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ORIGINAL ARTICLE

Stress and psychological wellbeing among parents of children with autism spectrum disorder

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Abstract

Objective: To investigate the prevalence of parental stress and psychological wellbeing among parents with autistic children and their associations with dimensions of support system. *Methods:* This is a preliminary cross sectional study which randomly selected parents with clinically diagnosed autistic children. Those parents who attended psycho-education session on management of autistic children at Health Psychology Unit were randomly selected to enroll in the study. Psychological wellbeing, parental stress and dimensions of support system were assessed by using General Health Questionnaire (GHQ-28), Parenting Stress Index (PSI) and Provision Social Relation (PSR), respectively. *Results:* Of the total 52 parents with autistic child (34 female and 18 male), about 90.4% of parents had significant parenting stress, and 53.8% of parents showed clinical disturbance in psychological wellbeing. Gender ($t=1.67$, $p=0.02$) and occupation ($F=4.78$, $p=0.01$) showed statistically significant association with psychological wellbeing. No association found between other socio-demographic factors, parental stress and psychological wellbeing with dimensions of support system among parents with autistic child. *Conclusion:* Parents with autistic children have high prevalence of stress and psychological disturbances. Interactions of various factors need to be acknowledged and considered in order to reduce the burden of parents with autistic children.

Keywords: *parental stress, psychological wellbeing, autism, social support*

Introduction

There is strong evidence from research literature that parents of autistic children face a high level of stress. Given that parenting a child with autism is uniquely challenging and can be extremely stressful [1, 2, 3], understanding factors that contribute to parental well-being is of utmost importance. In comparison to parents of typically developing children, parents raising children with disabilities experience more parenting stress [4] and have higher rates of depression [1,5]. Even among parents raising

children with disabilities, parents of children with autism report significantly higher levels of stress [1, 2] and are more likely to experience depression [6,7].

Another study [8] has also indicated that parenting an autistic child may have an impact on the parents' health and well-being. Given the multiple roles demand that working and nonworking mother experience [9, 10, 11], mothers with typically developing children or children with special needs unrelated to autism may also experience this

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global sense of guilt tied to a belief of not doing enough for their children. Many parents of children with pervasive developmental disorders reported experienced feelings of intense anger, guilt, depression or anxiety most of the time [12]. Apart from that, having a child with autism can drain a family's resources due to expenses such as evaluations, home programs, and various therapies [13]. Other than that, the source of stress may be a matter of strained emotional relationships, necessarily limited family activities and reduced career aspirations, reduced opportunities for social and leisure pursuits, problems of fitting to treatment demands and appointments, educational disadvantages, and the ongoing difficulty in coming to terms with the disability [14].

However, study reported that social support has differentiated high and low stressed mothers of children with autism [15]. Mothers who perceive social support as more accessible report fewer stress-related problems and depressive symptoms [16]. Apart from that, parents who receive social support relate better emotionally to their children and engage in more positive interactions with them [17].

Therefore, it is important for parents to have a good support system [18, 19]. With the lack of social support, the outcomes can be negative and disturbed the psychological wellbeing of the parents such as depression, social isolation and spousal relationship difficulties [20]. According to Holroyd and McArthur in examining mother's report of stress when raising children with autism, Down's syndrome and children being seen in an outpatient psychiatric clinic, they found that mothers with autistic children commonly engage in poor health, depressed mood, inordinate time demands and pessimisms in relation to their children's future [21].

Methods

This was a preliminary cross sectional

study which examined the parental stress, psychological wellbeing and dimensions of support system of parents with autistic children. The children were initially assessed by using Gilliam Autistic Rating Scale (GARS) and diagnosed with Autistic Spectrum Disorders by experience child psychologists in Health Psychology Unit, Universiti Kebangsaan Malaysia (UKM) following Diagnostic and Statistical Manual of Mental Disorder (DSM IV) criteria. The GARS has four subtests with 14 items for each: i) stereotype behaviors, ii) communications, iii) social interactions and iv) developmental disturbance. The GARS demonstrates a strong internal consistency ranged between 0.88 and 0.96 and item validity between 0.72 and 0.88.

The parents of these children who attended psycho-education sessions on management of autistic children in February 2006 were randomly selected. The subjects were given patient information sheet and explained about the study. The participation was on voluntary basis. Those parents aged between 30 and 60 years old, who had children with autism spectrum disorders aged between 2 and 12 years old were enrolled in this study. Exclusion criteria included parents with any history of psychological disorders such as depression or anxiety disorders and having any general medical conditions that might affect the study.

The parents were asked to assess their perceived severity of their children's autistic symptoms using a severity score of high, above average, average, below average and low. The psychological wellbeing, parental stress and dimensions of support system were assessed using General Health Questionnaire (GHQ-28), Parenting Stress Index (PSI) and Provision Social Relation (PSR), respectively. The GHQ-28 had been used widely, and the test-retest reliability for GHQ-28 ranges between 0.51 and 0.90 with the internal consistency of .78 [22] It has been validated in Malaysia by Abdul Hamid and Hatta in 1996 [23]. The PSI

contains 36 items and can be divided into 3 subscales: Parental Distress (Pd), Parent-Child Dysfunction Interaction (Pcdi) and Difficult Child (Dc). The PSI has been transculturally validated [24,25] and the reliability coefficients for the 2 domains and the Total Score Scales were 0.90 or greater. Whereas the PSR is a 15-item instrument designed to measure components of social support (attachment, social integration, reassurance of worth, reliable alliance and guidance), and it has good internal consistency, with alphas ranging between 0.75 and 0.87.

The data was analyzed by using the Statistical Package for Social Studies (SPSS) Version 11.5. Descriptive analysis was used to measure the parental stress levels and psychological well-being among parents with autistic children. As for the relationship between parental stress, psychological wellbeing and dimensions of support system received by parents with autistic children were evaluated by using correlation. Regression analyses on the other hand predicted the outcomes of social support received by the parents (independent variable) based on stress level and psychological wellbeing of the parent (independent variable). Student-t test was employed to see the differences between parental stress and psychological wellbeing between gender, where else ANOVA was used to see the differences in occupation.

Results

Prevalence of socio-demographic data, parental stress and psychological well being

A total of 52 parents with autistic children consented to participate in this study. Table 1 presents socio-demographic and psychosocial profiles of the subjects. Out of 52 subjects, 34 (65.4%) subjects were female and 18 (34.6%) were male. The age group was evenly distributed with 24 subjects (46.2%) falls within 21 to 30 years old and 28 subjects (53.8%) falls within 31 to 40 years old. As for ethnic groups, 65.4% of

the subjects were bumiputras and 34.6% were non-bumiputras. Of the 52 subjects, 94.2% come from urban area and 5.8% come from rural area. Among them, 34 (65.4%) subjects completed a tertiary educational level and 18 (34.6%) completed a secondary educational level. Majority of the subjects worked with private sectors ($n = 31$), followed by government sector ($n = 14$) and housewife ($n = 7$). Fifty percent of the subjects earned above RM2500, 9.6% earned between RM1600 RM2500, 23.1% earned between RM1000 and RM1500 and 17.3% earned below RM1000. In relation to the objectives of this study, most subjects did not involve with a support group ($n = 28$) and only 24 involved with support groups.

In terms of psychological well being and parental stress, high proportion of parents i.e. 90.4% ($n = 47$) of them were stressed up and more than half 53.8% ($n = 28$) of them showed poor psychological well being (Table 2).

Severity of autistic symptoms

More than half of the parents perceived that their child has average to high severity of autistic symptoms. Of the 52 subjects, 29 (55.8%) subjects perceived that their child's symptoms were within the average level, 15 (28.8%) subjects perceived it at below average level, 4 (7.7%) subjects perceived it at high level, 3 (5.8%) subjects perceived it at low level and only 1 (1.9%) subject perceived that his/her child's symptoms above the average level (Table 3).

Factors contributing to parental stress and psychological disturbances

Investigation on the associations between socio-demographic data with psychological well being and parental stress, revealed a significant difference between gender and psychological wellbeing of the parents with autistic child ($t = 1.67$, $p = 0.02$) but no significant association found between gender and with parental stress

Table 1: Socio-demographic characteristics of the respondents

Variables		Frequency (n)	Percentage (%)
Gender	Male	18	34.6
	Female	34	65.4
Age	21-30	24	46.2
	31-40	28	53.8
Ethnic group	Bumiputras	34	65.4
	Non-bumiputras	18	34.6
Housing area	Urban	49	94.2
	Rural	3	5.8
Occupation	Housewife	7	13.5
	Private Sectors	31	59.6
	Government	14	26.9
Total household income	Below Rm1000	9	17.3
	Rm1000-Rm1500	12	23.1
	Rm1600-Rm2500	5	9.6
	Above Rm2500	26	50.0
Level of Education	Primary	0	0.0
	Secondary	18	34.6
	Tertiary	34	65.4
Support group	Yes	24	46.2
	No	28	53.8

Table 2: Prevalent of the psychological well being and parental stress among parents of autistic children

Variables	Significance	
	N = 52	(%)
Psychological well being (GHQ \geq 3)	28	53.8
Parental stress (PSI \geq 69)	47	90.4
• Parental distress (Pd \geq 25)	37	71.2
• Parent-child dysfunctional interaction (Pcdi \geq 19)	52	100.0
• Difficult child (Dc \geq 25)	46	88.5

Table 3: The severity of autistic symptoms perceived by the parent of autistic children

Variables	Frequency (n)	Percentage (%)
High	4	7.7
Above average	1	1.9
Average	29	55.8
Below average	15	28.8
Low	3	5.8

gender and parental stress.

Moreover there was a significant difference between occupation and psychological wellbeing of the parents with autistic children ($F=4.78, p=0.01$). However, there was no significant difference between the levels of parental stress and occupation.

No significant association was found between other socio-demographic factors (i.e. parental age, ethnic group, housing area, occupation, total household income and education level), parental stress, psychological wellbeing and dimensions of support system received by parents with autistic children.

There was no significant correlation between severity of autistic symptoms perceived by the parents and parental stress, psychological wellbeing, and dimensions of support system received by parents with autistic children.

Moreover, comparing the factors that might contribute to the stress (Table 2), all of them ($n=52$) agreed that their stress was particularly contributed by parent-child dysfunctional interaction which focused on the degree to which the child was reinforcing to the parent and the degree to which the child met the parent's expectation. Apart from that, 46 (88.5%) subjects also agreed that their stress might be contributed by a difficult child factor, which represented behavior that children often engaged in that might make parenting easier or more difficult. This was followed by parental distress factor ($n = 37$), which measured the distress that parents felt about their parenting role in light of other personal stress.

Discussion

Our findings reveal that 90.4% of parents with autistic children have significant stress, and 53.8% of the parents show clinical disturbance in psychological wellbeing. These results confirm the earlier findings, which report that parents of children with

disabilities have more stress than parents of children without disabilities [26]. There is a call for further comprehensive study to explore their stress, and proper program should be applied to help them managing their stress. However, we did not find significant relationships between parental stress, psychological wellbeing, severity of autistic symptoms perceived by the parent and dimensions of support system received by parents with autistic children in this study. Possible explanations for these associations include the coping strategies [27, 28] and self efficacy of the parents [29, 30, and 31]

In this study also, the results revealed that mother report greater impact on psychological wellbeing compared to father. This finding is supported by earlier findings of Abbeduto and colleagues, who reported that mothers of youths with Down Syndrome were less pessimistic about their children's future and reported greater reciprocated closeness with their child than do mothers of the youths with fragile X syndrome (FXS) or autism [4]. Mothers of autism spectrum disorder children also reported significantly greater depression [32, 33], greater social isolation [34] and a lower level of marital intimacy when compared to mothers of normal children and mothers of Down's syndrome children [35].

Regarding the differences between maternal and paternal stress found in families of children with disabilities, research has produced inconsistent results. Some studies found that mothers reported higher levels of intrapersonal stress as well as stress relating to the children's characteristics [36, 37]. As for father, higher stress was related to low acceptability of the child and low family harmony. Acceptability of the children's characteristics had a significant impact on family harmony and parent stress. Contrary, in this study, maternal and paternal PSI stress scores did not differ significantly. This result was similar to that of a

study on parents of elementary-school-aged children with disabilities [38]. In their study, they found that fathers and mothers experienced similar levels of stress. This may indicate cultural shifts in middle class families, such that fathers now take more responsibility for the direct care and nurturing of their children [39].

Inverse relationships between socioeconomic status (SES) and health outcomes are well documented [40-42]. In these studies, in comparing parental stress and psychological wellbeing with occupation, type of occupation did not have an impact on parental stress. However, it did have an impact on parental wellbeing. In the literature on job design, occupational stress and ergonomics, various aspects of work influence workers' health and well-being in positive or negative ways [43]. Apart from that, for mothers, SES has a significant inverse relationship to stress and family harmony. Higher SES has previously been found to mediate stress for mothers [44, 45], who seem to be in a better position to meet the overall needs of children with disability. Given the multiple role demands that working and nonworking mothers experience [10, 11], mothers with typically developing children or children with special needs unrelated to autism may also experience this global sense of guilt tied to a belief of not doing enough for their children.

Provision of social support on the other hand is a positive strategy that can reduce the effect of a child's disability on the family. A study demonstrated that a lack of social support could lead parents withdraw from larger communities because of the negative characteristics associated with their children's ability [2]. However, in contrast to our hypothesis, the results showed that social support did not influence parental stress or psychological wellbeing. An unconstructive trend was also noted through the study done by Konstantareas and Homatidis whereby mother's

stress scores were negatively correlated with both the number and degree of supports [46]. This finding is further supported by Quittner's study [47]. In this study, she found that neither socioeconomic status nor social support had any direct effects on father's stress. In her analyses, Quittner found that the relationship between parental stress and psychological distress did not vary as a function of level of social support. In contrast, social support did not moderate or alter the strength or direction of the relationship between parental stress and psychological distress.

Limitations and recommendations

Various factors contributing to parental stress and their psychological wellbeing, parental background of adverse life events, family problems, financial problems, etc., might affect their stress. Moreover there are other co-morbidities such as learning disabilities, attention deficit hyperactive disorder, medical problems, etc., that the authors did not exclude in recruiting the subjects. By excluding those co-morbidities, it may not reflect the natural aspects of the illness, and it may result in losing many subjects. Sampling bias did occur because we recruited samples from a tertiary center providing care for autism. As a preliminary study, only small sample recruited, we hope to continue with larger sample and more comprehensive studies to delve further the complex factors that contribute to parental stress. We suggest a proper program to reduce and ease the burden of parents particularly mothers with autistic children.

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