

# Conceptualization and Development of Quality of Life Measure for Person with Autism (PWA) Caretakers in Malaysia

**Nuraimi Abu Hassan**

*Department of Postgraduate and Professional Studies, Faculty of Business and Management  
Universiti Teknologi MARA, 40450 Shah Alam, Selangor, Malaysia*

**Naffisah Mohd Hassan**

*Department of International Business and Management Studies, Faculty of Business and Management, Universiti Teknologi MARA, Cawangan Selangor, Kampus Puncak Alam, 42300 Bandar Puncak Alam, Selangor, Malaysia*

**Siti Noorsuriani Maon\***

*Department of International Business and Management Studies, Faculty of Business and Management, Universiti Teknologi MARA, Cawangan Selangor, Kampus Puncak Alam, 42300 Bandar Puncak Alam, Selangor, Malaysia  
Email: sitinoor123@uitm.edu.my*

*\* Corresponding Author*

## Abstract

**Purpose:** Quality of life (QoL) is a significant aspect of well-being for the caretakers of a person with autism, making it a remarkable effect. Despite the advent of a new norms transformation era, the obstacles and struggles experienced by the caretakers of Person with Autism (PWA) in Asian countries, particularly in Malaysia, and how these affect their quality of life, warrant further investigation. Therefore, to comprehend the contributing factors in detail, a research framework is proposed to indicate the influential underlying factors relative to improving the quality of life of the caretakers.

**Design/methodology/approach:** This paper describes the conceptualisation and development of an autism-specific measure of the quality of life, the family quality of life (FQOL) questionnaires for parents and caregivers of children with ASD, suitable to research settings. The study included parents and caretakers who had at least one son or daughter diagnosed with autistic disorder below the age of 18 years old and have a sibling. This study will use a quantitative research method. A stratified sampling technique will be employed to get responses from the target respondents. SmartPLS 3.0 and IBM SPSS 24 will analyse the obtained and valid data.

**Outcomes/Implications:** The outcomes of this present study will improve more to help families and caretakers who have autistic children to have a better quality of life.

**Keywords:** Quality of Life, Autism, Caretakers,

## Introduction

Many children each year are diagnosed with autism spectrum disorder (ASD) in Malaysia. Based on analysis of the national gross birth rate per year, it was estimated that around 8,000 to 9,000 born yearly may have autism in Malaysia (The Star, 2019). Prevalence studies on children with ASD in the Asia Pacific region are limited to Japan and China, with an estimated

median prevalence value of 11.6 in 10,000 and due to the limited data availability and the small sample size for the study, the actual prevalence of children with ASD in Asia is unknown. Similarly, in local settings, the actual prevalence of children with ASD registrations limits knowledge of prevalence (Asahar, 2021). Because of lack of ASD information, there is no official registration in Malaysia for the number of individuals diagnosed with autism, thus World Health Organization (WHO) estimates that 1 in 160 children has ASD and it appears to be increasing worldwide (The Star, 2019).

Statistics show a higher rate of divorce for families who have a child with autistic compared to families with an average child (Sheean, 2013). Moreover, the issue of caretakers' burden remains a hidden issue in the family members and the community in Malaysia because of socio-cultural constraints and lack of attention from each party; Malaysia is still weak in helping reduce the burden on the caretakers and improve the quality of life of families with a person with autism (Isa et al., 2021). Quality of life is an individual perception, position in life in their context culture, and value systems in which they live that are related to goals, expectations, standards, and concerns. It also covers a wide range of concepts of individuals' physical health, psychological state, degree of freedom, social relations, trust, and personal relationship significantly environmental characteristic (Isa et al., 2021). Besides that, family with ASD children somehow will affect their quality of life by causing feelings of overeating, anxiety, depression, poor physical health, low-income family functioning, and low quality of life compared to families with typical children (Ying et al., 2021).

However, in Malaysia, negative perception and cultural stigma from the society also leads to caretaker stress and even can harm their quality of life and mental health (Ilias, 2019). It is common for certain people to believe that if anything wrong happens to the child when they are still babies or newborn, it is because of the past mistake of the parents and need to be treated through mystical treatment, and because of this belief, parents with ASD children facing more challenging life every day (Ilias, 2018). This situation can be supported in the phenomenological analysis study, which finds that insufficient knowledge of ASD has resulted in some civilians in Malaysian society relying on cultural beliefs such as karma or religious mysticism to explain the cause of this condition (Ilias, 2017). Although some parents may not believe in this mystical event, they were still affected by society's perspectives which always affected their mental health and wellbeing in their everyday life (Ilias, Liaw, et al., 2017). Besides that, it shows that the community in Malaysia has a different perception towards the person with autism (Julianti, Noorhaneyza & Norhidayah, 2018). Therefore, it will affect the caretaker's quality of life in terms of relationship with family members, perceived support, stress, and how they will cope with the problem to maintain their quality of life in their families. Hence, this paper describes the conceptualization and development of an autism-specific measure of the quality of life, the family quality of life (FQOL) questionnaires for parents and caregivers of children with ASD.

## **Literature Review**

### ***Quality of Life***

Quality of life is a multidimensional concept that includes physical, psychological, and social health domains. Having children with autism usually will burden the caretakers regarding stress level, mental health and relationship, affecting their quality of life among family members (Picardi, et. al., 2018). Parents with children with ASD face various long-term challenges due to their child's developmental difficulties. The dynamic nature of the challenges faced by caretakers of ASD children puts them at greater risk for negative quality of life (QoL); when children are diagnosed with ASD, caretakers need to learn to adapt, accept and cope with the new information and need (Nik Adib, 2019).

It is essential for the family members to have good mental health, good family relationships, less stress, and coping strategies when they have a family with ASD to take good care of a person with autism and maintain their quality of life. Family with ASD children negatively affects the caretakers or family by causing feelings of overeating, anxiety, depression, poor physical health, low-income family functioning, and low quality of life compared to a family with an average child (Ying et al., 2021). Therefore, it is crucial to ensure caretake improves their mental health, family relationship, control of the level of stress, and coping strategies

### ***Interpersonal Relationship (Siblings)***

A positive relationship with one's siblings characterized by warmth, emotion, and support is related to psychological wellbeing, while negative relationships correlate with negative psychology adaptation (Longobardi et al., 2019). In contrast, siblings who had negative feelings about their autistic sibling shows that children and parents report less closeness in sibling relationship when one of them was diagnosed with autism, compared to normal relationships between siblings (Rum & Dromi, 2021).

ASD can threaten the quality of sibling relationships. It is mainly due to limited social and play skills behavior and communication and social deterioration response skill characterize children with ASD. These results appear alongside problematic behaviors such as being physically aggressive, the tendency to throw tantrums, and destructive attitudes when playing with toys (American Psychiatric Association, 2013). Smith and Elder (2010) found that children who have siblings with autism will have difficulties in terms of adjustment, coping, communication, interactions, and intimate relationship skill like other siblings because of the stress in the family from having a disabled child. Not all children can accept if one of their siblings has a disability; some might not believe they have a sibling with disabilities. Children with disabilities may be at risk of becoming victims of bullying either at school or home by their siblings or friends (Rose et al., 2011).

It is quite challenging for siblings who have brothers, sisters, or young siblings with autism as they have a few difficulties in terms of communication, interactions, and other connections. Because of the unique demands associated with having siblings with autism, normal siblings may experience changes in family roles, difficulties and stress in sibling relationships, restrictions on activities and home structures, feelings of embarrassment, different behaviors, and a lack of parental attention. Normal siblings are given extra responsibility for caring for their particular needs siblings due to a lack of parental affection (Shamsudin, 2018).

According to Lazarus and Folkman (1984), the construction of special siblings and individuals' experiences, influences elements of their evaluation development, which will influence their response. Hence the ordinary siblings' perception and construction, which tend to be influenced by several factors in different systems, can be essential in their evaluation and the subsequent overcoming response. Therefore, it is vital to identify the problem and help a person with autism siblings to have a good relationship and good quality of life with their family and siblings.

### ***Perceived Social Support***

Having a child with ASD is challenging for every parent and family. As caretakers for autistic children, parents and families need to have strong mental health and moral support to help them lower their stress levels. The benefits of social support are well documented for parents of individuals with autism, and social support is a social resource that the public sees as available, or that is provided to them by non-professionals in the context of formal support groups and informal assistance relationships (Weiss, 2021). It is not easy for parents with autistic children. Compared to parents with normal children, they have to sacrifice their time and work.

However, if the caretakers of children with autism have better support among family members, friends, and spouses, it can help to lower their stress level and maintain their quality of life. Challenges in the daily life of parents with autistic children can negatively contribute to their psychological well-being, especially on how they value themselves or self-worth; self-esteem, along with confidence, is considered an essential factor of happiness among Asians (Arnous & Yeo, 2020).

A higher level of self-esteem helps parents with autistic children perform better in parenting and social life, while parents with autistic children with inadequate self-esteem tend to believe that they lack acceptance by society for having a child with ASD (Arnous & Yeo, 2020). This study will investigate more on this social support to help families and caretakers who have autistic children to have a better quality of life.

Statistics in the year 2014, around 47,000 Malaysians with autism between the six months to late 20s, and the number of the statistics keep on increasing and recent statistics, there are 300,000 individuals living with ASD in Malaysia (Norhidayah Mohd Salleh et al., 2018). It is thus vital to have intense mental physical and have support from people when taking care of children with disabilities because when they have the support, they can take good care of their children and provide a good quality of life among themselves. In addition, according to Malaysia's Early Autism Project (EAP) Director, Jochebed Isaacs, if more people know about autism, this will increase people's acceptance towards children with autism, and their families will get more support from the public. It can help them have a good quality of life in their family (Norhidayah Mohd Salleh et al., 2018). Therefore, this study will investigate the effect of social support on the quality of life of parents and families with autistic children in Malaysia.

### ***Stress***

Children diagnosed with ASD eventually will affect their family system because of some challenges associated with the child's behavior; difficulty with communication, social skills, and repetitive behavior that the family must learn and adapt to (Shivers et al., 2017). According to Wayment & Brookshire (2018), it is common for parents to learn as they must cope with autistic children. However, prolonged stress can disrupt parenting and family patterns of relationship, and in some extreme cases, the caretakers or parents experiencing tension in caring for a child with ASD can also neglect and even abuse their children (Sa'diyah, 2016). Other stresses reported by families include financial difficulties caused by the cost of interventions and parental absence from work, challenges around traveling to several medical appointments, and problems getting temporary treatment (Kuhaneck et al., 2015).

Study shows that caretakers of children with developmental disabilities are more likely to report chronic illness, limited activity, more somatic symptoms, lower levels of general health, depressive symptoms, and higher levels of stress than caretakers of children with typical development (Isa et al., 2021). Parents or families were also found to experience changes in family relationships, marital relationships, and employment status (Isa, 2021). Self-stigma and stigma from society can also disrupt the social life of parents or family and can affect their quality of life.

In Malaysia, knowledge and support resources towards family with ASD children is very limited even though Malaysia is a developing, middle-income country with a multi-ethnic population (Ilias et al., 2017). Hayes and Watson (2013) revealed that a decrease in family functioning and increased stress on children's caretakers with ASD resulted from difficulties of caretakers when taking care of their child's behaviors and emotional problems (Braunstein, 2013). Statistics show that 53.8% of Malaysian parents of children with autism show a clinical disturbance in psychological well-being, which could affect their quality of life as a family

(Noor et al., 2019). Parents and family can get a good quality of life if Malaysian play a role as a team to help them rather than stigmatize the family with autistic children.

### *Coping Strategies*

Coping strategies are the solution or way taken by a person when dealing with stressors. It is crucial for an individual to have self-efficacy to deal with certain situations (Bandura, 1992). Indeed, it is not easy to deal with stress, but if we have an excellent strategy to overcome the problem, it can help us in the future. Study shows that parents who use positive strategies and focus on the problem are reported to have less stress and better well-being rather than a family who frequently used strategies to overcome emotional focus, which is ineffective and do not resolve the situation problem causing the stress (Miranda et al., 2019). Therefore, coping strategies are essential for parents and families with a person with autism in terms to handle and finding solutions for the situation and helping them to manage stress, maintain family relationships and mental health in good condition.

Even though there is a growing awareness of the need to integrate the concept of Quality of Life in the support services provided to children with disabilities and their parents, factors contributing to the quality of life such as parents, for example, their style of coping with life stress has received less attention (Dardas & Ahmad, 2015). According to Edwards, et al. (1999), there are two main categories of coping, which include efforts to remind problems that arise about a person's relationship and efforts to control emotional stress: including problem-focused coping and emotion-focused coping. Problem-focused coping involves specific strategies such as defining the problem, generating the problem, evaluating the problem, and selecting potential solutions and re-evaluating the situation or problem by changing level aspirations, reducing ego involvement, finding alternative ways to satisfy or developing new standards of behavior. At the same time, the emotion-focused coping that involves reduction, positive comparisons, finding positive values from adverse events, avoidance, staying away, exercise or meditation, alcohol use, anger, and seeking emotional support. These are some strategies that caretakers can use when in a particular situation when taking care of a person with autism. In addition to that, religious beliefs have been helpful for Muslim parents to have a positive mindset of their ASD children. Religious beliefs have been reportedly used as a coping mechanism for parents to help them accept their fate to have an ASD child. The same goes to other religions; they believe that the child is a present from God to them, whether he or she diagnoses with ASD, and they deal with their emotion through prayers, reading holy books, involving with church activities to comfort their true feelings (Ilias et al., 2018). Therefore, it parents need to know different methods and techniques to enhance the self-development of ASD children in a more positive direction. Besides that, the therapy approach is the best initiative that can be done to help a person with autistic (Copeland & Buch, 2013).

Based on the literature review, the present study proposes that the quality of life of caretakers is affected by interpersonal relationships, perceived social support, stress, and coping strategies. Families with children with ASD can show positive adjustment and well-being. However, family adaptation to stress is considered an ongoing process based on the double ABCX model because the result for family adaptation can be worse or better than to the level of family functioning prior to the stressor (Jones, 2019). Figure 1 highlights the primary constructs of the proposed model.

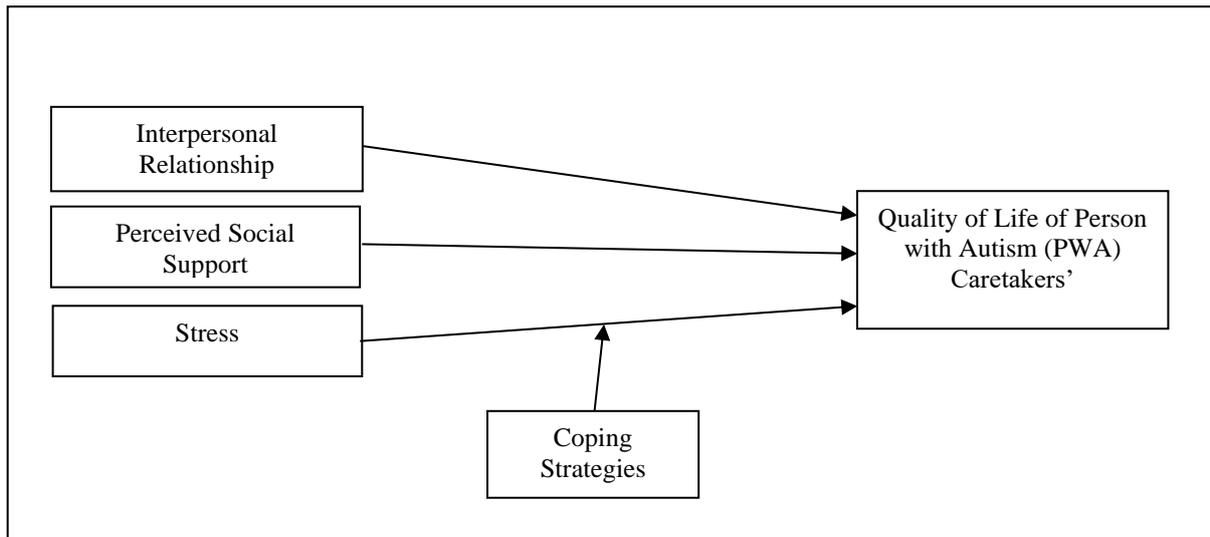


Figure 1: Proposed Conceptual Framework

## Methodology

### Research Design

This study employs a correlation and cross-sectional study design. The perceptions of caretakers will focus on of this study in examining the quality of life. In gathering data, a correlation and cross-sectional study involving caretakers who have autistic children will be used. Participants in this study were parents or families with children with autism. The study included parents, family, or caretakers, who had at least one son or daughter aged below 18 years old, diagnosed with autistic disorder by a registered mental health professional or developmental pediatricians. The study will focus on parents who lived in Selangor, Malaysia, raising their children in Malaysia. The community will recognize the more significant challenge these parents likely faced through this study, as their children often required more support services. All names have been changed to protect their privacy. Ethics will be obtained prior to data collection.

### Sampling and Population

In this study, a list number of children with autism who register to intervention centers such as Genius Kurnia or Permata Kurnia, and IDEAS Autism Centre, will be obtained. Participants in this study will be parents with children with autism. The sampling technique will be used in this study is the probability sampling method. Through this study, stratified sampling will be used, and this method is appropriate and the only method that suits this study.

### Data Procedure

In this study, a questionnaire will be used to obtain research data. The questionnaire will be adapted from previous studies, including ten items of family quality of life (FQOL), ten items concerning interpersonal relationships; 12 items of a multidimensional survey of perceived support, and ten items focusing on stress and coping.

- a) Family quality of life. Ten items from Beach Centre on Disability (2012). The family Quality of Life Scale (FQOL) will assess the relationship between persons with autism affected family quality of life.
- b) Interpersonal relationship. Ten items from the *Siblings Inventory of Behavior Scale* (Schaefer & Edgerton, 1981; Hetherington et al., 1999) will be used to assess the

relationship between persons with autism with their siblings. The researcher will focus on a person with autism who has siblings in this questionnaire.

- c) Perceived social support. 12 items from the Multidimensional Survey of Perceived Support (MSPSS) (Zimet, Powell, Farley, Werkman, & Berkoff, 1990) will be used to assess the relationship between perceived social supports that could improve the quality of life of person with autism (PWA) caretakers'
- d) Family stress and coping. Ten items from 'The family stress and coping interview for families of individuals with developmental disabilities: a lifespan perspective on family adjustment' (Nachshen, Woodford & Minnes., 2003) will be used to assess the relationship between persons with autism with family stress and coping strategy.

Prior to data collection, content validity will be conducted. A pilot study will be performed to ensure that respondents can clearly understand the questionnaire given and do not have any difficulties with the language, wording, or measurement scale. The questionnaire will be distributed to the respondents, and it will take about two months to collect the data.

### **Data Analysis**

A preliminary investigation and descriptive analysis will be performed using IBM SPSS version 24.0. SmartPLS 3.0 software will be used to examine the multivariate relationships. Both measurement and structural models will be performed. The measurement model examines consistency and validity, including item loading, composite reliability, and average variance extracted. The structural model evaluates the path coefficients value at a 5% level of significance to understand the patterns of relationship between the constructs.

### **Conclusion**

This study has indicated that, despite the advent of a new normal transformation era, the contributing factors towards a better quality of life of a person with autism (PWA) caretakers requires further investigation. The study findings can provide a better insight into the significant quality of life of a person with autism (PWA) caretakers. The present findings have identified several challenges for parents with autistic children in this Covid-19 period, parents experience a huge stressor over time, which include: 1) sustain time pressure; 2) changing life plans; 3) cost of care; 4) discrimination; and 5) inadequate social support. In addition, attention should be on the children with autism and their parent's mental health and quality of life as the parents need more support in this matter. This present study will investigate more to help families and caretakers who have autistic children to have a better quality of life.

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