



Quality of Life Among Malaysian Parents with Autism Spectrum Disorder Child: The Double ABCX Model Approach

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Abstract

This paper reported the quality of life (QoL) of 260 Malaysian parents with autism spectrum disorder (ASD) and factors which influencing it. About half of these parents reported to having good QoL. The factors identified in the double ABCX model showed that perceived social support and sense of coherence (SOC) were mediated by coping strategies and had a positive direct and indirect effect on parents' QoL. These finding reiterate the importance of social support, coping skills, and strong SOC reflection skills in influencing the QoL of parents with ASD child. We therefore suggest parents to utilize the widely available social and organization supports to gain good QoL, which is also important for the wellbeing of their child.

Keywords Autism spectrum disorder · QoL · ABCX model · Parents

Introduction

Autistic children may suffer from various functional challenges due to their low social interaction abilities, impaired verbal or non-verbal communication, and stereotypical behaviours (Kuhlthau et al., 2014). Due to the complexity of autism spectrum disorder (ASD), autistic children demand full-time attention. As parents, raising an autistic child requires a considerable amount of time, physical energy, emotional strength, and financial support (Obeid et al., 2015; van Tongerloo et al., 2015). Some parents have a hard time coping with the lifelong burden to care for the autistic child (Khanna et al., 2011). It can be challenging and burdening to fulfil the needs of an autistic child. Parents need to ensure that other family members are also being taken care. Often,

parents sacrifice their own needs to put their children needs first. As a consequent, parents experience high levels of concern and insecurity regarding the future of their autistic child from the moment of the diagnosis.

To date, there is no established cure for ASD. Early rehabilitation could reduce the autism severity (Ramey, 2019). Adequate social support for the parents has been found to be one of the protective factors towards reducing the severity of the autistic condition (Dyches et al., 2012; Kawabata et al., 2011). There is evidence that shows social support reduces parental pressure (Tichovolsky et al., 2013) and promote a high level of satisfaction among them (Cetinbakis et al., 2020). Faced with the hardship of raising an autistic child, parents need to look at their situation and redefine their sense of coherence and parenting roles. For instance, they need to improve their ability to control emotion, utilise resources, prioritise efforts to establish the new norm in their life for the benefit of the child.

Parents with ASD children will eventually go through a family adaptation phase, which is a transition period that occurs during family restructuring processes as a result of stressors and other burdens in life (McCubbin & Patterson, 1983). During this phase, it is vital for parents to apply appropriate coping strategies and acquiring help in order to deal with an autistic child (Paster et al., 2009).

As shown in the literature, the double ABCX model is commonly used to outline the various factors affecting family adaptation process undertaken by parents with an ASD

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