

The Influences of Parenting Stress, Children Behavioral Problems and Children Quality of Life on Depression Symptoms Among Parents of Children with Autism: Preliminary Findings

(Pengaruh Tekanan Keibubapaan, Masalah Tingkah Laku Anak dan Kualiti Kehidupan Kanak-kanak dan Gejala Kemurungan dalam Kalangan Ibu bapa Anak dengan Autisme: Dapatan Awal)

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ABSTRACT

Taking care of children with Autism Spectrum Disorder (ASD) could be a demanding task for parents. Consequently, parents of children with ASD may experience parenting stress and depression symptoms. This study examined parenting stress and depression symptoms among parents of children and adolescents with ASD. This study also examined the role of child characteristics (e.g., age, child quality of life and problem behavior) on parenting stress and depression symptoms and the effect of parenting stress on parental depression. A total of 78 parents were examined using a questionnaire survey. The result indicated that parents caring a younger age group of children with ASD have higher levels of depression symptoms compared to parents caring for older group of children with ASD. The result also revealed a significant difference in level of depression symptoms between parents with higher levels of parenting stress and parents with lower parenting stress. Only the children age significantly predicts depression symptoms in parents of children with ASD. This indicates that children age is potential to affect mental health among parents of children with ASD.

Keywords: Parenting stress; children quality of life; depression symptoms; parents of children with autism

ABSTRAK

Tugas ibu bapa menjaga kanak-kanak yang didiagnosis dengan Kecelaruhan Autisme Spektrum (ASD) adalah tugas yang mencabar. Kesannya, ibu bapa kepada anak-anak ASD mungkin mengalami tekanan keibubapaan dan gejala kemurungan. Kajian ini mengkaji tekanan keibubapaan dan gejala kemurungan dalam kalangan ibu bapa kanak-kanak dan remaja ASD. Kajian ini juga mengkaji peranan ciri-ciri kanak-kanak (contohnya, umur, kualiti kehidupan kanak-kanak dan tingkah laku bermasalah) ke atas tekanan keibubapaan dan gejala kemurungan dan kesan tekanan keibubapaan ke atas kemurungan. Sejumlah 78 ibu bapa mengambil bahagian dalam kajian yang menggunakan kaedah soal selidik ini. Dapatan kajian menunjukkan bahawa ibu bapa yang menjaga anak lelaki ASD yang lebih muda mempunyai tahap gejala kemurungan yang lebih tinggi berbanding ibu bapa yang menjaga anak-anak ASD yang lebih tua. Dapatan kajian juga menunjukkan perbezaan yang signifikan dalam tahap gejala kemurungan antara ibu bapa dengan tahap tekanan keibubapaan yang lebih tinggi dan ibu bapa dengan tekanan keibubapaan yang lebih rendah. Hanya umur kanak-kanak yang meramalkan gejala kemurungan pada ibu bapa kanak-kanak ASD secara signifikan. Hal ini menunjukkan bahawa umur kanak-kanak berpotensi untuk mempengaruhi kesihatan mental antara ibu bapa kanak-kanak ASD.

Kata kunci: Tekanan keibubapaan; kualiti hidup kanak-kanak; gejala kemurungan; ibu bapa kanak-kanak dengan autisme

INTRODUCTION

Parents play a significant role in a child's development and growth. Parent's experience of stress is frequently identified as a main issue for families with children with Autism Spectrum Disorder (ASD). Children with ASD have a persistent deficit in social communication and social interaction across various contexts, restricted, repetitive patterns of behavior, currently or by history. Three major domains under social communication and social interaction are deficits in social-emotional reciprocity, deficits in nonverbal communicative behaviors used for social interaction, and deficits in developing, maintaining,

and understanding relationship (American Psychiatric Association 2013).

Since the numbers of children diagnosed with autism are increasing in Malaysia, it is estimated that a greater number of parents of children with autism will have to deal with stress and additional difficulties. It is essential for service providers and professionals to understand the stressors that parents experience while raising children with ASD. Consequently, raising a child with autism could be stressful for some parents. Research indicated that parents of children with autism tend to experience a higher level of stress compared to parents of children with other disabilities (Baker-Ericzen, Brookman-Fraze & Stahmer

2005; Estes et al. 2009; Wachtel & Carter 2008). Parenting stress may be present across children's developmental ages, such as from toddlerhood through middle childhood, adolescence and into adulthood (Myers, Mackintosh & Goin-Kochel 2009).

Numerous studies have shown that parents of children with developmental disabilities reported significantly high level of stress compared to parents of normally developing children (Pisula 2011), including for parents of children with ASD (Davis & Carter 2008; Johnson et al. 2011; Nikmat 2008; Pisula 2007; Pisula 2011). The heightened stress levels are associated with the challenges they face in fulfilling their core responsibility to care for their children (Pisula 2011). There are numerous factors contributing to parental stress. These factors can be divided into three domains such as children characteristics, parent characteristics and family characteristic as well as other external factors such as social perspective and social support (Estes et al. 2009). The characteristics of the child include child's problem behavior and the age of the child (Rezendes & Scarpa 2011). Children with ASD have delayed and deficits in several areas of developmental compared to typically developed children. They tend to have behavior problems such as throwing tantrum, harming self, aggression, self stimulation, destructive behavior and harming others (Pisula 2011). Some parents may find their children very difficult to handle due to their characteristics while other parents may have limited knowledge on appropriate techniques in managing their children (Dawson & Burner 2011).

The lack of professional support is another aspect that plays a role in the elevated stress and other psychological issues among parents of children with ASD (Serrata 2012). Although the awareness regarding autism is on the rise in Malaysia, the understanding of the ASD is still poor and there is social stigma associated with it (Azizan 2008). In Malaysia, there is a shortage of health specialists such as psychiatrist, psychologist, physiotherapist and speech therapist (Azizan 2008). The shortage has resulted in long waiting lists of patients to consult these specialists and the average frequency of a child having therapy has reduced to one in three months especially in government hospitals (Azizan 2008). Reduced in the number of therapy may lead to reduced amount of improvement in the child's abilities hence resulting frustration and stress among parents (Pisula 2011). In addition, the focus on parents' perceived child quality of life (QoL) is another research interest in ASD literature. The positive relationship between perceived child QoL and negative impact on parent is supported by research by Kazak and Barakat (1997). The finding showed that poorer perceived child QoL, contributed to greater emotional distress among parents caring for children with severe medical condition.

As Malaysian society begins to discuss disability issues and mental health in a more open manner and families are actively seeking out social support beyond family members, it would be worthy to examine the nature

and extent of parenting stress and depression symptoms among parents of children with ASD. Therefore, the main objectives of this study are to examine the differences in parenting stress and depression symptoms among parents of children and adolescents with ASD, and to examine the predicting role of age, perceived child quality of life and problem behavior on parenting stress and depression symptoms among parent of children with ASD and effect of parenting stress on parental depression. This may enable the society to assist parents of children with ASD to function better and provide a clearer view on issues related to parenting among parents of children with ASD. Nevertheless, appropriate social support which meets the parents' needs can be provided in the future.

METHODOLOGY

PARTICIPANTS

This research utilizes a cross-sectional design, where data was collected at a single time point. The participants in this study were 78 parents, consisting of 32 fathers and 46 mothers who reside in Klang Valley and have children with ASD between ages of 2 and 18 years old. The participants were recruited from a Parents NGO's and a few Autisme centers. A total of 110 copies of explanatory statements and questionnaires were distributed to potential participants who met the criteria and consented to participate in the study. Eighty (80) questionnaire sets were returned, resulting in a 72.73% response rate. Among the 80 responses, 78 (97.5%) were included in the data analyses and 2 were excluded due to incomplete response.

The inclusion criteria for the participants are (a) the children were officially diagnosed as having ASD by clinicians; (b) the chronological age of the children is between 2 years to 18 years old, and (c) parents are able to communicate and read in Malay or English language. The exclusion criterion is children with ASD whose main caretakers are their non-biological parents, grandparents, maternal or paternal relatives are excluded even though they fulfill the above inclusion criteria.

INSTRUMENTS

The following measures were used to assess parenting stress, depression symptoms, parent perceived quality of life and child's behavioral problems.

PARENTING STRESS INDEX-SHORT FORM (PSI/SF)

The Parenting Stress Index-Short Form (PSI/SF; Abidin 1995) is an instrument developed to assess the impact of parenting role on an individual's stress level. The questionnaire has 36-items with 3 subscales: Parental Distress (PD), Parent-Child Dysfunctional Interaction (P-CDI) and Difficult Child (DC). Child and Parent domains combine to form Total Stress Scale. The reported

reliabilities of .79 for PD, .80 for P-CDI, .78 for DC, and .90 for total stress (Roggman et al. 1994). The correlation between the PSI/SF and full-length PSI are .94 for total stress, .92 for PD, .87 for DC, and .73 for P-CDI. The PSI has been widely used in Malaysia in research involving children with mental retardation (Ong et al. 1999), children with depression (Tan & Rey 2005), and children with ASD (Nikmat 2008). The reliability for the present study is 0.93.

BECK DEPRESSION INVENTORY (BDI)

The Beck Depression Inventory (BDI) test is a 21 item self-report using a four-point scale ranging from 0 (symptom not present) to 3 (symptom very intense). The instrument takes approximately 5 to 10 minutes to complete. High concurrent validity ratings are given between the BDI and other depression instruments as the Hamilton Depression Scale; 0.77 correlation rating was calculated when compared with inventory and psychiatric ratings. The BDI also showed high construct validity with the medical symptoms it measures. The BDI-II positively correlated with the Hamilton Depression Rating Scale, $r = 0.71$, had a one-week test-retest reliability of $r = 0.93$ and an internal consistency $\alpha = 0.91$. The validity of BDI-II Malay was satisfactory and the internal consistency (Cronbach's α) ranging from = 0.71 to 0.91 (Mukhtar & Tian 2008). The reliability for the present study is 0.83.

CHILD BEHAVIOR CHECKLIST (CBCL)

The Child Behavior Checklist (CBCL; Achenbach 2001) is a parent-report questionnaire in which the child was rated on various behavioral and emotional problems. It assessed internalizing (i.e., anxious, depressive, and over controlled) and externalizing (i.e., aggressive, hyperactive, noncompliant, and under controlled) behaviors. Internal consistency for the Child Behavior Checklist scales used was good to excellent ranging from .72 to .96 (Achenbach 2001). In Malaysia, the CBCL has been used in different kinds of research involving children (Normah et al. 1999; Shahla et al. 2011; Teoh 2010). The reliability for the present study is 0.85.

PEDIATRIC QUALITY OF LIFE INVENTORY (PEDSQL)

The Pediatric Quality of Life Inventory (PedsQL; Varni et al. 2001) is a 23-items parent questionnaire developed to assess perceived child quality of life of occurrence problems in the past one month. There are four domains of functioning assess by PedsQL which are physical functioning, emotional functioning, social functioning and school functioning. Each item can be answered on a 5 point scale ranging from 0 (never) to 4 (almost always). Good reliability and validity had been reported for total score of PedsQL (Cronbach's $\alpha = 0.89$) (Varni et al. 2001) and (Cronbach's $\alpha = 0.91$) (McStay et al.

2014). High internal consistency also was obtained in the study by McStay et al. (2014) for both ASD (Cronbach's $\alpha = 0.83$) and TD (Cronbach's $\alpha = 0.91$) groups. In Malaysia, the PedsQL has been used in different kinds of research involving different children and adolescent population (Ab Rahman et al. 2011; Ainuddin et al. 2015). The reliability for the present study is 0.83.

The readability of the Malay version set was accepted by the parents. The Malay version of BDI (Mukhtar & Oei, 2008) had been validated. In this questionnaire set only PedsQL, PSI-SF and CBCL were back translated. The final set of the Questionnaires which comprises of all measure (Parenting Stress Index-Short Form (PSI-SF), Paediatric Quality of Life Inventory (PedsQL), Child Behavior Checklist (CBCL), and Beck Depression Inventory (BDI) were validated with the parents. A pre-test to identify the time needed to complete the questionnaire set has been done with parents. The approximate time to complete the questionnaire set is around 30 to 40 minutes.

PROCEDURES

The questionnaire consisted of two parts. Part A comprises of information sheet regarding the study, consent form, and demographic sheet. Part B comprises the PSISF, BDI-II, CBCL and PedsQL. The participants were informed briefly about the study and the aims of carrying out the study by the researcher. The ethical approval from the UKM's ethical board was obtained before carrying out this study.

As this research deals with parenting stress and depression symptoms, it is important to ensure the welfare and referral needs of the participants. For the purpose of contacting participants, the participant's identification number was used (in the consent form and questionnaire) and participant's contact details (i.e., email address and telephone number) were collected in the consent form. The participants were informed about (1) the purpose of identification number and the collection of contact details, and (2) were also be informed that only researchers have access to the information accordingly. The participants were contacted if they show high level of parenting stress or depression symptoms as measured by Parenting Stress Index – short form (PSI-SF) and Beck Depression Inventory (BDI). Parents, who obtain a total stress score above a raw score of 90 on PSI-SF, were advised to seek professional assistance and the necessary referrals. For BDI, a persistent score of 17 or above indicates the needs of the parents to seek for professional assistance and the necessary referrals. Besides that, the dissemination of information sheet about parenting stress, depression symptoms and available psychological services in Klang Valley and Selangor to all participants were carried out during the recruitment and data collection. The psychoeducation were offered to the participants to give necessary information about parenting stress and depression symptoms during the data collection process. The researchers were present to facilitate participants completing the questionnaire and

responding to participant's inquiries. The recruitment of the participants has also been done by contacting the parents via emails to explain about the study and to get their consent to participate in the research. The questionnaires were also emailed to the parents who are unable to come for the appointment but were interested to be participants (after their consent).

Besides that, appointments were also arranged with participants at the respective centres (or place of their convenience) to fill in the questionnaires. Parents caring for children with ASD group complete all the questionnaires. After the data collection was completed, the data was compiled into the computerized statistic program, Statistical Package for the Social Sciences version 20 (SPSS ver. 20). Each variable was screened using the descriptive and frequency statistics as data cleaning purposes.

STATISTICAL ANALYSIS

Demographic details such as age, gender, ethnicity, marital status, religion, education level, employment status, SES, number of children in the home, as well as the information about the child such as age, gender, and autism diagnosis were analyzed descriptively to examine the distribution in the study group. A series of t-test were carried out to examine firstly the difference in level of depression parents caring younger age group with ASD (and parents caring older age group children with ASD). The second t-test examined the difference in level of depression symptoms between parents with higher parenting stress and parents with lower parenting stress. A series of multiple regression analysis were performed to examine the predicting role of child age, perceived child quality of life and problem behavior on parenting stress and depression symptoms among parents of children with ASD.

RESULTS

The descriptive findings show that majority of the parents are females ($n = 46$; 59.0%), age 35-35 years old ($n = 35$; 44.9%), Malays ethnicity ($n = 67$; 85.9%), degree and diploma holders ($n = 60$; 76.9%), with monthly household income RM3001-RM5000 ($n = 25$; 32.1%) and with 2 children ($n = 44$; 56.4%).

Table 1 summarizes the descriptive statistics regarding the characteristics for the parents who participated in the study.

With regards to children's characteristics, majority of the children are males ($n = 67$; 85.9%), aged group between 13-18 years old ($n = 22$; 28.2%), children who have not started their education ($n = 27$; 34.6%) and in secondary schools ($n = 20$; 25.6%) and majority have been diagnosed with ASD between period of 1-3 years ($n = 50$; 64.1%). Table 2 summarizes the characteristics of the children with ASD.

TABLE 1. Demographic characteristics for the parents (N = 78)

	Frequency	Percent (%)
Gender		
Male	32	41.0
Female	46	59.0
Age (Years)		
30 -35	35	44.9
36-40	14	17.9
41-45	24	30.8
46 and above	5	6.4
Race		
Malay	67	85.9
Chinese	3	3.8
Indian	8	10.3
Education Level		
SPM	6	7.7
STPM	2	2.6
Diploma	31	39.7
Degree	29	37.2
Master	10	12.8
Employment Status		
Civil service worker	12	15.4
Private sector worker	41	52.6
Self-employed	14	17.9
Unemployed	11	14.1
Monthly Household Income		
< RM1,000.00	6	7.7
RM1,000.00-RM3,000.00	20	25.6
RM3,001.00 to RM5,000.00	25	32.1
RM5,001.00 to RM8,000.00	10	12.8
RM8,001.00 to RM10,000.00	7	9.0
> RM10,000.00	10	12.8
No. of Children		
1	15	19.2
2	44	56.4
3	11	14.1
4	3	3.8
5	5	6.4

TABLE 2. Demographic characteristics of the children with ASD (N = 78)

	Frequency	Percent (%)
Gender		
Male	67	85.9
Female	11	14.1
Age (Years)		
3-4	14	17.9
5-7	31	39.7
8-12	11	14.1
13-18	22	28.2
Education Level		
Not Started	27	34.6
Pre-School	10	12.8
Primary School	16	20.5
Secondary School	20	25.6
Others	5	6.4
Period of child have been diagnosed with ASD (Years)		
1-3	50	64.1
4-6	5	6.4
7-9	3	3.8
10 and above	20	20

A series of t-test were carried out to examine firstly the difference in level of depression between parents of children with ASD (2 years -6 years old) and parents with children with ASD (7 years -17 years). The results showed that there was a significant difference in depression level between parents caring younger age group with ASD ($M = 9.00, SD = 7.48$) and parents caring older age group children with ASD ($M = 4.80, SD = 4.19$), ($t = 3.10, df = 76, p < .05$). Parents of younger age group with ASD have significantly higher level of depression compared to parents of older age group with ASD.

The second t-test examined the difference in level of depression symptoms between parents with higher parenting stress and parents with lower parenting stress. The t-test showed that there was a significant difference in depression level between parents with higher parenting

stress ($M = 9.46, SD = 7.73$) and parents with lower parenting stress ($M = 4.13, SD = 2.48$), ($t = 4.11, df = 76, p < .05$). Parents with higher level of parenting stress have significantly higher level of depression compared to parents with lower parenting stress.

In addition, a series of standard multiple regression analysis were used firstly to examine the role the child age, perceived child quality of life, internalising behavior and externalizing behavior in predicting parenting stress among the present sample. Results showed that that the child age, perceived child quality of life, internalising and externalising behavior accounted for a non-significant 4% of the variability in parenting stress among parents of children with ASD, $R^2 = 0.04$, adjusted $R^2 = -0.02$, $F(4,73) = 0.69, p = 0.61$. A summary of the standard multiple regression analyses reported in Table 3.

TABLE 3. Standard multiple regression predicting parenting stress

Variable	B [95%CI]	β	sr^2	t	p
Child Age	0.01 [-0.83,0.85]	0.01	0.01	0.02	0.98
Perceived child quality of life	0.01 [-0.25,0.26]	0.01	0.01	0.03	0.98
Internalising Behavior	0.07 [-0.30,0.44]	0.06	0.00	0.37	0.71
Externalising Behavior	0.31 [0.32,0.93]	0.15	0.01	0.99	0.33

Note. $N = 78$. CI = confidence interval
* $p < 0.05$. ** $p < 0.01$

The second standard multiple regression analysis was used to identify the role the child age, perceived child quality of life, internalising behavior and externalizing behavior predicting depression symptoms among parents

in the present sample. Results indicated that child age is the only significant predictor for depression symptoms. A summary of the standard multiple regression analyses is reported in Table 4.

TABLE 4. Standard multiple regression predicting depression symptoms

Variable	B [95%CI]	β	sr^2	t	p
Child Age	-0.36 [-0.65,-0.07]*	-0.28	0.07	-2.47	0.02
Perceived child quality of life	-0.03 [-0.12,0.06]	-0.07	0.01	-0.64	0.52
Internalising Behavior	0.01 [-0.12,0.13]	0.02	0.00	0.09	0.93
Externalising Behavior	0.13 [-0.09,0.34]	0.17	0.01	1.16	0.25

Note. $N = 78$. CI = confidence interval
* $p < 0.05$. ** $p < 0.01$

DISCUSSION AND CONCLUSION

The finding showed that there was a significant difference in depression level between parents caring younger age group with ASD and parents caring older age group children with ASD. This indicated that parents who had younger children with ASD experienced higher depression symptoms than parents who had older children with ASD. This could be partially attributed the difficulty for parents to provide care for their children when they are young and parents may continue to encounter different types of difficulties in rearing their children as the children phase into different developmental stage (Lee 2011). In addition,

there was a significant difference in depression level between parents with higher parenting stress and parents with lower parenting stress. This indicates that the higher level of parenting stress experienced by the parents, the higher depression symptoms also would be experienced by parents. This could be attributed to the daily stress of parenting a child with ASD was associated with quite severe anxiety and depression (Bitsika et al. 2013; Olsson & Hwang, 2001; Winter, Dawson, & Munson 2013). This finding is consistent with Weitlauf et al. (2012) where higher level of parenting stress in some extent, given impact on maternal depression.

In terms of predicting roles, only the child age is the significant predictor of depression symptoms among the parents of children with ASD compared to internalizing and externalizing behavior, and perceived child quality of life. The role of age of the children as one of the best predictors for depression symptoms among parents of children with ASD also have been reported by other studies (e.g., Dabrowska & Pisula 2010; Rezendes & Scarpa 2011; Weitlauf et al. 2012). In fact, parents are likely to deal with multiple facets of difficulties in accepting, understanding, and coping with the condition of their child during initial diagnose of ASD which may increase depression symptoms among parents of young children with ASD (Lee 2011). Osborne et al. (2008) also drew similar conclusion from their study. They found that caregiver depression of the children with ASD may be deleterious following the diagnosis, negatively impacting the day to day life of the entire family.

The results of non-significant predicting roles of other variables from regression analysis may partially indicate that parents may not perceive these factors to be due to their individual parenting styles or parenting skills. Such results could be speculated to indicate that parents do not blame themselves for their child's ASD, as they may attribute this to an external aetiology. The child's problem behaviors are characteristics that could be perceived by parents to be more likely attribute responsibility for their child's well-being and negative behavior. As a result, parent's worry about their role in the development of such behaviors and the child's wellbeing may increase their levels of parenting stress and depression symptoms. The non-significant predicting role of problem behavior in the regression model may suggest that implicit factors may be overlooked and considered less problematic (McStay et al. 2013).

Although this study includes a various range of children age groups, there are some limitations of the present study. For instance, there is no data about parents psychological functioning and parenting stress prior to child diagnosis. Besides that, the measurement of the child characteristics was reported by parents based on their perceptions of their child's behavior. It might be worthwhile to obtain a perspective from a third person such as child care givers or teachers. For future research, it could be potential to investigate the role of perceived control and public perceptions on parenting to explore the contributing and protective factors for parents of children with ASDs.

This study showed that the 'parents' of children with ASD experience parenting stress and depression symptoms. In terms of implication, it would be beneficial for these parents to receive information regarding how to raise and care for their children with autism. Furthermore, parents should be empowered to find appropriate supports for themselves. As parents are varied in their ability to access information, some parents may be in a better position to seek information for their children because they are more knowledgeable in looking for related information and better

able to take advantage of community and social support resources compared to other parents. Thus, parents may need specific supportive information depending on their needs (child's age and condition) and their child's current situations. To alleviate the level of parents' feeling of being depressed, it is possible to utilize parents support groups in relieving parents' emotional distress (Karst & Van Hecke, 2012; Laugeson et al. 2009).

In sum, the findings show that parents of younger age group with ASD have significantly higher level of depression compared to parents of older age group with ASD and Parent with higher level of parenting stress have significantly higher level of depression compared to parents with lower parenting stress. Besides that, only the child age significantly predicted the depression symptoms among the parents of children with ASD.

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