted repertoire of activities and interests (APA, 2013). The prevalence of ASD appears to be rising worldwide with an estimated prevalence of 1 in

every 44 persons (Maenner et al., 2018).

As compared to raising healthy children, the caregivers of children with disabilities reported poorer general health and mental health, chronic conditions, activity limitations, elevated depressive symptoms, more somatic symptoms, and higher levels of stress (Brehaut et al., 2009; Hoffman et al., 2009; Gallagher et al., 2010; Ha et al., 2011; Ong et al., 2011; Guillamón et al., 2013; Gallagher & Hannigan, 2014). Studies have consistently found higher levels of psychological distress in parents of children with ASD when compared to parents of typically developing children or children with other disabilities (Abbeduto et al, 2004; Mugno et al., 2007). Likewise, qualitative studies also demonstrated that caring for a child with disability affected parents' physical well-being, social well-being, freedom and independence, family well-being, work lives, marital relationship and financial stability (Davis et al., 2009; Myers et al., 2009; Nimbalkar et al., 2014). This is an important finding as the parents' positive attitudes and psychological well-being play an important role in the progress of the children with developmental disability (Shobana & Saravanan, 2014).

Given the limited ASD research in Southeast Asia and in particular Malaysia, researchers have noted that there is a tremendous need for more investigation (Ilias, Ponnusamy, and Normah, 2008; Clark et al., 2012; Neik et al., 2014; Golden and Liaw, 2015). Hence, the Ministry of Health Malaysia (2011) has urged that more studies be conducted on children with disability and their caregivers.

In Malaysia, much research studied the level of stress of parenting of a child with ASD, however limited research is available on how it affects the subjective happiness and QOL of parents with ASD children. This study aims to determine the level of subjective happiness and quality of life (QOL), the correlation between them and to identify the associated factors among parents of children with ASD.

2.2 Problem statement

There is not much data available regarding subjective happiness and QOL of caregivers with ASD in Malaysia. The possible reason of subjective happiness and QOL among these caregivers are hardly being explored is probably due to the cultural influence, whereby publics are less exposed to neurodevelopmental disorders, thus caregivers of these children may experience lack of support. The problem may also be due to the stigma of having ASD children. Some of the parents may be in denial for such diagnosis and afraid that people will start labelling the children as abnormal. Some parents may also feel shy to share their problem and do not know where to seek help and support from available services, so they tend to suffer alone. Due to the limited public awareness, children, and adults alike who suffer from this developmental disorder are often not given their due dignity but treated as people with mental problems instead (Hew, 2000). In our study setting, we expect that the subjective happiness and QOL of parents of children with ASD are lower as compared to parents with typically developing children.

2.3 Study rationale

ASD, as one of the neurodevelopmental disorders among children, is a real-life situation and imposes burden to caregivers in view of the extra care needed by them. Furthermore, most of the mental disability has no proven pharmacological treatment and depends on rehabilitative treatment, which demands more time and patience from the caregivers.

Although it is a known fact that every parent of children with any disabilities will face psychological stress, no proper intervention had been done for them. This study is hoped to provide adequate information and evidence to further plan appropriate

intervention to improve their subjective happiness and quality of life by providing more information in creating awareness and education for the parents as well as community.

My proposed research will provide information regarding the contributing factors that affect the level of subjective happiness and quality of life of the caregivers with ASD children. We hope that findings from this study through the literature reviews and analysis, considering Malaysia's sociocultural perspective, may add value to early intervention and special education for parents in our study population in order to strengthen their knowledge regarding available programmes and professional consultation available.

2.4 Study objectives

2.4.1 General objective

To explore the factors affecting the subjective happiness and quality of life (QOL) of caregivers of children with ASD and its associated factors in Hospital USM Kubang Kerian, Kelantan.

2.4.2 Specific objectives

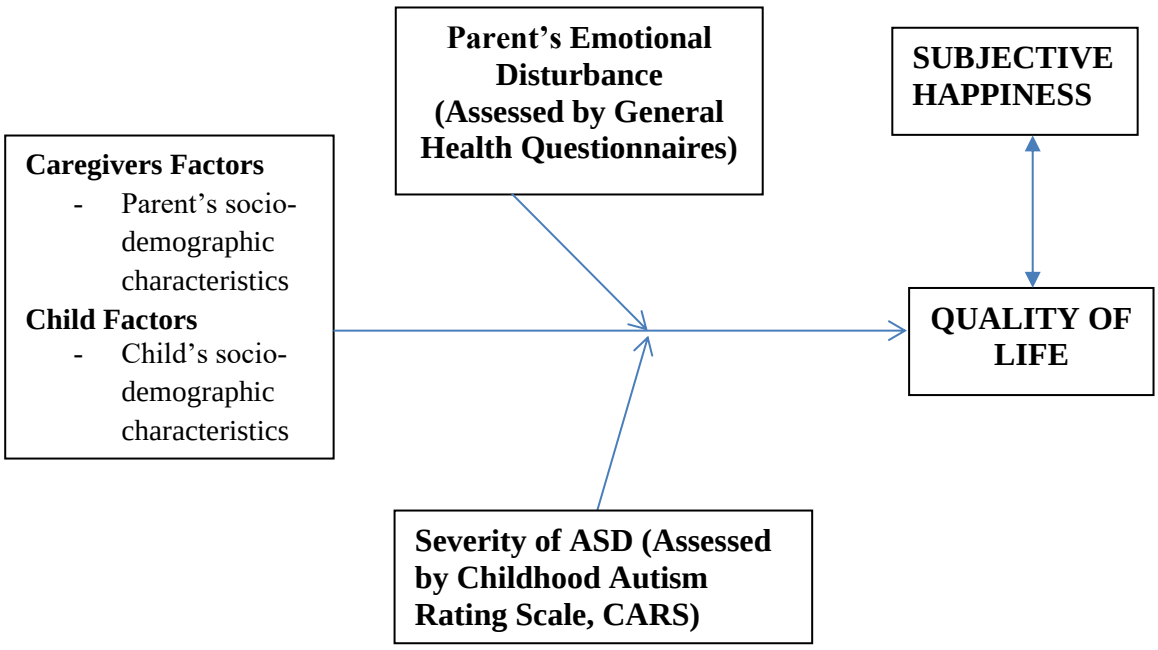
- To determine the level of subjective happiness and quality of life (QOL) of caregivers of ASD children.
- To determine the correlation between subjective happiness and quality of life (QOL) in caregivers of ASD children.
- To determine the factors associated with subjective happiness and quality of life (QOL) among caregivers of ASD children based on caregivers'-related factors (race, gender of the caregivers, caregiver's status, socioeconomic status, education level of caregivers, number of children with disability) and child's-related factors

(duration of diagnosis, duration of treatment, child's disability, medical illness and severity of ASD).

2.5 Hypothesis/expected research outcome

1. The caregivers of children with ASD experience low level of subjective happiness and quality of life (QOL) as compared to caregivers of normal children.
2. There is a correlation between subjective happiness and quality of life (QOL) in caregivers with ASD.
3. The factors associated with subjective happiness and quality of life (QOL) in caregivers of ASD children include socio-demographic characteristic, such as socioeconomic status, educational level, number of children with disability and ASD severity.

2.6 Conceptual framework



2.7 Literature review

2.7.1 Subjective happiness

Werner and Sulman (2013) found that caregivers of children with ASD reported the lowest level of subjective well-being as compared to their counterparts with Intellectual Disability (ID) or physical disabilities (PD), and there was an interaction between affiliated stigma and child diagnosis in predicting the subjective well-being. Mothers of individuals with ASD have also been shown to display lower levels of wellbeing and higher levels of stress than mothers of individuals with Down syndrome, fragile X syndrome, and cerebral palsy (Abbeduto et al., 2004; Eisenhower et al., 2005). The mothers faced difficulty in taking care of their child with ASD due to certain child characteristics, such as frequent behaviour problems, hyperactivity and sleep issues which impacts on parental wellbeing (Ilias et al., 2016; McStay et al., 2014).

However, research reported that families of children with ASD can demonstrate positive adaptation and wellbeing (Manning, Wainwright, & Bennett, 2011). Researchers study parental well-being in the context of three central domains: (1) individual characteristics of both parents and child, including psychological variables, (2) social/environmental characteristics, including family resources, financial barriers, support systems, and (3) subjective appraisals, including perceptions of the meaning and influence of the disability on family life and concerns for the future (Cantwell, Muldoon, & Gallagher, 2014; Resch et al., 2010; Resch et al., 2012; Worcester et al., 2008).

A study by the University of Miami found the impact of individual traits, such as optimism, social and spouse support, benefit finding and coping styles on relationship satisfaction in parents of ASD children. The study also showed that each of these traits was positively associated with better relationship satisfaction. The findings imply that

there are factors that could potentially enhance family functioning, marital quality, and parenting, and that strengthening these qualities should be the target of family-focused interventions (Ekas et al., 2015).

Malaysia is a multiracial country with different definition of subjective happiness and quality of life across cultures (Veenhoven, 2012). Lai et al. (2015) emphasised the relevance of exploring culture-specific coping behaviours while Benson (2010) also found significant interactions between coping styles and child maladaptive behaviour in determining maternal depression, anger and well-being.

Guillamon et al. (2013) reported that parents with higher self-efficacy showed better physical health, mental health, and more satisfaction with their relationship with the environment and have less anxiety. Rezendes & Scarpa (2011) indicated that increased stress was associated with a decreased self-efficacy, which in turn accounted for increases in anxiety or depression. Vice versa, self-esteem was found to be the strongest predictor of subjective well-being, as higher level of self-esteem relates to positive subjective well-being (Werner and Shulman, 2013). Parental stress can also mediate other factors such as restricted caregivers' social activities on the psychological well-being (Cramm & Nieboer, 2011).

Nikmat, Ahmad, Oon, and Razali (2008) found that 53.8% of Malaysian parents of children with autism showed a clinical disturbance in psychological wellbeing, conceptualised as clinically elevated scores on the General Health Questionnaire (GHQ-28), and 90.4% of parents demonstrated significant parenting stress on the Parenting Stress Index – Short Form (PSI-SF).

2.7.2 Quality of Life (QOL)

Isa et al. (2016) in their literature review noted factors affecting quality of life of

caregivers to include socio-demographic factors, child disability-related factors, types of disability, child functioning and psychosocial factors as mediators and moderators, coping strategies, social support, parental stress, self-efficacy and self-esteem.

While there is a growing body of literature on the QOL of families of children with disabilities in the Western countries, little attention has been given to investigate the QOL of family caregivers in the Southeast Asia, especially in Malaysia. An initial exploration of the QOL of families of children with disabilities found a high percentage of Malaysian families indicating they were 'satisfied' or 'very satisfied' in each of the nine domains of Family Quality of Life Survey—Short Version (Clark et al., 2012). Clark et al. (2012) suggested a number of useful research questions for future studies on Malaysian families.

Studies have demonstrated different patterns of family adaptation to a child with disability between different cultures. For example, a Malaysian study reported that non-Malay caregivers had lower parental health related QOL and family functioning compared with Malay caregivers (Isa et al., 2013). In Netherlands, Hatzmann et al. (2009) found that parents from the Netherlands had better health related QOL, potentially contributed by better family and emotional support, provision of governmental support and special leave. These findings may aid healthcare professionals in multicultural countries to consider geographical, cultural or ethnicity factors when dealing with families of children with disabilities.

Socio-economic factors of the family are also investigated as an important determinant of health status and QOL of the caregivers of children with disabilities. Parents need to adapt a special way of taking care of children with neurodevelopmental disorders. Therefore, financial as well as emotional burden may overwhelm them (Xiong, 2011).

The family dynamic tends to change to keep up with having a child with neurodevelopmental disorder. A study on parents of children with learning disabilities found negative emotional reactions of guilt feelings which further caused marital tension, strained family life and parenting dissonance which was due to lack social support from extended family members, friends, and society in general (Dyson, 2010).

Apart from not having support from close friends and family members as discussed earlier, Heiman (2002) found that the parents of the disabled child tend to react in emotionally and psychologically negative way to the diagnosis of their child's disabilities. Many of them need to adapt themselves to the significant changes in family's social life, resulting in frustration and dissatisfaction. Some parents stated that building new social support networks as a result of meeting new people through their children can positively impact their QOL (Davis et al., 2009)

Education showed a significant benefit not only to the caregivers but also positive impact to the child. Hatzmann et al. (2009) showed that high educational level and living with a partner were associated with better health-related QOL indirectly via emotional support and leave allowed for taking care of the child. Gosztyla & Prokopiak (2017) found that better educated parents will have more knowledge and expectation about social support compared to less educated parents.

Family factors were also found to be significantly related with the health and QOL outcomes. Divorced or widowed mothers had higher parenting stress and lower health-related QOL and family functioning compared to married mothers (Norizan & Shamsuddin, 2010; Isa et al., 2013). In addition, caregivers in nuclear families had better health satisfaction scores than those in the extended families (Hsieh et al., 2009).

Furthermore, complexity of disability was found to be significantly related to parental health-related QOL and family functioning, in which the parents of children

with multiple disabilities had lower health-related QOL and family functioning when compared to parents of children with one disability (Isa et al., 2013) as comorbidity of behavioural problems will cause difficulty for parents to cope.

Social supports have been identified as a significant predictor and a mediating and moderating factor in determining health-related QOL of the family of children with disabilities (Ha et al., 2011; Hatzmann et al., 2009; Marchal et al., 2013; Werner & Shulman, 2013). Parents who had better emotional support reported better cognitive and social functioning (Marchal et al., 2013) and physical and mental component of health-related QOL (Hatzmann et al., 2009).

Similarly, parents of children with ASD also showed higher scores on somatic symptoms, anxiety, social dysfunction, and negative attitudes and higher level of stress when compared with parents of children with Down syndrome (Dabrowska & Pisula, 2010; Narkunam, et.al., 2012; Shobana & Saravanan, 2014).

Studies showed that having children with any disabilities may cause psychological distress to the parents, and to the mothers in particular (Heiman, 2002; Schieve et al., 2007; Jiar & Xi, 2012). Many studies have shown the different level of stress between mothers and fathers. This is supported by a number of studies which found that mothers were significantly more stressed, more involved, reported higher levels of stress and coping related to caregiving, and had poorer health-related QOL and family functioning when compared to the fathers (Aras et al., 2014; Tehee et al., 2009 & Isa et al., 2013). Additionally, Hatzmann et al. (2009) also found direct disparities in health-related QOL between mothers and fathers, while indirect relationship was found by Isa et al. (2016). Being a female caregiver had a direct negative effect on the physical component score of the health-related QOL, and an indirect positive effect on emotional support. This implies that both parents have different experiences and challenges during

the caregiving process. In constrast, a qualitative study found no noticeable differences in parental QOL between mothers and fathers (Davis et al., 2009).

Parents also experienced psychological fear and may worry about their child's future (Dhar, 2009; Nimbalkar et al., 2014). A study in Kenya by Mbugua et al. (2011) revealed that 79% of caregivers of children with intellectual disability (ID) were at risk of clinical depression. Several factors have been identified as having an impact of parental QOL including the severity of the disease, presence of comorbidities, presence of maladaptive behaviour, and presence of emotional symptoms such as depression, anxiety and impairment of daily living activities (Eapen & Guan, 2016). Shobana & Saravanan (2014) reported that 52% of mothers of children with developmental disabilities experienced psychological health problems. Most of the mothers have children with ID (62%), followed by ASD (59%) and Down syndrome (34%).

2.7.3 Correlation between Subjective Happiness and Quality of life

A study by Toghyani et al., (2011) among 100 male adolescents found quality of life therapy (QOLT) can increase positive affect and decrease negative affect and as a result can boost overall subjective well-being. A recent study by Medvedev and Landhuis (2018) found high positive correlations between happiness, psychological and health domains of quality of life, life satisfaction, and positive affect. Social and environmental domains of quality of life were also poor predictors of happiness and subjective well-being after controlling for psychological quality of life.

2.7.4 Conclusion

Therefore, early identification of potential at-risk families is necessary so that interventions aimed at reducing stress in child-parent relationship can be implemented

and possibly reduce/prevent future behavioural and emotional problems for both parent and child (Cheeseman, 2011). Due to the expected high level of parenting stress among caregivers of ASD children, special education and early intervention are needed for the caregivers to learn better on the disorder and receive adequate professional consultation on stress management (Feizi et al., 2014). It highlights the importance of creating family-friendly policies to reduce mental, physical, and psychological burden of juggling work and family (Hibel, 2012). More programmes should be organised to support the family while educating them regarding coping strategies and building social support networks. The policy makers or service providers must work together to meet the needs of ASD caregivers to reduce long-term negative impacts on parental well-being and QOL.

2.8 Methodology

2.8.1 Research design

Cross-sectional study

2.8.2 Study period

Study will be conducted in between December 2019 till June 2020.

2.8.3 Study setting

Child and Adolescent Psychiatric Clinic or Occupational Therapy unit, Hospital Universiti Sains Malaysia, Kubang Kerian, Kelantan.

2.8.4 Sample of Study

- Reference population: Parents of children with ASD.

- Source of population: Parents of children with ASD attending Child and Adolescent Clinic or Occupational Therapy unit, Hospital Universiti Sains Malaysia, Kubang Kerian, Kelantan.
- Study population: Parents of children with ASD attending Child and Adolescent Clinic or Occupational Therapy unit, Hospital Universiti Sains Malaysia, Kubang Kerian, Kelantan, during study period and fulfil the inclusion and exclusion criteria for this study.

Inclusion Criteria

1. Parents of children who are clinically diagnosed with ASD based on DSM 5 criteria (American Psychiatric Association, 2013).
2. Parents of children with ASD attending Child and Adolescent Clinic, Hospital Universiti Sains Malaysia, Kubang Kerian, Kelantan, during study period and fulfil the selection criteria for this study and agree to participate in this study.
3. Parents of children under the age of 18 (United Nations Convention on the Rights of the Child UNCRC, 1989).
4. Parents of children who can read/write and communicate in Malay language.
5. Voluntarily agree to participate in the study.

Exclusion criteria

1. Parents who are illiterate.

2.8.5 Sampling procedure

Sample size calculation

Sample size is calculated to fit all objectives and variables. The biggest sample size is calculated from the study's first objective which is to identify the subjective happiness in parents of children with autism spectrum disorders is 170.