Competency of Autism Spectrum Disorder Parents in Home-Based Occupational Therapy Intervention

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Abstract
During COVID-19, parents only relied on online materials to provide occupational therapy intervention at home. However, their competency is less studied. Thus, the objectives of the study were to examine parents’ sense of competence and the level of stress in providing home-based therapy. Data were collected via an online survey using the Parenting Sense of Competence Scale and Parental Stress Scale. 125 parents were recruited using a purposive sampling technique. The result shows that parents have a high level of sense of competence and a low level of stress in handling children with ASD during the pandemic.

Keywords: Competency; Autism Spectrum Disorder; Parents; Occupational Therapy

1.0 Introduction
In a smaller-scale study conducted by the Ministry of Health in 2014, they found that children between the ages of 18 to 26 months showed a rate of 1.6 in 1000 children, or approximately 1 in 625 have autism spectrum disorder (ASD). Social distancing and restricted movement have raised lots of eyebrows amongst Malaysians. During the peak of COVID-19 infections, intervention centres were closed, hospitals were not accepting any appointments for therapy sessions, and everyone was advised to stay at home to prevent the spread of the virus.

This increased the burden on caregivers and parents of children with ASD. For example, GENIUS Kurnia, a government-run early intervention centre under the Ministry of Education was closed due to movement control order (MCO) restrictions. Therefore, parents were encouraged to complete interventions provided by occupational therapists at home (The Star, 2020).

Children with ASD were supported with continuous online coaching and video materials given by occupational therapists during earlier phases of MCO. However, this was deemed insufficient as parents found themselves incompetent in completing tasks given and were experiencing a significant amount of stress in taking care of their special needs children. Thus, it is vital to explore the level of competence and stress levels among parents of children with ASD in providing home-based occupational therapy intervention during the COVID-19 outbreak. Hence, the study is aimed to examine parents’ sense of competence and the level of stress in providing home-based therapy.
2.0 Literature Review

2.1 Occupational Therapy Intervention Implementation During COVID-19: Overcoming Barriers to Its Continuity
Implementing occupational therapy intervention is essential for children with ASD to improve their functional skills, level of cognition and overall quality of life. Continuity of receiving intervention during the pandemic is vital to optimise function and quality of life (Longo, 2020). The following literature review implies that there are several challenges experienced by parents in managing children with ASD during the COVID-19 outbreak, which impacted parents’ well-being. Therefore, several strategies are discussed for continuing occupational therapy intervention at home.

2.2 Defining the Problem
Children with ASD benefit from consistent therapy sessions and comprehensive treatment plans to improve their functional skills. The inability to attend therapy sessions or receive daily preschool-based intervention was recognised as a potential issue for children with ASD during the pandemic outbreak. Rose (2019) stated that many families face difficulty in obtaining appropriate health care, managing special needs children who require one-to-one support and receiving continuous service for the children where access to them is being restricted or prohibited due to the imposition of social distancing and isolation measures. Colizzi (2020) found that many parents with children with ASD stopped working due to the emergency outbreak. Both authors also found that parents have difficulties in managing their children’s daily activities, especially in terms of playtime and structured activities. Thus, parents would require support from healthcare services and benefit from home-based therapy interventions.

2.3 Establishing the Effect
Several studies have found the impact of handling their special needs children on parents’ and caregivers’ well-being. A study conducted by Nikmat (2008) has found parents with children with ASD have a high prevalence of stress and clinical disturbance in psychological well-being. The authors also found mothers showed a statistically significant impact associated with reduced psychological well-being (Alias, 1999; Nikmat, 2008). This happens due to a global sense of guilt tied to a belief in not doing enough for their children. Authors believe that there should be further comprehensive studies to explore parents’ stress and appropriate support should be provided to manage their stress. Ilias (2018) has stated six main factors associated with parenting stress in caring for children with ASD which are social support, severity of autism symptoms, financial difficulty, parents’ perception and understanding toward ASD, parents’ anxiety and worries about their child’s future, and religious beliefs. Authors believe poorer policy and economic support for mental health and special needs in the Asian region may have exacerbated the difficulties and challenges faced by parents of children with ASD in these countries in comparison to those in a Western context (Ilias et al., 2022).

On the other hand, managing children with ASD was more challenging during this predicament. Rose (2019) discovered many families experienced a significant amount of stress caring for their special needs children during the pandemic outbreak. Longo (2020) concluded that the information received by parents regarding interventions was overwhelming. The effectiveness of the interventions was poorly supported by the evidence and was also found not to be cost-effective. Feeling incompetent and ineffective in providing adequate care for their children at home even with appropriate coaching and supervision are the challenges that lead parents to feel fragile. Colizzi (2020) emphasised that there was an increase in challenging behaviours among children with ASD due to routine changes and reduced school support during the pandemic. Authors believe increasing age and living with a separated or single parent were associated with a reduction in the likelihood of exhibiting more intense behaviour problems. Meanwhile not receiving indirect school support during the emergency tended to be associated with an increased likelihood of exhibiting more intense behaviour problems.

However, there are some positive outcomes from managing children with ASD during this pandemic outbreak. Rose (2019) stated some parents have reported that there were fewer challenging behaviours due to the implementation of social isolation which created a simpler lifestyle for their children. Thus, it promoted more opportunities for parents to create positive interactions.

2.4 Investigating Parenting Sense of Competence
It is essential for parents to feel competent when carrying out interventions for their special needs children. A study conducted by Arellano (2019) has demonstrated that mothers with lower support needs had greater parenting satisfaction and mothers with more positive expectations perceived themselves to be more effective in handling their ASD children. This study also found that ethnicity, expectations, and lower levels of perceived family support needs were predictors of greater satisfaction. Higher positive expectations predicted a greater sense of efficacy among parents. Another study conducted by Mathew (2019) agrees that mothers displayed higher levels of satisfaction. The study found that child symptom severity was associated with maternal parenting competency with these relationships amplified among mothers with higher familial socioeconomic status and who lived in areas of greater neighbourhood advantage. Increased adaptive functioning was associated with better maternal well-being, particularly among mothers who lived in areas of greater neighbourhood advantage.

2.5 Searching for Solutions
A variety of modalities have been implemented in continuing intervention during the pandemic. Colizzi (2020) presented several types of school support received by the parents during the COVID-19 outbreak which include both direct (calls and video calls) and indirect (text messages, homework assignments). Longo (2020) suggested several modified interventions to be carried out delivered at home.
which may improve the results of participation in the rehabilitation process such as goal-directed functional therapy and constraint-induced movement therapy.

2.6 Prepare for Tomorrow, Today
The continuity of intervention for children with ASD relies heavily on feedback gathered from parents' past experiences in providing care for their children. The research in providing continuity occupational therapy intervention at home has been both general and sparse. The literature reviewed in this report highlights several challenges faced by parents with children with ASD during the pandemic outbreak and provides recommendations which increase the effectiveness of interventions. Further research regarding home-based occupational therapy interventions is required to support parents' psychological well-being and to reduce the carer burden on parents of children with ASD at home.

3.0 Methodology

3.1 Study Design
This study design involves gathering data from one population at a specific time frame. The goal of this study design was to collect precise data that can be used to draw solid conclusions and to produce new hypotheses which can be tested in future research. This study was conducted from March 2023 until July 2023.

3.2 Location of Study
This study involved the parents or caregivers of children from GENIUS Kurnia Early Intervention Centre Sentul, and GENIUS Kurnia Early Intervention Centre Putrajaya who have been applying home-based occupational therapy intervention.

3.3 Sampling Design
The sample of this study was parents of children with ASD who have been applying home-based occupational therapy intervention. The purposive sampling method was used to recruit the participants. This consists of identifying and selecting individuals or groups of individuals who are proficient and knowledgeable about a phenomenon of interest (Guest & Fleming, 2015). The use of purposive sampling leads to accurate results which are relevant to the research context.

3.4 Inclusion and Exclusion Criteria
Inclusion
- Parents or guardians who had received occupational therapy intervention coaching via online method during the MCO in GENIUS Kurnia.
- Parents who had attempted to complete the home-based therapy at home individually were coached by therapists.
- Able to read and understand English and Malay to complete the questionnaire.

Exclusion
- Parents of children with ASD who have other comorbidities such as epilepsy, attention deficit disorder, or other conditions related to developmental disability.

3.5 Sample Size

\[ n = \frac{Z^2 p(1-p)}{d^2} \]

\[ Z = 1.96 \text{ (95%)} \]
\[ p = 0.16 \]
\[ d = 0.05 \text{ (5%)} \]
\[ n = 207 \]

Fig. 1: Sample size formula

The sample size for this study was calculated using the sample size formula. According to the Malaysian Ministry of Health, the prevalence of ASD children was 0.16% in 2014 and it was used as the expected proportion \( p \) for the sample size calculation. For the level of confidence of 95%, the Z statistic (Z) value is 1.96 and the precision value (d) is 5% is in Fig 1. Hence, the minimum sample size \( n \) obtained from the calculation is 207 parents of children with ASD.

3.6 Instruments
The questionnaire and instruments used in this study are the demographic questionnaire, Parenting Sense of Competence Scale (PSCS), and Parental Stress Scale (PSS). A self-reported method was used to assess parenting’s sense of competence and its association with parental stress among parents of children with ASD.

3.7 Data Collection Procedure
The data collection process was started after obtaining ethical approval from Universiti Teknologi MARA. The data collection for this study was collected via an online survey and it was made available in Google Forms. According to Regmi et al. (2016), data collection via an online survey appears to have the potential to collect large amounts of data efficiently and with less error. Thus, this method was relevant to this study. Potential participants were approached through GENIUS Kurnia to offer participation in this study. They were recruited based on inclusion and exclusion criteria. All participants were given a consent form that explained the purpose of this study, procedures, the benefits of participating, voluntary participation, and the researcher’s contact information. Next, they were required to answer the demographic questionnaire, Parenting Sense of Competence Scale (PSCS), and Parental Stress Scale (PSS). After the data collection was completed, the data analysis was completed through Statistical Package for Social Science Software (SPSS). The flowchart of data collection as in Fig. 2.

![Flowchart of data collection](image)

3.8 Data Analysis
Data was analysed using the Social Science Software (SPSS) version 29. Descriptive analysis was used to identify the level of sense of competence and stress among parents of children with ASD in providing home-based occupational therapy intervention during the COVID-19 pandemic.

3.9 Ethical Consideration
Ethical approval was obtained from the Research Ethics Committee (REC) of the Universiti Teknologi MARA before the commencement of the study. Reference number: REC/03/2023 (ST/MR/75).

4.0 Findings
4.1 Level of Sense of Competence, Satisfaction, and Efficacy among Parents of Children with ASD
Table 1 displays a comprehensive descriptive analysis of the level of sense of competence among parents of children with ASD during the COVID-19 pandemic, specifically in providing home-based occupational therapy intervention. Regarding the sense of competence, a score between 17-59 was categorized as low while 60-102 was categorized as high. Approximately 36.9% of parents reported a lower sense of competence, with an average score of 55.52. In contrast, most parents, comprising 63.1%, expressed a high sense of competence, with a higher mean score of 65.04. In terms of satisfaction, a score of 9-31 is categorized as low while 32-54 is high. The data showed that 52.3% of parents reported a low level of satisfaction, with a mean score of 25.34. Conversely, 47.7% of parents reported a high level of satisfaction, with a mean score of 37.29. Moving on to efficacy, the score 8-28 is categorized as low while 29-48 is high. It was revealed that 35.4% of parents reported a low sense of efficacy, with an average score of 23.13. On the other hand, a larger proportion of parents, comprising 64.6%, expressed a high sense of efficacy, with a mean score of 35.21.

<table>
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<th>Low Frequency</th>
<th>Low %</th>
<th>Low Mean</th>
<th>High Frequency</th>
<th>High %</th>
<th>High Mean</th>
</tr>
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<tr>
<td>Sense of Competence</td>
<td>48</td>
<td>36.9</td>
<td>55.52</td>
<td>82</td>
<td>63.1</td>
<td>65.04</td>
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Table 1: Level of Sense of Competence, Satisfaction, and Efficacy among Parents of Children with ASD
4.2 Level of Stress among Parents of Children with ASD
Table 2 provides a comprehensive descriptive analysis of the level of stress among parents of children with ASD during the COVID-19 pandemic, specifically in providing home-based occupational therapy intervention. A score of 18-54 is categorized as low stress while 55 to 90 is high stress. It shows that 102 parents (78.5%) reported a low level of stress, with an average score of 42.27. In contrast, 28 parents (21.5%) reported a high level of stress, with a significantly higher mean score of 59.39.

<table>
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<tr>
<th>Variables</th>
<th>Stress</th>
<th>Frequency</th>
<th>Low</th>
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<td></td>
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<td>102</td>
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<td>42.27</td>
<td>21.5</td>
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5.0 Discussion

5.1 Level of Sense of Competence among Parents of Children with ASD
This study found that most parents have a high sense of competence in handling occupational therapy intervention for their children with ASD. This result is similar to another study which found that many parents felt successful and confident in their ability to guide their child's therapeutic needs at home during a pandemic (Zeidan et al., 2022). The use of gadgets as a learning medium during occupational therapy sessions also helped children with ASD to engage better during learning sessions (Kamaruzaman, 2022). Nevertheless, the data analysis confirmed that a minority of parents suggested a low sense of competence. These parents may have possibly experienced poor social support and experienced difficulty in completing occupational therapy intervention at home. The moderate level of overall sense of competence reported by parents indicates a reasonable degree of confidence in their caregiving abilities (Fahim & Nedwick, 2013).

However, the lower satisfaction scores suggest that parents may be experiencing challenges and uncertainties despite feeling effective in their role. This could be due to external factors that are uncontrollable and may be inevitable (Slaughter & Ong, 2014). The findings from previous studies indicate that parents generally perceived themselves as efficient in their caregiving role but expressed less satisfaction with their performance (Beneytez-Barroso et al., 2020).

5.2 Level of Stress among Parents of Children with ASD
Most previous studies have reported that parents have indeed suffered from stress during the pandemic (Ilias, 2022; Wahab, 2022). However, this study found contrasting results as the majority of the parents managed to cope well with the responsibility and needs of home-based remedies (Botha et al., 2020). Conversely, a small percentage of parents stated an excessive degree of stress. This subset of parents faced good-sized stressors, that may have been exacerbated by way of different factors, such as financial constraints, limited access to help services, and the want to balance work and caregiving obligations (Vivanti, 2019). High degrees of strain were also related to the uncertainty and adjustments delivered about with the aid of the pandemic, similarly, impacting the well-being of parents and their capacity to provide effective remedies.

Furthermore, the findings from this study are like previous studies which indicate that a considerable proportion of parents experienced less significant stress while providing home-based occupational therapy intervention to their children with ASD during the COVID-19 pandemic (Ardıç & Olçay, 2020). The slightly reduced level of perceived stress reported by parents highlights the significant blessing they encountered while managing their child's therapy at home during the pandemic (Frye et al., 2013). The COVID-19 pandemic brought about disruptions in routine, limited access to essential resources, and increased responsibilities, which likely would have increased stress levels among parents (Furrukh & Anjum, 2020). However, the increase in personal time being spent at home would have helped reduce a considerable proportion of stress that the parents may have felt when providing care for their children with ASD while working in the office during the pandemic (Jang, 2021). Social support is essential to reduce the burden of stress among parents with ASD children (Wahab, 2022). Plus, identifying play preferences and improving play skills among children with ASD will be beneficial to reduce stress among parents (Vetrayan, 2016).

6.0 Conclusion & Recommendations
Throughout this study, there has been in-depth research and exploration completed to correlate the relationship on the intricate relationship between a sense of competence and stress experienced by parents of children with ASD while providing home-based occupational therapy intervention during the COVID-19 pandemic in Malaysia. The investigation aimed to shed light on the unique challenges and experiences faced by these parents in navigating their roles as primary caregivers and therapists amid unprecedented circumstances. Based on the results and discussion above, the research questions were proven and answered to their fullest understanding and extent.

A recommendation that would be suitable to put forth to enhance future research and increase the support for parents of children with ASD would be to carry out more longitudinal studies on the matter. Conducting longitudinal studies could provide a more comprehensive understanding of the long-term impact of home-based occupational therapy intervention on parental stress and level of competence. Examining a handful of factors over an extended period would reveal how interventions and support services evolve and...
adapt to changing circumstances (Mahmood et al., 2015). To gain a more holistic understanding, future studies should explore the relationship between the level of competence and stress among parents of children with ASD from diverse cultural backgrounds (Slaughter and Ong, 2014). This will help identify culturally sensitive interventions and support services tailored to the unique needs of various communities.

By implementing the recommendations mentioned above, it is essential to aspire to foster a more supportive and nurturing environment for parents, ultimately enriching the lives of children with ASD and empowering families to thrive in the face of adversity. The limitation of this study is the lack of respondents. Further study is needed to get a better understanding of the level of competence and stress level among parents with children with ASD in managing occupational therapies at home. The new direction of the research should be focused on the strategies to overcome challenges that parents have experienced in managing occupational therapy intervention at home.

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Paper Contribution to Related Field of Study
This study identified that there are still many parents who suffer from stress and low competency in handling occupational therapy intervention for children with ASD at home. Occupational therapists can overcome the barriers and modify methods of interventions accordingly to suit parents’ competency to foster more effective interventions. This study also will provide needed data for the Ministry of Education by providing a better picture of the consequences for children with ASD for not being able to attend preschool-based early intervention centres. Having this result will prepare the occupational therapists and special education teachers to come up with ways of teaching the parents to continue the intervention plan at home which contributes to the body of knowledge.

References


