

THE LEVEL OF STRESS AMONG THE PARENTS OF CHILDREN WITH LEARNING DISABILITIES (LD) IN MALAYSIA

*Kamarulzaman Kamaruddin (kamarulzaman@fppm.upsi.edu.my)
Sultan Idris Education University*

Abstract

The main purpose of this study is to investigate the level of stress among the parents of children with learning disabilities (LD) attending the inclusive program in Malaysian primary schools. The data were solicited from Parental Stress Scale – a self report scale which involved 66 parents from in the district of Batang Padang in the state of Perak. The results showed that a total of 21 (19.1%) parents experiencing stress at low level and they are in the state of normal. Whilst 80 (72.7%) of the parents were suffering average level of stress (a score of 14 to 19) which is considered as mild. Furthermore, the analysis also showed that only 9 (8.2%) of them experienced high level of stress which is classified as severe. The findings have shown that parents of girl with disabilities was associated with higher stress. Parents engaged in more lucrative and prestigious occupations had more stress than parents engaged in less prestigious and lucrative occupations irrespective of their income. The findings also show there is no significant different in term of stress between the different ethnic groups (Malays, Chinese and Indian) and religious group (Muslims, Christians, Buddhists and Hindus) in Malaysia. Furthermore, religion was found to be a common coping resource used by the parents. This study implies that there are critical roles for parents in coping their emotional stress. Apart from this, all parties especially the government agencies such Special Education Department, Department of Social Welfare and etc should formulate programs to help the parents by providing services such counselling, interpersonal skills and early intervention.

Key words: stress, learning disabilities

Introduction

The presence of children with disabilities often shrouded by negative experience, difficulty and often accompanied by high levels of stress, because of the difficulties, the frustration, and the challenges faced by parents in their daily lives. The presence of this children within the family bring an unexpected demands and challenges to the parents, which they often are not prepared. Having a child with disabilities brings life-changing implications and long-lasting effects in the lives of the whole family (Simmerman, Blacher & Baker, 2001). Numerous studies conducted on this area shows that the parents of these children suffer from higher levels of stress compared to parents of children with typical development (Sanders & Morgan, 1997). The impact that children with disabilities have the family is not only linear and it does not lie in only one

direction. This effect is multidimensional, reciprocity, it affects the whole family system, it affects the relationship between family members (Breslau 1982; Breslau & Prabucki 1987). The welfare of siblings of the children may be affected by the stress experienced in the family (Rossiter and Sharpe 2001).

Past studies indicated that parents of disabled children with disabilities experience higher levels of emotional disorders compared to parents of children without disabilities. Many studies conducted in United States indicated that parents of disabled children experienced higher levels of stress (Sanders & Morgan 1997). Stress is a feeling of strain and pressure. Small amounts of stress may be desired, beneficial, and even healthy. Positive stress helps improve athletic performance. It also plays a factor in motivation, adaptation, and reaction to the environment. Excessive amounts of stress, however, may lead to bodily harm. Stress can increase the risk of strokes, heart attacks, ulcers, and mental illnesses.

Past studies also shown that there were reasonably consistently high rates of depressive and anxiety disorders; where 10-44% of people suffer from depression and anxiety (World Health Organization, 2001). *Depression* is a state of low mood and aversion to activity that can affect a person's thoughts, behaviour, feelings and sense of well-being. People with *depressed* mood can feel sad, anxious, empty, hopeless, helpless, worthless, guilty, irritable, ashamed or restless. Several studies indicated that the presence of a disabled child in the family also have led the parents suffering from depression and anxiety (Beckman, 1991; Dyson 1991). Mirza & Jenkins (2004) reported that there were high rates of both stress and anxiety disorders among the parent of disabled children. A study by Ahmad, Saeed, & Mubbashar (2001) reported that prevalence rates of 34% for stress and anxiety in Pakistan and it was found parents in rural area, 72% of mothers and 44% of fathers reported stress and anxiety.

Malaysia is a multi-ethnic country which comprises of three main groups in the country that is the Malays, who are Muslims, form the majority in the country. The other two main racial groups are the Chinese, who are mostly Buddhists and the Indians, who are mainly Hindus. In addition, there are also those among them who are Christians. Therefore, any study in Malaysia that involves demographic variables inevitably it has to be linked with ethnicity and religion apart from SES.

Methodology

Sample

This was a cross-sectional study conducted at the rehabilitation centers and school that provides inclusive program in the district of Tanjong Malim, Perak. Participants were 66 parents of children with learning disabilities were chosen for the study. The parents were purposively selected from various backgrounds.

Instruments

Perceived Stress Scale (PSS) by Cohen (1989) was used to assess level of stress among the sample. the measure consisted of 10 statements and each item is rated on a 5-point scale ranging from never (0) to almost always (4). Positively worded items are reverse scored, and the ratings are summed, with higher scores indicating more perceived stress. The PSS scores are obtained by reversing the scores on the four positive items: For example, 0=4, 1=3, 2=2, etc. and then summing across all 10 items. Items 4, 5, 7, and 8

are the positively stated items. Scores below 13 are considered low, 14 – 19 are considered and scores of 20 or higher are considered high stress.

Procedure

For the purpose of collection of data, rehabilitation centres and schools conducting inclusive program around the Batang Padang District, Perak were visited by the research assistant and requested the manager/headmaster of the addresses of children studying in their centers / schools on the basis of addresses provided by their parents. Parents were contacted personally and data were collected with the help of above instruments. The parents of disabled children were also contacted individually.

Results

In this study, mean age of mothers was 37.42 (S.D 8.8) years and of fathers was 42.9 (S.D 8.8) years. The mean age of the children was 10.5 (S.D 5.0) years (range: 2 - 18 years), with 30% females and 70% males. 25% of the children had mild disabilities, 42% moderate ID, 20% severe learning disabilities and 13% had profound disabilities. The children included in this study: cerebral palsy 22%; epilepsy 34%; and, autistic disorder 11%. Eighty-two percent of the children had ID since birth. Seventy-nine percent of the children had various behavioral difficulties, including ADHD.

The Level of Parental Stress

The Level of Parental Stress is determined based on the feedback of parents of Perceived Stress Scale that has been translated. This instrument consists of 10 items and its scores based on ratings parents are as shown in Table 1 below. Each item is rated on a 5-point scale ranging from never (0) to almost always (4). Positive items are reverse scored, and the ratings are summed, with higher scores indicating more perceived stress. It is considered as low level of stress if the scores are below 13, scores of 14-19 is considered as average and scores of above 20 is considered as high level of stress.

Table 1: Level of Stress According to No. of Respondents and Percentage

Score	Level of Stress	No. of Respondent	Percentage (%)
Below 13	Low	21	19.1%
14 -19	Average	80	72.7%
Above 20	High	9	8.2%

The analysis in Table 1 shows the total of 21 (19.1%) parents experiencing stress at low level (scores below 13) and they are in the state of normal. Whilst 80 (72.7%) of parents were suffering average level of stress (a score of 14 to 19) and it is considered as mild. Furthermore, the analysis also showed that 9 (8.2%) of them experienced high level of stress which is classified as severe.

Parental Stress Based on Demographic Background

Table 2 shows the level of stress among the parents based on their family background. The background characteristics accounted for this study were gender parents, ethnic, religious and socio-economic status (SES).

The result in Table 2 shows that the level of stress of mothers with disabled children are higher than the fathers. As can be seen in the analysis 9.4% mothers are in the score

of high level of stress compared to fathers 6.5% and the result shows that only 9.4% mothers at the low level of stress as compared to fathers is 32.6%.

In term of ethnicity, the result shows that the level of stress among the Malay parents is lower than the Chinese and Indian parents. This can be seen that only 3.8% Malay parents, 15.0% Chinese parents and 10.8% Indian parents are in the score of high level of stress. It also can be seen at the score of average level of stress whereby 67.9% are the Malays parents, 75.0% are Chinese parents and 78.4% are Indian parents. Therefore, a significantly high proportion of Chinese and Indian had stress as compared to Malays.

Table 2: Parental Stress Based on Demographic Background

Score	Below13	14 – 19	Above 20	Total
Gender				
Mother (n=64)	6 (9.4%)	52 (81.2%)	6 (9.4%)	(64) 100%
Father (n=46)	15 (32.6)	28 (60.9%)	3 (6.5%)	(46) 100%
Ethnic				
Malay (n=53)	15 (28.3%)	36 (67.9%)	2 (3.8%)	(53) 100%
Chinese (n=20)	2 (10.0%)	15 (75.0%)	3 (15.0%)	(20) 100%
Indian (n=37)	4 (10.8%)	29 (78.4%)	4 (10.8%)	(37) 100%
Religion				
Islam (n=53)	12 (22.7%)	36 (67.9%)	5 (9.4%)	(53) 100%
Christian	3 (20.0%)	10 (66.7%)	2 (13.3%)	(15) 100%
(n=15)	2 (13.3%)	11 (73.4%)	2 (13.3%)	(15) 100%
Buddhist	4 (14.8%)	23 (85.2%)	0 (0.0%)	(27) 100%
(n=15)				
Hindus (n=27)				
SES				
High (n=30)	8 (26.6%)	20 (66.7%)	2 (6.7%)	(30) 100%
Medium	5 (12.5%)	30 (75.0%)	5 (12.5%)	(40) 100%
(n=40)	8 (20.0%)	30 (75.0%)	2 (5.0%)	(40) 100%
Low (n=40)				

In terms of religious groups, it can be seen that there is a difference level of stress among parents of different religious groups. The Muslim parents (22.7%) experiences stress at low level of stress compared to those who are Christians (20.0%), Buddhists (13.3%) and Hindus (7.4%). While stress at the average level the Hindus parents dominated with 85.2% and Buddhists parents (73.4%) seems to have no significant difference. It seems to be significantly difference with Muslim parents (67.9%) and Christians (66.7%). However, the high level of stress seems to be difference because the high level of stress among the Christian (13.3%) and Buddhist (13.3%) parents are higher than the Muslims (6.7%) and Hindus (0.0%) parent. This situation indicates that the stress experienced by the Christian and Buddhist parents need to be addressed.

Although there are differences of stress in SES groups but they do not show there is significant difference. This position can be seen at the average level of stress between the SES groups i.e the high SES group scored 66.7%, medium SES group scored 75.0% and the low SES group scored 75.0% and it shows that there is no significant difference.

This situation also applies to the low level of stress. However, the high level of stress seems to be difference because the high level of stress of medium SES are higher than the high and low SES. As can be seen in the analysis 12.5% medium SES are in the score of high level of stress compared to high SES 6.7% and the low SES shows only 5.0%.

Discussion

The psychological well-being of the parents are regarded as very important. Research emphasizes the importance of intervention programs in parental stress in order to alleviate it (Gray, 2003), because of the high level of parental stress may have a negative impact on the functioning of children with disabilities. Parents may behave in ways that have a negative impact on children (Hastings 2002). Research shows that parents who experience higher levels of stress interact differently with their children, compared with parents who have lower levels of stress, and they respond differently to their child's problematic behaviour (Conger et al 1995). According to Rossister & Sharpe (2001) Self-reported depression of the parents is a stronger predictor for their efforts to actively and successfully manage their child's behavior problems.

Overall, in the context of Malaysian society, the situation of stress among the parents experienced by all races, religious beliefs and SES. The study showed that the level of stress of mothers with disabled children are higher than the fathers. This study supported the study done by Hastings et al.,(2005); Oelofsen and Richardson (2006); Gray (2003) that mothers experience greater impact than fathers by their child's disability. This also can be seen in a study conducted by Gray (2003) on families of children with autism, he found that mothers and fathers were affected on different ways and levels by their child's condition. Fathers claimed that their child's condition did not affect them personally as it did with their wives. They also admitted that the way their child's autism affected them was through the stress that their wives experienced. According to Gray different levels of stress experienced by mothers and father may be explained by gender roles connected to work and child rearing. While mothers usually are more involved in child rearing, fathers are more into working harder in order to support their family's financial needs. There is difference between mothers and fathers in the coping strategies they use. While fathers tend to suppress their feelings, or to avoid them by working until late or staying away from home, mothers tend to vent their feelings. Mothers tend to experience a wider range of feelings (from grief, sadness, anger and crying) and talk more about their emotional distress with others. Mothers are found to be more stigmatized by their child's disorder (Gray. 1993).

Malaysia is a multi-ethnic country which comprises of three main groups in the country that is the Malays, who are Muslims, form the majority in the country. The other two main racial groups are the Chinese, who are mostly Buddhists and the Indians, who are mainly Hindus. In term of ethnicity, the result shows that the level of stress among the Malay parents is lower than the Chinese and Indian parents. In terms of religious groups, it can be seen that there is a difference level of stress among parents of different religious groups. The Muslim parents (22.7%) experiences stress at low level of stress compared to those who are Christians (20.0%), Buddhists (13.3%) and Hindus (7.4%). While stress at the average level the Hindus parents dominated with 85.2% and Buddhists parents (73.4%) seems to have no significant difference. It seems to be significantly difference with Muslim parents (67.9%) and Christians (66.7%). However, the high level of stress seems to be difference because the high level of stress

among the Christian (13.3%) and Buddhist (13.3%) parents are higher than the Muslims (6.7%) and Hindus (0.0%) parent. May be a study done Gupta, Mehrotra, & Mehrotra (2012) can support this situation whereby more than half of the respondents turned to God, mosques and temples for coping, after they had exhausted all avenues of treatment and were told by the physicians that there was "no hope" of a cure. Many researchers from India have reported that people often find relief in religious propitiation and surrender to the will of God when faced with intractable disease and disability (Dalal, 2000; Brown et al, 2003; Farheen et al, 2008; Gupta, 2011).

Although there are differences of stress in SES groups but they do not show there is significant difference. This situation indicates that the stress experienced by the medium and high SES parents need to be addressed. According to a study done by Gupta, Mehrotra, & Mehrotra, (2012) parents who engaged in more lucrative and prestigious occupations had more stress than parents engaged in less prestigious and lucrative irrespective of their income occupations. In their role as parents, those who worked as professionals, managers and had small businesses experienced higher stress than those who worked as labourers and clerks, due to impaired sense of competence, restrictions placed on other life roles, marital conflict, lack of social support and depression. This finding is in contrast to most published studies which report higher stress among parents of low SES. Higher stress among parents who are engaged in a prestigious occupation may be due to the thwarting of their generally higher expectations of their children, higher perception of shame, frustration at not being able to restore the condition of the child and more restrictions on their social and professional activities (Duncan et al, 1972). The parents in less prestigious occupations may have lower expectations of their children and may be accustomed to feelings of helplessness (Kumar, 2010).

A family who has a child with LD, experiences many challenges such as repeated physical and emotional crises, interactive family issues, ruined schedules, and additional expenses, which can create financial burden and emotional distress for a family (Dervisalij, 2013). Having a child with LD often requires a reorientation and reevaluation of family goals, responsibilities and relationships. A significantly high proportion of parents of disabled children have psychiatric diagnosis of anxiety, depression or both, needing mental health services and support. Nearly 50% of the parents were severely anxious and about two-thirds were clinically depressed (Bitsika & Sharpley, 2004). In a study done in Turkey, Firat et al. reported high rates of depression in mothers of children with autism (72.5%) and in mothers of children with mental retardation (44.7%) (Firat, Diler, Avci, & Seydaoglu, 2002).

The high level of stress or mental health problems experienced by parents of disabled children could be related to subjective factors such as feeling social isolation and life dissatisfaction (Dervisalij, 2013). Parents of these children may struggle with a multitude of emotions interchangeably over years, and often have feelings of guilt that somehow they caused the child to be disabled, for logical or illogical reasons (Gupta & Kaur, 2010). Other factors related to parenting a child with LD that may negatively impact parent mental health may include disappointment that their child will not reach the career ideals they had envisioned or feelings of embarrassment, shame, and isolation. In this study, higher risk for psychiatric diagnosis of anxiety, depression and anxiety and depression together was associated with the gender of the parent. This can also be explained in cultural context since in some Malaysian mothers are the main primary care takers of their children. Within that context, in two parent families, stress

and care demands are expected to be strongest for mothers as opposed to fathers because of the greater responsibility; mothers tend to have for direct childcare (Dervisali, 2013). Accordingly, mothers appear to be more vulnerable to the stress associated with child's behavioural problems (Lopez et al., 2008). Since mothers are more under pressure to balance child care needs and household chores, physical support from the family is reported as a relief (Gupta & Kaur, 2010). Mothers, who are housewives without additional help, can feel restricted in pursuing their social and leisure activities, and experience more stress (Gupta, 2011). Fathers have lower rates of anxiety and depression as compared to mothers, but higher rates than males in the general population (Lopez et al., 2008). As typically fathers are the sole bread winners for their immediate and extended families, in Malaysian culture, having a child with LD can impose further financial pressures on fathers. Because of social stigma towards disabled, parents, especially fathers, can feel shame and embarrassment in taking their child to social and family gatherings. This can lead to social isolation for the whole family, contributing to further stress.

The diagnosis of anxiety, depression or both among mothers was associated with severity of ID in their children, which has been shown in previous studies (Kumar, 2010). In our study, presence of high rates of behavioral issues and comorbid illnesses with LD most likely have contributed to high rates of parental anxiety and depression. Previous studies have reported parental stress and health outcome being related to child characteristics such as the severity of the core disability, main diagnosis, the age of the child, and the extent of coexisting behavioral issues (Hastings, 2002). In a study done by Gupta and Kaur in India, both mothers and fathers of disabled reported high rates of mental stress as compared to physical stress, especially women (Gupta & Kaur, 2010).

Conclusion

As a whole there was a low rate of stress among parents of children with LD in this study. However, the rate of stress among the fathers was even better as compared to mothers. Nevertheless, the mental health providers should be prepared to meet the needs of a small number of parents who are suffering stress at a high level in this situation. Therefore, appropriate mental health screening can be utilized among the care givers of disabled.

References

- Ahmad, I., Saeed, K., & Mubbashar, M. H. (2001). Minor psychiatric morbidity and socio-economic factors. *Medical Forum Monthly*, 12, 5-8.
- Beckman, P.J. (1991). Comparison of mothers' and fathers' perceptions of the effect of young children with and without disabilities. *American Journal on Mental Retardation*, 95, 585-595
- Bitsika, V., & Sharpley, C. (2004). Stress, anxiety and depression among parents of children with autism spectrum disorder. *Australian Journal of Guidance and Counselling*, 14(2), 151-161.
- Breslau, N. (1982). Siblings of disabled children: Birth order and age-spacing effects. *Journal of Abnormal Child Psychology*, 10, 85-96.
- Breslau, N., & Prabucki, K. (1987). Siblings of disabled children. *Archives of General Psychiatry*, 44, 1040- 1046.
- Brown, I., Anand, S., Fung, A. (2003). Family quality of life: Canadian results from an international study. *Journal of Developmental and Physical Disabilities*; 15 (3): 207-230.
<http://dx.doi.org/10.1023/A:1024931022773>.
- Conger, R., Patterson, G.R., Davis, E., & Ge, X. (1995). It takes two to replicate: A mediational model for the impact of parents' stress on adolescent adjustment. *Child Development*, 66, 80-97.
- Cohen, S. (1991). Psychological stress and susceptibility to the common cold. *New England journal of medicine*, 325(9), 606-612.
- Dervishalaj, E. (2013). Parental Stress in Families of Children with Disabilities: A Literature Review. *Journal of Educational and Social Research*. Vol. 3 No. 7. 579-584.
- Duncan OD, Featherman DL, Duncan BD (1972). *Socioeconomic Background and Achievement*, New York: Seminar Press.
- Farheen, A., Dixit, S., Bansal, S.B. & Yesikar V (2008). Coping strategies in families with mentally retarded children. *Indian Journal for the Practicing Doctor*; 5: 11-12.
- Firat, S., Diler, R., Avci, A., & Seydaoglu, G. (2002). Comparison of psychopathology in the mothers of autistic and mentally retarded children. *Journal of Korean Medical Science*, 17, 679-685.
- Gupta, V.B., Mehrotra, P & Mehrotra, N. (2012). Parental Stress in Raising a Child with Disabilities in India. *Journal of Intellectual Disability*. vol 23, no.2, 119
- Gupta, V.B. (2011). How Hindus Cope with Disability. *Journal of Religion, Disability & Health*; 15: 72-77. <http://dx.doi.org/10.1080/15228967.2011.540897>.
- Gray, D.E. (2003). *Gender and coping: The parents of children with high functioning autism*. *Social Science and Medicine*; 56: 631-642.
- Gray, D.E. (1993). *Perceptions of stigma: The parents of autistic children*. *Sociology of Health and Illness*; 15: 102-120.
- Gupta, R. K., & Kaur, H. (2010). Stress among parents of children with intellectual disability. *Asia Pacific Disability Rehabilitation Journal*, 21(2), 118-126.
- Hastings, R. P. (2002). Parental stress and behaviour problems of children with developmental disability. *Journal of Intellectual Developmental Disability*, 27(3), 149-160.
- Kumar M (2010). Poverty and culture of daily life. *Psychology Developing Societies*; 22 (2):331-359.
<http://dx.doi.org/10.1177/097133361002200205>.
- Lewis O (1998). The culture of poverty. *Society*; 35 (2): 7-9. <http://dx.doi.org/10.1007/BF02838122>
- Lopez, V., Clifford, T., Minnes, P. & Ouellette-Kuntz, H. (2008). Parental Stress and Coping in Families of Children With and Without Developmental Delays. *Journal of Developmental Disabilities*, 14 (2), 99-104.
- Mirza, I., & Jenkins, R. (2004) Risk factors, prevalence, and treatment of anxiety and depressive disorders in Pakistan: A systematic review. *British Medical Journal*, 328 (7443), 794.
- Oelofsen, N., & Richardson, P. (2006). Sense of coherence and parenting stress in mothers and fathers of preschool children with developmental disability. *Journal of Intellectual & Developmental Disability*, 31, 1-12.
- Rossiter, L., & Sharpe, D. (2001). The siblings of individuals with mental retardation: A quantitative integration of the literature. *Journal of Child and Family Studies*, 10, 65-84.
- Sanders, J. L., & Morgan, S. B., (1997). Family stress and Adjustment as perceived by parents of children with autism or down syndrome; implications for intervention. *Child & Family Behavior Therapy*, Vol. 19 (4) (pp. 15-32) The Haworth Press, Inc.
- Simmerman, S., Blacher, J., & Baker, B. L. (2001). Fathers' and mothers' perceptions of father involvement in families with young children with a disability. *Journal of Intellectual and Developmental Disability*, 26, 325-338.
- World Health Report: 2001: Mental health: New understanding, new hope. [Online] [cited 2001] Available from: http://www.who.int/whr/2001/en/whr01_en.pdf.