

Depression among Parents with Disabled Children in Northeastern Malaysia

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Abstract: Taking care of a disabled child requires patience and more time as well as energy. Previous studies found that parents with disabled children are at increased risk to develop psychological disorders. Hence, the present work was carried out to determine the prevalence of depression and its associated factors among parents with a disabled child in northeastern Malaysia. A total 148 parents with a disabled child in northeastern Malaysia were recruited in this cross-sectional study. The Malay translated and validated Depression, Anxiety and Stress Scale-21 was used as a research tool. The prevalence of depression among parents with a disabled child was calculated and its associated factors were determined using multiple logistic regressions analysis. It was found that the prevalence of depression among parents with a disabled child was 25.0% (95% CI: 18.4, 32.9). The factors that were significantly associated with depression among parents with a disabled child were non-Malays [OR_{adj} 7.76 (95% CI: 2.67, 29.0)], age of disabled child [OR_{adj} 0.87 (95% CI: 0.79, 0.96)] and poverty [OR_{adj} 2.49 (95% CI: 1.01, 6.14)]. In conclusion, there is a relatively high prevalence of depression among parents with a disabled child in northeastern Malaysia. It is recommended to deliver interventional packages to manage depression among parents with a disabled child especially to non-Malay parents who earned below the poverty line and having a young disabled child.

Key words: Parents • Disabled Child • Depression • Malaysia

INTRODUCTION

Taking care of a disabled child requires patience and more time as well as energy. Previous studies found that parents with the disabled child are at increased risk to develop psychological disorders. It seems reasonable to assume that parents of disabled children are at increased risk for high levels of personal stress. When a parent feels stress, which is associated with caring for their disabled children, there can be an undesirable effects on the child and the family. For example, heightened parent stress is associated with coercive parent-child interactions [1], dropout from parent training interventions [2] and is linked to parental depression [3].

Many studies have shown that parenting a child with special needs or chronic condition affects the health of caregivers and family functioning. Few previous studies

find that parents with disabled children experienced deep sadness and feelings of being overwhelmed [4], anxiety and depression [5], worry [6] and lower quality of life [7]. In addition, mothers of children with intellectual disabilities were at increased risk of psychosomatic problems, child-related stress, and poor family relationships [7]. Caregivers of disabled children also reported to have lower marital happiness, family cohesion and family adaptability than the normal groups [8].

Having children with disabilities may lead to high stress level among parents since they are more likely to experience a larger number of tasks in a daily basis as opposed to parents with typical and normal children. In Iran, it was found that parents with intellectual disabilities children experienced more psychological problems as compared to those having normal children [9]. The continuing, repetitive, complicated but essential tasks

must be performed by parents of disabled children with tolerance to adequately raise their child. The elevated stress can disrupt the parent's well-being as they are constantly attempting to relieve the tension [10].

The difference in the availability of care for the disabled person in Malaysia from other countries could affect the severity of the disabilities and comorbidities. The cultural, socioeconomic and educational background differences of the caregivers may influence their adaptation strategies to manage the disabled children. Anxiety and depression affect negatively on the parent with disabled children. Apparently, their child situation made them think and worry about their children's future. Because of mothers' dominant roles in caregiving and responsibilities at household, trait anxiety levels were higher in mothers. Hence, the present work was carried out to determine the prevalence of depression and its associated factors among parents with a disabled child in northeastern Malaysia so that individualized and targeted interventions can be designed.

MATERIALS AND METHODS

A cross-sectional study was conducted at community-based rehabilitation centers in the selected districts in northeastern Malaysia. A parent who takes care of any disabled child was randomly selected as a respondent. The inclusion criteria for the present study were biological parents lived with the disabled child of any type of disability as well as those parents whose disabled child aged between 2-18 years. Those parents with a child registered with the institution of less than 1 year and parents with any form of cognitive impairment such as dementia and mental retardation were excluded from the study.

Parent of disabled children was either biological mother or father of disabled children and did not include the guardians. In the present study, parents who were still married and living together with their spouse were grouped as "Married" while parents who were single, divorced or widowed were grouped into "Unmarried". Meanwhile, parents who were not schooling and only have primary education level were categorized as having lower education and those who have secondary education level and higher were grouped as having higher education. Pertaining to income group, those with monthly household income of RM763 and less were grouped as "Below poverty line". Whereas, those with more than RM763 were grouped as "Above the poverty line" [11].

Using a single proportion formula and based on the previous study which reported the prevalence of stress as 21.4% among parents with cleft lip and palate children [12] the required sample size for the present study was 145 after considering 10% non-response rate. Selected respondents were subjected to fill up a designed proforma which was consisted of two parts; one on parent's information and the other on disabled child's information. In determining the prevalence of depression among the respondents, a Malay translated and validated Depression, Anxiety and Stress Scale 21 Items (DASS 21) was used [13]. Those scored of more than 9 from the DASS questionnaire were considered as having depression.

The DASS questionnaire measures the negative emotional state which is based on clinical symptoms and meets the requirements of both researchers and professional clinician. Respondents were asked to use 4-point scales to rate the extent to which they have experienced each state over the past week [14]. Norizan and Shamsudin (2010) [15] used DASS to identify depression, anxiety and stress disorder in mothers of children with Down syndrome. They revealed that the psychometric properties of the DASS questionnaire are suitable for use in a family health setting.

After getting permission to enter the institution from the principal or director, the respondents were briefed regarding the study and a written consent was obtained. Data were collected using a self-administered questionnaire at their children learning institution. The questionnaires were collected on the same day.

Data were entered and analysed using Statistical Package for the Social Sciences (SPSS) version 20 software. After data entry, it was explored, checked and cleaned. Preliminary data description was done to detect any missing value. The data set was checked for any errors and corrections were made. The data was first tabulated for descriptive statistics to have an overview of the overall distribution of the data. All categorical variables were summarized in frequency (*n*) and percentage (%). Numerical variables were described in mean and standard deviation (SD) or median and interquartile range (IQR) depending on normality of their distribution.

The association between depression and sociodemographic and child factors were analysed using multiple logistic regression. A simple logistic regression (SLogR) was applied to select the preliminary variables. Clinically important variables were selected for multiple logistic regression (MLogR) analysis to evaluate for

factors associated with depression. Preliminary main effect model was obtained after comparing model using forward LR and backward LR methods. Multicollinearity was checked using correlation matrix in which if the correlation between variables were weak it indicated no multicollinearity. Variance Inflation Factors (VIF) was also used to check for multicollinearity, in which VIF of less than 10 was acceptable and indicated no multicollinearity problem.

All possible two-way interactions were checked. The fitness of the model was tested by the Hosmer-Lemeshow goodness of fit test. Other than that, the classification table and area under receiver operation characteristics (ROC) curve were also used to determine the fitness of the model. The Hosmer-Lemeshow goodness of fit test with p -value more than 0.05 indicated that the model was fit. Classification table which shows more than 70% was considered a good model. The area under ROC curve above 0.7 with a p -value of less than 0.05 also indicated that the model was fit. The final model was presented with adjusted odds ratio (Adj. OR) and 95% confidence interval (CI), Wald statistics and p -value. The level of significance was set at a p -value of less than 0.05.

Ethical approval to conduct the present study was obtained from Human Research Ethics Committee, Universiti Sains Malaysia [USMKK/ PPP/ JEPeM [261.3. (1)]. Confidentiality of the data was kept throughout the study.

RESULTS

A total of 148 parents fulfilled the criteria for the present study and responded by answering the DASS 21 questionnaire. The mean (SD) age of parent was 46.0 (9.14) years old. The youngest parent was 22 years old while the oldest was 69 years old. Table 1 shows the sociodemographic characteristics of the respondents in the present study.

Most of them 130(87.8%) had only one disabled child. Only 46 (31.1%) of them had attended any courses related to the management of a disabled child. The mean (SD) age of the disabled child was 11.3 (4.42) years old. The youngest disabled child was 2 years old while the oldest was 18 years old. Pertaining to the number of disabilities, 75 (50.7%) of the them have a single disability while 73 (49.3%) have multiple disabilities.

The present study found that 12.2, 9.5 and 3.4% of parents with disabled child had a mild, moderate and severe depression respectively. None of them had extremely severe depression. The mild, moderate and severe depression was grouped together giving the prevalence of depression among parents with disabled child in northeastern Malaysia as 25.0% (95% CI 18.4, 32.9).

Simple logistic regression analyses of the interested variables showed that race ($p=0.010$), age of disabled child ($p=0.230$) and gender of disabled child ($p=0.157$) could be selected to be included in multiple logistic regression

Table 1: Socio-demographic characteristics of the parents with disabled children (n = 148)

Variables	n (%)
Gender	
Male	28 (18.9)
Female	120 (81.1)
Race	
Malay	136 (91.9)
Chinese	12 (8.1)
Marital status	
Married	127 (85.8)
Unmarried	21 (14.2)
Educational status	
Lower education	26 (17.6)
Higher education	122 (82.4)
Income group	
Below poverty line = RM763	59 (39.9)
Above poverty line > RM763	89 (60.1)
Received financial aids	
Yes	114 (77.0)
No	34 (23.0)
Gender of disabled Child	
Male	77 (52.0)
Female	71 (48.0)

Table 2: Factors associated with depression among parents with disabled children in northeastern Malaysia using multiple logistic regression analysis (n=148)

Variable	Crude OR ^a (95% CI)	Adjusted OR ^b (95% CI)	Wald Statistic ^b (df)	p-value ^b
Race				
Malay	1.00	1.00	9.27 (1)	0.002
Chinese	4.95 (1.47, 16.71)	7.76 (2.67, 29.0)		
Age of disabled child	0.91 (0.83, 0.99)	0.87 (0.79, 0.96)	8.11 (1)	0.004
Income Group				
Above Poverty Line	1.00	1.00	3.89 (1)	0.049
Below Poverty Line	1.21 (0.57, 2.56)	2.49 (1.01, 6.14)		

^a Simple logistic regression^b Multiple logistic regressionHosmer-Lemeshow $p = 0.972$

Classification table 78.4%,

ROC area under the curve 0.711

analysis to determine factors associated with depression among 148 parents of disabled child. Although income group ($p=0.628$) was not statistically significant in simple logistic regression, it was included in the multiple logistic regression due to its clinical significant from the literature reviews. Table 2 shows the factors associated with depression among parents of disabled child in northeastern Malaysia using multiple logistic regression analysis. There was no interaction and multicollinearity problem in the model.

DISCUSSION

The present study revealed that the prevalence of depression was 25% among parents with disabled children in northeastern Malaysia. Among them, 3.4% had a severe depression. This finding is much lower compared to a study done in Tehran where it was found that 73% of mothers of disabled children had depression, and approximately 21% of them suffered from severe depression [16]. The difference in the findings could be due to the difference in the duration of the study and also different research tool used.

In India, it was found that 70% of the mothers were suffering from mild to moderate level of depression and it affected their quality of life [17]. On the other hand, 45% of mothers with intellectual disabilities children and 50% of mothers with autistic children in Sweden had elevated depression scores [18]. The difference in the sociocultural background of each country can also be the reason why the prevalence of depression differs. On top of that, there was a significant difference between fathers and mothers with regards to hostility behavior, depression and anxiety in which the mothers tolerated those problems more than fathers of intellectual disabilities children [9].

The experience of parenting a disabled child increases the risk of aggravating feelings of loss, helplessness and failure. For example, they felt as if they

are not able to change the situation and to get the help needed. This situation could make some parent to be sensitive to these feelings, especially if they do not have an adequate or positive coping mechanism. Clak and Beck [19] further stated that since parenting a child with a disability is likely to provoke these feelings more often, there is a greater risk of the repeated activation of the dysfunctional coping mechanism, which could explain why most studies find more depressive symptoms in parents of disabled children.

The present study also found that there were three factors that associated with depression among parents with the disabled child. The factors were race, the age of the disabled child and poverty. Cognitive theories of depression mentioned that stressors play an important role in both the onset and the course of the depressive disorder. A person can develop depression when they are no longer able to cope with stress [19]. This statement is supported by several studies which show that parental depression strongly correlates with stress [20].

This study has demonstrated that Chinese have about 8 times higher risks to develop depression as compared to Malays. This study is in line with the studies by Pearson and Chan in 1993 [21] who also found that Chinese mothers have a higher risk than their Malay or Indian counterparts. A study among Chinese mothers of children with learning disabilities using the same questionnaire showed that parenting stress in the control group was also relatively high when compared with what are considered to be normal levels in the Western world. Another recent study also found that non-Malay caregivers had lower parent health-related quality of life and family functioning compared with Malay caregivers [22].

This study also showed that with 1-year increase in age of the disabled child, the risk of their parent to develop depression was reduced by 13%. A disabled child age in our study was ranged from 2 to 18 years old

which included a wide age range. This finding is consistent with a previous study which showed that increase in the age of the disabled child will reduce stress to their parent [23].

In contrast, a previous study among mothers of young children with cerebral palsy in Bangladesh demonstrated that the significant associated factors to develop stress among mothers were, living in the rural area within a poor family with a relatively older child [24]. This is probably because of the disabled child's age selection which was between one and half years to five years old compared to this study which used a wide age range. The burden of caring for children that are expected at two to three years of age seems to be the reason for the greater maternal stress. Usually, most of the disabled child can take care of their self to a certain limit when they grow up. This will reduce the burden on the mother, hence reducing the stress and depression.

The third factor that is significantly associated with depression was poverty. Many studies have shown the similar association throughout the years. Parents with poverty were prone to suffer from mental health problems due to difficult life events such as not being able to pay their bills, losing their jobs, moving frequently, being homeless and worrying about money [25]. When the family has a child with disabilities, more stress is added to the strain that was already caused by poverty. Families with higher income have more choices available to help them cope with their daily livings [26].

A recent study in Pakistan which uses DASS also support the finding in which they revealed a highly significant correlation between poverty and depression among parents with disabled child [27]. A similar finding was recorded in Turkey which also shows that financial problem as one of the important factors that affected mental health of parents with disabled children [28].

The present study did not find any association between depression and marital status of their parents. However, Olsson and Hwang [18] demonstrated that single mothers of children with disabilities were found to be more vulnerable to severe depression than mothers living with their partners. Single parents experienced lack of spouse assistance, which results in an increase in their burden of care and physical, psychological, economical and social stresses. Unlike in the present study, they also found that mothers of children with disabilities are at a markedly increased risk of suffering from depression compared to fathers. Mothers usually take on a larger part of the extra care and practical work compared to fathers. They also give up their job and feel unable to pursue their

own interests [18]. The important limitation of the present study was recall bias by the parents while answering the DASS questionnaire. The questionnaire is sensitive to assess one-week recall event.

CONCLUSIONS

The present study demonstrated a relatively high prevalence of depression among parents with a disabled child in northeastern Malaysia. Intervention packages are recommended to be applied to parents with disabled children especially to non-Malay parents who earned below the poverty line and having a young disabled child.

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