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Dimensions of stress in parents of children with autistic spectrum disorder

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Abstract

Background: Parents of children with Autistic Spectrum Disorder (ASD) are at an increased risk for stress and other mental health problems. While treatment is mainly focused on the child, somehow parents' stress is exacerbated. Accordingly, the purpose of this study was to identify the sources of stress in the parents of children with ASD. **Methods:** The 52 parents of children with ASD who participated in the study completed the child domain (CD) and parent domain (PD) subscales of the Parenting Stress Index Fourth Edition (PSI-4). Subsequently, the scores of the PSI-4 subscales were analyzed and compared. **Results:** The respondents scored the highest for the distractibility/hyperactivity subscale in the child domain and highest for the depression subscale in the parent domain. **Conclusion:** The results of this study may help to determine suitable treatment for parents of children with ASD. Child and parent characteristics contribute equally to parental stress, distractibility/hyperactivity and depression were most prevalent in the CD and PD respectively.

Keywords: autism spectrum disorder, child, parenting, stress disorders

Introduction

Although parents commonly experience stress, research has revealed that parents of children with Autism Spectrum Disorder (ASD) experience higher levels of stress in comparison to parents of typically developed children^{1,2} and even those who have children with other disabilities.³ ASD is a developmental disorder defined by behavioral features that emerge during the first years of life.⁴ The disorder is characterized by deficits in social interaction and communication as well as the presence of repetitive behavior and restricted interest patterns.⁵ As suggested by the name, children with ASD fall on a spectrum with a range of symptoms that vary in severity. Therefore, each child with ASD has unique characteristics, which may not be the same as those of other children with ASD. In Malaysia, findings have revealed that parents of children with ASD consistently experience higher stress levels compared to parents of typically developed children.⁶ Furthermore, in 53.8% of Malaysian parents of children with ASD, there was a clinical disturbance in psychological well-being.⁷ Furthermore, The National Autism Society of Malaysia reported an increase in the number of children with ASD in their organization.⁸ Although this report revealed an increase in the awareness of ASD, it suggested that more parents are potentially at risk of high stress levels.

Previous studies have found that there are various factors that contribute to parental stress. Children's characteristics are one of the most noted factors. Caring for children with ASD can be highly stressful for parents as they require extra attention and support,⁹ This does not afford parents much time for themselves. The child's lack of social skills may also contribute to parenting stress,¹⁰ because difficulties in communication and limited understanding between the parents and child may occur. Moreover, children with ASD may display behavior problems,¹¹ which may exacerbate their parents' stress. Previous study found that the latter factor is the most challenging aspect of raising a child with ASD.¹² Furthermore, revealed that these children's problem behaviors have a negative relationship with their parents' psychological acceptance.¹³ A study found that problem behavior increases parenting demands, which subsequently increases parenting stress.¹⁴ Consequently, it is understandable that the children's different characteristics may contribute to their parents' stress. However, the factor of stress may also be associated with parents' characteristics. Resilience is a predictor of parenting stress. In essence, the higher the resilience, the lower the parenting stress, and vice versa.¹⁵ Therefore, parents with low resilience may experience their situations as more challenging compared to those with high resilience. A faulty coping style, particularly escape-avoidance has also been found to be a source of stress in parents with autistic children.¹⁶ Although this

coping style may lead to adverse outcomes, parents use it to manage their situations. In addition, high stress levels are also associated with parents who experience isolation,¹⁷ family dysfunction,¹⁸ and a lessened sense of control.¹⁹

Previous studies have shown that it is evident that parents of children with ASD experience high levels of stress because of the characteristics of both the children and their parents. Accordingly, the purpose of this study was to assess the dimensions of stress in parents of children with ASD in Malaysia by employing the Parenting Stress Index 4th Edition (PSI-4). A number of previous studies of parents of children with ASD have employed short-form versions of the Parenting Stress Index.^{1,6} Because the aim of the present study was to conduct an in-depth examination of the sources of parenting stress, the long version of the PSI-4 was administered so as to examine the scores, particularly the highest scores, in order to identify the main sources of stress in parents with children with ASD. The researchers are of the view that the intervention or prevention of parental stress may be more efficient if the main sources of stress are known. Knowledge of the sources will provide direction for intervention and prevention programs. Therefore, the results of this study may help future studies and policy makers to determine suitable interventions and prevention measures to manage the stress that parents with children with ASD experience.

Methods

Participants. The participants included 52 parents of children with ASD. Of the 52 parents, 30 sent their child to the Ideas Autism Centre, 17 to the Insani Autism Academy, and five used home-based therapy in Malaysia. Although a total of 150 questionnaires were distributed to these centers, only 52 parents gave informed consent to participate. The study was carried out in accordance with ethical standards of the Helsinki Declaration. Only one of the parents of each child participated in this study. The majority of the children with ASD were male ($N = 45$) and their mean age was 7.5 years ($SD = 2.9$). Other demographic background information is not available as a result of missing data. Furthermore, only demographic information of the children was obtained. Both may be viewed as limitations of the study.

Measures. The Parenting Stress Index 4th Edition (PSI-4),²⁰ is a 120-item instrument used to measure the degree of stress in the parent-child system. The instrument is suitable for parents with children who are 12 years old and younger. The PSI-4 comprises three constructs: The child domain (CD), parent domain (PD), and life stress scale. The CD subscales assess child behaviors and characteristics that their parents experience as stressful while the PD subscales assess dimensions of parent stress related to personal adjustment and family functioning.

The life stress scale determines the stress caused by uncontrollable circumstances. However, this scale may be too general and unable to determine the specific life event that contributes to the stress. Therefore, it was omitted from the study. The CD and PD domains are more specific and thus, were employed in the study. The CD comprises six subscales: Adaptability, acceptability, demandingness, mood, distractibility/hyperactivity, and reinforces parent. The PD includes seven subscales: Depression, attachment, restriction of role, sense of competence, social isolation, relationship with spouse, and parent health. The subscale scores are totaled to reveal the PD and CD. According to another study,²⁰ the instrument possesses good reliability with an internal consistency of 0.96 or greater for both the CD and PD domains. The alpha reliability coefficients ranged from 0.78 to 0.88 for the CD subscales and 0.75 to 0.87 for the PD subscales. In addition, the test-retest coefficients for this instrument ranged from 0.55 to 0.82 for the CD subscales and 0.69 to 0.91 for the PD subscales.²⁰

Procedure and data analysis. A quantitative approach was employed. Prior to the study, emails were sent to respective autism centers to request permission to distribute the PSI-4 questionnaires to their clients, the parents of children with ASD. After receiving approval from the centers, the questionnaires were distributed to the centers to hand out to the parents. The parents were allowed to complete the questionnaire at home and were requested to return them a week later to give them optimal time to complete it. Some of the parents were contacted directly, and the questionnaire sent to them to be completed at home because these parents were working or not available. Allowing these parents to complete the questionnaire at home was the only rational solution to obtain the data from them. After the questionnaire collection phase was completed, the data were keyed into the Statistical Package for the Social Sciences (SPSS) software to be analyzed. A descriptive analysis was conducted on each CD and PD subscale to identify the highest t-scores. T-scores were used as they allow score comparison across subscales.²⁰ Finally, a paired sample t-test was performed on the CD and PD scores to test for any mean difference between these two variables.

Results

The results of the PD and CD subscales of the PSI-4 were analyzed. The mean and standard deviation of the CD subscales are presented in Table 1. The results revealed the respondents scored the highest for the distractibility/hyperactivity subscale (61.81 ± 8.41), followed by the mood (61.57 ± 11.92), and adaptability (57.93 ± 9.57) subscales.

The mean and standard deviation of the PD subscales are displayed in Table 1. The results showed that the

Table 1. Mean and standard deviation of the PSI-4 subscale (child domain and parent domain)

Subscales	Mean	SD
Child Domain		
Distractibility/ Hyperactivity	61.81 ±	8.41
Adaptability	57.93 ±	9.57
Acceptability	54.02 ±	9.22
Reinforces Parent	57.20 ±	10.73
Demandingness	52.20 ±	10.67
Mood	61.57 ±	11.92
Parent Domain		
Sense of Competence	55.81 ±	9.36
Social Isolation	56.15 ±	10.13
Attachment	57.11 ±	8.54
Parent Health	54.74 ±	10.20
Restriction of Role	56.46 ±	11.44
Depression	61.13 ±	10.15
Relationship with Spouse	52.28 ±	11.57

Table 2. Paired sample T-test result for child domain and parent domain

Subscale	Mean	SD	t	p
Child Domain	59.20	7.74	1.669	0.094
Parent Domain	57.50	9.21		

depression subscale had the highest mean (61.13 ± 10.15), followed by the attachment (57.11 ± 8.54), and restriction of role (56.46 ± 11.44) subscales.

A paired sample t-test was performed on the CD and PD subscales to identify any mean difference between them. The results of the test are shown in Table 2. The results revealed no significant difference between the CD (59.2 ± 7.74) and PD (57.5 ± 9.21), t (53) = 1.669, with p-value of 0.094.

Discussion

The purpose of this study was to examine the highest scores of the PSI-4 to identify the main sources of parenting stress. The paired t-test results suggested that there was no mean difference between the CD and PD. This implies that the sources of stress that originate from the children’s characteristics and parents’ characteristics are equal despite the fact that the CD had a higher mean than the PD. Because both the children’s characteristics and parents’ characteristics contribute to an equal amount of parental stress, future intervention, and prevention strategies need to consider both aspects.

Many studies have revealed the influence of children’s characteristics on parental stress.⁹⁻¹⁴ Other researchers²¹ found that the severity of the ASD symptoms in children was positively associated with both parents’ parental stress. In other words, parents of children with severe ASD symptoms have higher levels of stress. The results of this study have helped to identify child characteristics that cause their parents’ stress. Distractibility/hyperactivity contributes the most to stress in parents. Distractibility/hyperactivity refers to the behavioral aspects that indicate symptoms of attention deficit hyperactivity disorder (ADHD). As noted previously, issues related to children’s behavior are one of the greatest challenges that parents encounter.^{11,12} Revealed that parents of children with both ASD and ADHD symptoms had more prominent depressive symptoms.²² Although ASD and ADHD are two different neurodevelopmental disorders, they have a high comorbidity rate in which each disorder may increase the severity of the other disorder.²³ In other words, a child with ASD who also exhibits ADHD symptoms may have a more severe condition. Noted the combination of ASD and ADHD symptoms decreases performance on inhibitory control tasks and adaptive functioning.²⁴ This explains the high amount of parental stress that emanated from distractibility/hyperactivity in this study.

The results of the PD subscales revealed that parents scored the highest for the depression subscale. This subscale assesses the dissatisfaction with the self in relation to their parenting roles and life’s experiences. A high score on this subscale does not reveal clinical depression symptoms, but rather feelings of guilt and unhappiness.²⁰ This is consistent with previous findings,⁷ which have revealed that parents of children with ASD show signs of clinical disturbance, which can also include negative feelings. As noted previously, resilience is correlated with stress in parents.¹⁵ In relation to the current study, it may suggest that the parents lack resilience and thus, they are more vulnerable to depressive feelings. However, the study could not further explain the stress that emanates from parents’ characteristics because only a limited number of studies have examined this aspect. Most studies conducted on parenting stress have focused on factors related to the child instead of the parents themselves. Hence, future studies are recommended to explore this issue in greater depth.

This study has a number of limitations. First, the small number of respondents may have influenced the results. The literature has revealed that most studies of parents of children with ASD only had a small number of participants.^{6,7,25} The parents’ lack of demographic data as a result of missing data is another limitation. This may be the result of allowing the parents to complete the questionnaire at home. This may also have had an adverse effect on the participants’ response rate. However, as explained previously, this was the most convenient

method to collect data as the respondents were unable to complete the questionnaire at the same time because of various commitments.

The present study has only examined parenting stress factors by employing descriptive analysis. It is recommended that future studies use inferential analysis so that cause-and-effect factors can be determined. Moreover, a quantitative approach was adopted to collect the data, which may have limited the identification of various factors that cause parenting stress. It is recommended that future studies consider employing mixed methods in which both quantitative and qualitative approaches are used to obtain richer information related to parenting stress. Accordingly, more effective stress management strategies and prevention programs may result. Furthermore, it is recommended that future quantitative studies use different types of instruments to measure the sources of parenting stress instead of just one. It is also recommended that future studies further explore the sources of parenting stress from parents' characteristics because most studies have concentrated on parenting stress that has emanated from their children's characteristics.

Conclusion

The results of this present study provide a clear direction for future intervention and prevention programs. The results revealed that both child and parent characteristics contribute equally to parental stress. Therefore, strategies to handle parental stress should consider both of these aspects equally. It was also found that distractibility/hyperactivity and depression were most prevalent in the CD and PD, respectively. Therefore, future intervention and prevention strategies should place more emphasis on these aspects without disregarding the other aspects assessed in each domain.

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Conflict of Interest Statement

The authors declare that they have no competing interests.

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