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Mental Health Literacy among Parents of Children with Autism Spectrum Condition: A Concept Paper

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Abstract

Parents of children with Autism Spectrum Condition (ASC) are highly exposed to mental health problems. Low mental health literacy is one of the barriers in accessing mental health services provided, leaving mental health problems untreated, yet mental health literacy among parents of children with ASC is poorly understood. This conceptual paper of the ongoing study aims to emphasize the significance of understanding the mental health literacy concept within the specific population. Findings will be able to highlight the implications of mental health literacy among parents of children with ASC and will also provide further opportunities to explore the literature gap.

Keywords: mental health literacy; mental health; parents with Autism Spectrum Condition (ASC) children; concept paper

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1.0 Introduction

Autism spectrum condition (ASC) is usually diagnosed since childhood, which is characterised by tenacious deficits in social cooperation and social conversation in multiple environments. This neurodevelopmental condition is further explained with the deficits within three areas which are social-emotional reciprocity, nonverbal communication, and initiating and continuing relationships with others (Tan et al., 2018). Raising and caring for children with ASC have been widely documented to have an adverse effect on the parents' mental health. Without proper treatment and intervention for mental health problems among parents of children with ASC, there is a higher risk for the parents to suffer from poor quality of life and psychological well-being. This, in turn, will affect the family functioning for both children with ASC and the parents (Catalano, Holloway & Mpofu, 2018). Literature on the effectiveness of mental health services has shown a growing pattern. However, behaviour in seeking help from the mental health services provided had been identified as low (Wright et al., 2012). A lower level of help-seeking behaviour is often associated with a poor attitude towards mental health problems. Besides, negative cultural stigma when seeking professional help also caused the limited use of mental health services provided (Wei, 2017). The inaptitude in seeking either formal or informal mental health-related help for oneself or another person is considered as poor mental health literacy. Mental health literacy (MHL) is a term coined by Jorm (1997) and was defined as "knowledge and beliefs about mental disorders which aid their recognition, management or prevention" (Jorm et al., 1997). Researchers have reported that parents are lacking in mental health literacy skills in identifying mental health problems, mental disorder symptoms, and finding professional treatment available when needed

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(Dylan, 2019). Literacy on mental health was also found limited among parents and caregivers (Hurley et al., 2019). Moreover, contrasted to a western country, a developing country has poorer mental health literacy (Furnham & Hamid, 2014). Therefore, it is necessary to increase individuals' knowledge and understanding of mental health not only to reduce the stigma and discrimination of individuals who have mental health problems but also to enhance the public attitude towards seeking help from mental health professionals. Understanding the level of mental health literacy skills perhaps will also be able to help overcome the mental health issues, and parents of children with autism spectrum conditions can improve their quality of life and psychological well-being. Thus, this quantitative study is going to identify the level of mental health literacy and its relationship with parenting stress and quality of life among parents of children with ASC in a few selected government-supported intervention centres for ASC children.

1.1 Research Objectives and Research Questions

This ongoing research is intended to determine mental health literacy, parenting stress, and quality of life among parents of children with ASC by focusing on the following objectives:

1. To identify the level of mental health literacy, parenting stress, and quality of life of parents of children with ASC
2. To identify the relationship between mental health literacy among parents of children with ASC with parenting stress and quality of life.

The objective shall answer the following research questions:

1. What are the level of mental health literacy, parenting stress, and quality of life among parents of children with ASC?
2. What is the relationship between mental health literacy parents of children with ASC with parenting stress and quality of life level?

1.2 Significance of the study

The results of this ongoing study will be able to highlight the importance of mental health literacy and encourage the need to pay attention to the psychological well-being aspects of caregivers of children with ASC. It also may highlight the management of stress and mental health issues among the parents of children. ASC is in the Clinical Practice Guidelines for Autism Spectrum. Besides, the contribution of this study will help in the growing literature on parents of children with autism spectrum conditions by examining the outcome of their mental health literacy and its relationship with parenting stress and quality of life that was previously unstudied within this population.

2.0 Literature Review

2.1 Hypothesis of the study

1. The lower the mental health literacy, the lower the quality of life of parents of children with autism spectrum condition.
2. The lower the mental health literacy, the higher the level of parenting stress of parents of children with autism spectrum condition.
3. The higher the level of severity symptoms of ASC children, the higher the mental health literacy parents of children with ASC.

2.2 Challenges as parents of children with Autism Spectrum Condition (ASC)

Autism Spectrum Condition (ASC) affects approximately 1 in 54 American children (Maenner et al., 2020). Despite the estimation of ASC prevalence in other Asian countries, the prevalence data in Malaysia are still lacking. In the Southeast Asia context, the prevalence of autism spectrum conditions was also reported lacking, including in Malaysia. The situation that occurred might be due to the possibility of ASC diagnosis in Malaysia being categorised under Learning Disabilities instead of being distinguished as an independent diagnosis, hence the lack of prevalence of ASC. Nevertheless, the National Autism Society of Malaysia (NASOM) reported increasing intake numbers of children diagnosed with ASC in their organisation from year to year (The National Autism Society of Malaysia, 2013). In addition, children with ASC are often comorbid with other psychological and medical conditions symptoms. These comorbid symptoms, in addition to the primary symptoms of ASC, can affect the quality of life of individuals with ASC and their families.

Moreover, the adaptive behaviour among these ASC children is much poorer than their typical development and other developmental disorders peers. Adaptive behaviour commonly refers to an independence ability related to individual skills such as daily living skills, social skills, and communication skills. Although not all children with ASC showed impairment in the adaptive behaviour, when present, they will have difficulties performing activities of daily living, lack of communication skills, having difficulties interacting and socialising with others (Ooi et al., 2016). These problems can be exhausting and taxing for the parents in their parenting experience.

2.3 Impact on mental health and psychological well-being parents of children with ASC

Being parents of children with ASC is a lifelong endeavour with many challenges and might pose the parents to develop mental health-related symptoms. In 2017, it was estimated that 970 million people are suffering from mental health symptoms globally. Closer to home, one of three Malaysians suffered from mental health. Multiple contributor factors such as parental factors and children-related factors were associated with the mental health problems among parents of children with ASC (Zaidman-Zait et al., 2017). It also has been reported that parents of children with ASC are more susceptible to mental health problems such as parenting stress, anxiety, and depression. They also become more vulnerable to other health-related problems than parents without ASC children (Pisula & Porębowicz-Dörsmann, 2017). Parents of children with ASC have been found to have poorer family functioning across multiple domains. Family dysfunction has been suggested to have detrimental effects on parents' overall well-being. Family dysfunction is also more prevalent in families with ASC children than typical (Zaidman-Zait et al., 2017). These unfavorable situations affect the said children in growing up and elevate the risk of poor

health outcomes to the caregivers (Nik Adib et al., 2019). A local study in Kelantan suggested that caregivers of children with ASC sustained significant stress while raising their children (Nik Adib et al., 2019).

Similarly, a study reported a 40% rate of anxiety or depression among caregivers with ASC (Leontine et al., 2020). However, compared to developed and even other developing countries worldwide, limited mental health support resources remain available in Malaysia (Ilias et al., 2017). Therefore, it is necessary for parents with ASC children to receive social support and training in coping strategies for stress management (Catalano, Holloway & Mpofu, 2018; Da Paz & Wallander, 2017). Moreover, attending to mental health problems in parents of children with ASC is necessary to improve the overall health outcome for both parents and ASC children. However, albeit much-growing evidence is being synthesised on best treatment and strategies provided for helping parents of children with ASC regarding their mental health problems, there is still limited use of mental health treatment services (Sweileh, 2021).

2.4 Barriers in using mental health services provided among parents of children with ASC

Previous research identified poor help-seeking behaviors among people with mental health problems as primary reasons for the limited use of mental health services among the populations (Sweileh, 2021). A recent finding in Iran showed that 36% of the participants struggled to find help for mental health disorders (Nejatian, Tehrani, Momenian & Jafari, 2020). Some reports found that parents and caregivers not only do not understand the mechanism or procedure in finding help for their children, but also they have limited knowledge for helping themselves concerning mental health problems (Hurley, Swann, Allen, Ferguson & Vella, 2020). When parents of children with ASC fail to identify and point out health-related problems, it has been found associated with help-seeking postponement. Delayed in getting help can indirectly affect the individual either physically or mentally. Having poor physical and mental conditions can lead them to poor quality of life and psychological well-being in general.

Meanwhile, when parents of children with ASC can recognise their mental health state correctly, it has been found related to a help-seeking preference and intention to seek help. Seeking help as early as possible can help prevent further deterioration of an individual's health's condition. Therefore, it is essential to enhance the individual help-seeking efficacy and self-management capabilities in managing issues related to mental health (Kutcher et al., 2016). Apart from poor help-seeking behaviour, cultural stigma towards mental health problems also become one of the barriers that can impede the ability of parents of children with ASC to acknowledge mental disorders and recognise the treatment provided (Wei, 2017). Lack of understanding of the issues regarding mental health problems within society is constantly associated with societal stigma. Most cultural or societal stigma and negative attitudes towards mental health problems hindered individuals from gaining good mental health literacy skills.

2.5 Mental health literacy

Mental health literacy (MHL) is an essential skill that aids a person's recognition, management, or prevention regarding mental health problems, hence promoting resilience. MHL can be operationalised into three major components; (1) knowledge of mental health, (2) attitude and stigma, and (3) help-seeking behavior (Kutcher et al., 2016; Munawar et al., 2020). They can further expand into six main components, which are 1) ability to recognise disorders 2) knowledge of risk factors and causes 3) knowledge of self-treatment 4) knowledge of professional help available 5) knowledge of where to seek information, and 6) attitudes that promote recognition or appropriate help-seeking behaviour (Jorm et al., 2006). The World Health Organization (WHO) has stressed the role of health literacy as a stronger predictor of health outcomes, including mental health. Parents of children with ASC are considered specific populations who need coping strategies to prepare for their mental health during raising and caring for their ASC children. The mental health-related quality of life of parents of children with ASC could be improved by directly reducing parental stress through the involvement of parents in effective mental health support strategies. When communities, groups, and individuals participate in the campaign regarding mental health literacy, it can manifest the increment in knowledge not only to help others but also for themselves and able to reduce stigma by engaging in help-seeking behaviour towards untangling mental health problems (Gulliver, Griffiths & Christensen, 2012). Good mental health literacy will allow parents to raise ASC children preparedly (Catalano, Holloway & Mpofu, 2017). Few studies also showed that education, stigma reduction, and help-seeking attitude had been expected to improve mental health (Krakauer et al., 2020).

In contrast to the importance of health literacy found in the literature, the study also found that limited health literacy is still evident in society. Often poor health literacy is associated with poor health outcomes across different diseases. For example, regarding mental health problems, identifying mental disorders is a primary step for parents of children with ASC to seek information for treatment provided and help regarding their mental health problems (Jafari, Nejatian, Momenian, Barsalani & Tehrani, 2021). Therefore, the inability to identify and know how to access treatment provided from professional help or informal help can be considered one of the major gaps in mental health literacy (Jorm, 2012), which can directly affect their psychological well-being.

Many research supports that factors that contributed to the lower level of mental health literacy among the population can be derived from demographic characteristics such as gender, educational background, and age (Piper, Bailey, Lam & Kneebone, 2018; Mendenhall & Frauenholtz, 2015; Reavley, McCann & Jorm, 2011). Most studies found a significant relationship between gender and mental health literacy (Jafari, Nejatian, Momenian, Barsalani & Tehrani, 2021). For example, a study of university students showed that female students were more likely to recognise depression in a vignette (Reavley, McCann & Jorm, 2011). A similar finding in Malaysia also documented that the female gender has a higher knowledge of depression symptoms. The study also found that Chinese female students had relatively better knowledge ($p=0.058$) than Malay and Indian university students (Khan, Sulaiman & Hassali, 2010).

Meanwhile, a study among caregivers of adolescents with bipolar disorder also reported that female caregivers are more likely to know better about treatment for mental health (Mendenhall & Frauenholtz, 2015). However, despite the female gender showing distinct gender differences in mental health literacy, a study in Arab reported a contradict finding. The adult Arab male was stated to have more knowledge,

beliefs, and attitude regarding mental health than females due to cultural beliefs in Arab women (Bener & Ghuloum, 2011). These overall findings showed the complexity of this relationship.

In addition to that, frequent participation in clinical mental health training courses can significantly predict higher MHL scores (Vermaas, Green, Haley & Haddock, 2017). Educational background in psychology was the strongest predictor of MHL among university students in Lebanon (Naal, Tavitian-Elmadjian & Yacoubian, 2020). However, the predictors' study was conducted using vignettes of suicide, depression, and generalised anxiety disorder (GAD) which the instruments used are not fully included all the three MHL components as discussed in this study. Studies among caregivers of youth with a mood disorder also showed that their knowledge about mood disorder increased with caregivers' higher education level (Mendenhall & Frauenholtz, 2015). In the Iran study, the educational level has a significant relationship with mental health literacy (Jafari, Nejatian, Momeniyan, Barsalani & Tehrani, 2021). Nonetheless, the findings still do not reveal the caregivers' knowledge about mental health in general. Despite mentioned literature findings of demographic factors (i.e. gender and education background), the child-related factors (e.g. child severity symptoms) and parent-related factors (e.g. parenting stress and poor quality of life) may need extensive research on its relationship with the level of mental health literacy as the evidence regarding mentioned variables still inadequate in general (Garcia-Lopez, Recio, Pozo & Sarria, 2021; Baker et al., 2011; Padden & James, 2017).

3.0 Methodology

This ongoing study will be conducted using a cross-sectional survey designed to collect information regarding mental health literacy, parenting stress, and quality of life among parents of children with ASC. This study intends to use a set of questionnaires, including the Mental Health Literacy Scale (MHLS), Parenting Stress Index-Short Form (PSI-SF), EuroQoL Five Dimensional Questionnaire (EQ5D-3L); and the Social Responsive Scale-2 (SRS-2). Parents of children with Autism Spectrum conditions will be asked to complete a history and demographic data and will be given a set of questionnaires to be answered. The quantitative data collected will be analysed using descriptive statistics, including distribution of percentage, mean or median, and frequency counts. Meanwhile, a simple linear regression test will be performed to determine the relationship between the continuous variables; mental health literacy parents of children with ASC) with parenting stress and quality of life. All quantitative data entry will be analysed using The Statistical Package for the Social Sciences (SPSS) version 25. This study will include participants with the mentioned criteria below:

1. Parents of children with ASC who is a Malaysian citizen and able to read and understand English or Bahasa Malaysia sufficient to be able to complete the consent forms and questionnaire.
2. Parents that send their children with ASC in the selected centres in Selangor, Kuala Lumpur and Putrajaya.
3. Parents that has children with ASC that is without comorbidities of medical condition, psychiatric and/or physical condition.

4.0 Findings

Most studies concerning mental health literacy were conducted within populations such as general populations, high school students, or university students, and also found within medical students populations. One study has been conducted for family members or caregivers; however, it focused on family members of schizophrenia. To our knowledge, there is still no study concerning MHL in general among parents of children with ASC. Moreover, the analysis of the research conducted often aimed to identify one or more components of MHL (e.g. knowledge of mental health problems, help-seeking behaviour, stigma, and attitude) instead of identifying MHL as a whole. Furthermore, the theory within mental health literacy is still growing in the research field, and the literature is mainly ventured in specific populations only without using a standardised instrument for mental health literacy. In overall, the main findings of this study will be researcher answering the objectives stated: 1) to identify the level of mental health literacy, parenting stress, and quality of life of parents of children with ASC, and 2) to identify the relationship between mental health literacy among parents of children with ASC with parenting stress and quality of life.

5.0 Discussion

Mental Health Literacy (MHL) is a concept that elicits the ability to recognise signs of mental health issues and identify practical help from various sources. The high prevalence of mental health disorders of parents of special needs implied a need to assess mental health literacy in the parent or caregiver population. This ongoing study has set the grounds for a significant study and offers a literature review on topics relevant to the research. In support of The World Health Organization (WHO) global policy on Mental Health Action Plan (2013-2030), which outline principles, objectives, and implementation strategies to promote good mental health in the community, findings from this study are expected to offer better insight on the roles of mental health literacy and its relation to the psychological well-being and parenting stress among parents with ASC children. These research findings will expand the knowledge and a theoretical understanding of mental health literacy among parents of children with ASCs in the Malaysian context. In particular, the psychological well-being and parenting stress experiences of parents of children with ASCs in the Malaysian context will be analysed, leading to theory development and formulation of a preliminary preventive framework for mental health for a caretaker of children with special needs. This also includes the open of new opportunities for researchers to find appropriate interventions for cultural stigma within parents of children with ASC in getting treatment related to mental health issues.

6.0 Conclusion & Recommendations

In conclusion, this ongoing paper has further explained that it is essential for parents with ASC children to have a good level of mental health literacy. Mental health literacy will help promote help-seeking behaviour, promote a good attitude, and reduce the negative cultural stigma regarding their mental health problems. Furthermore, a good level of mental health literacy will also contribute to the increased use of mental health services provided among parents of children with ASC. However, this concept paper is solely based on a review of the mental health literacy field literature, and the collection of data is yet to be taken. Furthermore, the ongoing study will only cover the parents' and child-related variables, including the severity of symptoms, parenting stress, and the quality of life of parents of children with ASC. Besides, this study does not consider parents of children with other medical conditions or physical conditions such as Down syndrome, seizures, and cerebral palsy.

Nevertheless, the examination of MHL in a sample of parents of children with ASC contributed information regarding factor constitution and an approach to compare MHL scores between groups of parents of special needs children. Therefore, a future study is suggested to explore an in-depth understanding of mental health literacy for parents with special needs children and suggestions on how to help the population to overcome the stigma of getting mental health assistance. The researcher also suggests that future studies conduct a scoping review for summarising concepts on mental health literacy in Malaysia.

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Paper Contribution to Related Field of Study

The concept paper perhaps will provide a potential contribution towards mental health providers and other healthcare professionals (i.e. psychologists, occupational therapists, speech therapists, and others) who are dealing with ASC children also concerned about the caregiver's mental health.

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