ORIGINAL ARTICLES

Stress of the mothers in caring for children with developmental disabilities and some related factors

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ABSTRACT

Objective: to determine the stress status of mothers in caring for children with intellectual disabilities from 4-9 years old and survey some related factors in order to design an intervention program to improve maternal stress.

Methods: A cross-sectional study design was implemented in May 2022 in Phuoc Long district, Binh Phuoc province on a sample of all 55 mothers of children with developmental disabilities (4-9 years old) who were screened and diagnosed by interdisciplinary approach in locality. The Parenting Stress Index (PSI) was used to collect information from mothers in a self-completed form. The t-test and linear regression was used to compare and find the association of the stress levels with the independent variables.

Results: The mean total PSI score of mothers was 97.2. Maternal stress was associated with level of disability and time of continuous care in univariate analysis and linear regression.

Conclusion: The focus of the intervention program can be considered to target groups of mothers with children with more severe disabilities and older age groups in order to improve the effectiveness of the intervention program towards improving the stress status of mothers.

Keywords: *Stress, children with intellectual disabilities, PSI, maternal health.*

INTRODUCTION

Developmental disability encompasses a wide range of conditions, with both known and unknown causes. It refers to any condition that delays or impairs an individual's physical, cogni- tive, physiological, and/or psychological development (1). Developmental disabilities include limitations in function resulting from disorders of the developing nervous system. These limitations manifest during infancy or childhood as delays in reaching developmental milestones or as lack of function in one or multiple domains, including cognition, motor performance, vision, hearing and speech, and behavior (2). Common developmental disabilities include autism spectrum disorder, intellectual disability, fetal alcohol spectrum disorder (FASD), Down syndrome and other genetic disorders as well as general developmental delay and cerebral plasy. Age-related disabilities (3, 4) and behavioral problems in children with developmental disabilities can exacerbate difficulties in functioning and lead to more restrictions in living environments and more burdens in emotion and finance to individuals, families and communities (5). Several studies have found that parents of children with developmental disabilities have an increased risk of parenting stress compared with parents of normally developing

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children (6), and with children's behavior (7, 8). A family-centered approach based on the belief that most parents of children with special needs have psychological investment needed to encourage and promote their child's development, especially with appropriate and private support from professionals (9, 10) and families, especially parents play an important role in regulating the behavior of children with intellectual disabilities (11, 12).

Raising a child is stressful and is often cumulative over time and many factors (13), but raising a child with a developmental delay can create special challenges for parents (14). Parents often experience pressure when caring for children, especially children with disabilities (15-19), children have learning disabilities (20), developmental delays (21) or behavioral problems (8). Correlation analyzes show that parental stress during parenting is positively correlated with children's autism spectrum disorder (ASD) symptoms and behavioral problems in children with disabilities (22, 23), to the age of the child with intellectual and neurological disability (spina bifida) (24, 25) and level of the disorders and disability of the child (26, 27). On the other hand, parenting stress was negatively correlated with reported levels of maternal involvement and support for social functioning (16, 28). The Parenting Stress Index (PSI) (29), is a self-completed scale of 36 items divided into 3 sub-scales or domains including Parental distress, Troubled parent-child interaction, and Troubled child's influence on parents. PSI is used in research on parental pressure in caring for children with disabilities in many countries around the world (30-33). PSI was chosen for this study because of its sensitivity to measuring parenting stress in low-income mothers (34), unemployed parents (35) and parents of children with disability (17, 32, 36, 37); and especially the PSI scale with 36 items has been adapted and deployed in researches in Vietnam (38).

We carried out this study to identify stress in caring for children with intellectual disabilities aged 4-9 years old and survey some related factors to design an intervention program to improve the mothers' stress and children's learning ability.

METHODS

Study design: The cross-sectional study.

Study subjective: Mothers of children with developmental disabilities who had agreed to participate in the study. These children with disabilities had been screenedand diagnosed in the local community by group of experts (doctors and therapists) on rehabilitation (physical, speech and language, and occupational therapies), and special education.

Study site and time: The study was conducted in the first week of May 2022 with the participant of the mothers in 5 wards (Long Phuoc, Long Thuy, Phuoc Binh, Son Giang, Thac Mo) and 2 communes (Long Giang, Phuoc Tin) in Phuoc Long district, Binh Phuoc province.

Sample size and sampling: The study approached the list of children from screening (in February 2022) and diagnosing (in April 2022) activities conducted in the Phuoc Long community by Phuoc Long District Health Center and VietHealth. The list includes 520 children aged 4 – 9 in Phuoc Long community, among whom 55 children were diagnosed with development disability. The study utilized information of the parents/mothers obtained during these activities. Subsequently, the researchers contacted the mothers to invite them to participate in the study. All of 55 mothers agreed to participate in the study.

Study variables

The data used in the study included demographic information of the mother (the household

included), mothers' age and occupation, the number of children in the family, and the presence of children with disabilities in the family (other than children participating in the study) and household economic status. Information of children with disabilities including age, gender, birth order, along with level of disability (mild, severe and very severe) of the child is collected from the records of interdisciplinary examination and diagnosis in rehabilitation and special education by experts from Children's hospital 1, University of Education, conducted by VietHealth, in collaboration with Phuoc Long District Health Center, at district preschools.

Maternal pressure or stress was collected from 36 items from PSI's scale through the Abidin self-complete form (29, 38). The parenting stress scale has 36 items (short form) distributed in three subscales or domains including: Parents' distress (PD 12 items), Parent-child interaction (P-CDI- 12 items) and children with disabilities (DC-12 items). For example, for the sub-scale "Parents' distress", there are items such as: "I feel encumbered by the responsibility of being a parent"; "Having a baby has caused me more trouble in my relationship than I thought." Or in the sub-scale "parent-child interaction", there are items such as: "Sometimes I feel that my child does not like me and does not want to be close to me"; "When I do things for my child, I get the feeling that my efforts are not appreciated"; "I used to wish that I will have more friendly and close feelings with my child than now, and this difference bothers me". And for the 3rd sub-scale "Influence of children with disabilities on parents", there are items such as: "My child seems to be fussier than most other children"; "My child gets very upset over the smallest things"; "It turns out that my child has more problems than I thought".

The PSI scale is implemented using a self-fill form. The mother is asked to read each question carefully. For each question, the mother needs to focus on thinking/relating to the child (child's name) and fill in the answer that best fits her opinion on 5 levels (from 1-5 and corresponding to the raw score of each subsection/item). For example, Fill in A if you strongly agree with that statement (5 points); Fill in B if you agree with the statement (4 points); Fill in C if you don't know, don't care about it (3 points); Fill in D if you disagree with the statement (2 points); Fill in E if you strongly disagree with the statement (1 point).

The Total PSI score is calculated as the sum of the three subscales and ranges from 36 to 180, higher scores indicating higher level of parenting stress. A score of 90 or more may indicate clinical stress (39).

Data collection: The investigators, who are preschool teachers, were trained and explained about the content and meaning of the questions, how to respond, and notes on using the PSI self-filling toolkit. During data collection, after explaining how to fill out the questionnaire, the interviewer also asked mothers to carefully read the instructions for self-filling written on the questionnaire. The investigator did not interfere in the mother's form filling process, but kept the necessary distance for the mother to approach when she needed further explanation on how to fill out the form.

Data analysis: Data was entered by Epiinfo, processed and analyzed by IBM SPSS Statistics software. The continuous variable of the PSI score will be compared with the corresponding score in the control area using the t-test. Multivariable linear regression was used to investigate the association between several independent variables with PSI. The significance level <0.05 was used in assessing the significance level of the statistical.

Ethical approval: The study was approved by the Ethics Committee of the Hanoi University of Public Health under Decision No. 302/2022/HD3.

RESULTS

There was total of 55 mothers participated in this study. All mothers had children with developmental disability, among whom 20% of the mothers have children with severe and very severe disability. The disabilities were mainly hearing, speech and intellectual disabilities. None of the households participating in the study were classified as poor based on local classification data.

Table 1. Disability status and maternal demographics by geography (n=55)

Characteristic	Classification	Geography		Total (%)
		Ward n (%)	Commune n (%)	
Children gender	Male	26 (72.2)	12 (63.2)	38 (69.1)
	Female	10 (27.8)	7 (36.8)	17 (30.9)
Time of continuous care (Children's age) group	4-6	30 (83.3)	13 (68.4)	43 (78.2)
	>6-9	6 (16.7)	6 (31.6)	12 (21.8)
Children's Birth order	First born	18 (50.0)	13 (68.4)	31 (56.4)
	Later born	18 (50.0)	6 (31.6)	24 (43.6)
Additional children with disability in the family	No	32 (88.9)	17 (89.5)	49 (89.1)
	Yes	4 (11.1)	2 (10.5)	6 (10.9)
Mother's age	18-24	14 (38.9)	7 (36.8)	21 (38.2)
	25-29	15 (41.7)	8 (42.1)	23 (41.8)
	30-40	7 (19.4)	9 (21.1)	11 (20,0)
Mother's occupation	Self-employed workers_Farmer	27 (75.0)	11 (57.9)	38 (69.1)
	Workers_Officers	9 (25.0)	8 (42.1)	17 (30.9)
Level of disability of the children	Mild	29 (80.6)	15 (78.9)	44(80)
	Severe and very severe	7 (19.4)	4 (21.1)	11 (20)

The result showed that there were 38 mothers have male children, accounting for 70%, 56% of them had the first children with development disabilities in the family, the group of mothers had children aged 4-6 were 43 and group of mothers had children aged >6-9 were 12, accounted for 78.2% and 21.8% respectively. This result showed that the mothers invested the same amount of time and continuous care of children, regardless of the children's age. Mothers with occupations as farmers and self-employed workers account for about 70% and are mainly in the age group at birth from 18-29 years old (80%). In the family participating in the study, about 11% of families have additional children with disabilities (besides the children diagnosed participating in the study). According to the classification of disability in the interdisciplinary diagnostic record, the majority of mothers had children (80%) with mild developmental disability, the number of children with severe and very severe disabilities is 11 (20%).

Table 2. Distribution values of areas and sum of scales and measures of normal distribution (n= 55)

Area	Medium	95% confidence interval	Median	Minimum -Maximum	Skewness and Kurtosis
1-Parent's distress	31.7	29.4-34.0	30	17-51	0.47/-0.55
2-The interaction between parents and children with disabilities	32.9	31.0-34.8	31	16-54	0.70/1.2
3-The influence of children with disabilities on their parents	32.6	30.0-35.2	33	14-51	-0.21/-0.67
Total area 1 and 2	64.6	60.9-68.3	64.0	34-102	0.62/0.96
Total scale (3 areas)	97.2	91.7-202.7	98	48-152	0.33/0.76

Table 2 shows that the average PSI scale score is 97.2 (CI 91.7-202.7), the average scores for each domains "1-Parent's distress", "2-The parent-child interaction", "3-Influence of children with disabilities on their parents" were 31.7 (CI 29.4 – 34.0); 32.9 (CI 31.0 -34.8) and 32.6 (CI 30.0 – 35.2), respectively. The results of the distribution test also showed that PSI scale and all of its domains had a normal distribution.

Table 3. Comparison of maternal stress status (PSI scores in domains and total scale scores) by the maternal demographic (n = 55)

		n	1-Parent's distress [a]	2-The interaction between parents and children with disabilities [a]	3-The influence of children with disabilities on their parents [a]	Total PSI score [a]
Children gender	male	38	31.9 (7.9)	33.4 (7.0)	34.0 (8.6)	99.2 (18.1)
	female	17	31.4 (9.9)	32.0 (7.6)	29.5 (11.2)	92.8 (25.0)
Time of continuous care (Children's age) group	4-6 years	43	**30.1 (7.7)**	**31.3 (5.4)**	31.6 (9.2)	**92.9 (17.3)**
	>6-9 years	12	**37.7 (8.9) ****	**39.0 (9.3)*****	36.1 (10.6)	**112.8 (24.0)****
Children's Birth order	First child	31	32.4 (9.1)	34.0 (7.4)	32.1 (10.0)	98.5 (22.2)
	Later child	24	39.8 (7.8)	31.5 (6.6)	33.2 (9.3)	95.6 (18.3)
Additional children with disability in the family	No	49	31.7 (9.0)	32.4 (7.2)	32.1 (9.8)	96.1 (21.1)
	Yes	6	32.2 (3.4)	37.7 (5.0)	36.5 (7.8)	106.3 (12.8)
Mother's occupation	Self-employed workers_Farmer	38	31.9 (8.8)	33.3 (7.6)	32.8 (9.9)	98.0 (21.6)
	Workers_Officers	17	31.4 (8.1)	32.2 (6.1)	32.1 (9.4)	95.6 (18.1)

		n	1-Parent's distress [a]	2-The interaction between parents and children with disabilities [a]	3-The influence of children with disabilities on their parents [a]	Total PSI score [a]
Level of disability of the children	Mild	44	31.5 (9.0)	**31.6 (6.3)**	**31.3 (9.2)**	**94.4 (19.1)**
	Severe and very severe	11	32.6 (6.5)	**38.4 (7.8)****	**37.8 (9.8)***	**108.8 (22.5)***

a. Mean (Standard deviation)
*b. Independent t-test: * p < 0.05, ** p < 0.01, *** p < 0.001*

When comparing the distribution of PSI status by age group (table 3) of children with disabilities, stress level of mothers in 3 areas including "1-Parent's distress", "2-The parent-child interaction", "3-Influence of children with disabilities on their parents" and the total PSI score are both significant higher in group of mother have more time of continuous care (over 6 to 9 years) than mothers in lower group (4-6 years). However, the difference was not statistically significant for field 3 (p>0.05).

The results showed that the total PSI scores tended to be higher in the group of mothers had male children (99.2 compared to 92.87), had first child with developmental disability (98.5 compared to 95.6), and in families with more children with disabilities (106.3 compared to 96.1) but this difference is not statistically significant with p>0.05.

Compare to the distribution of PSI by maternal demographic factors shows that maternal stress is higher in mothers who are farmers and self-employed (98.0 compared to 95.6), but this difference is not statistically significant with p>0.05.

Similar to the age group, maternal stress in caring for children is associated with the level of disability in children. Maternal stress were higher in children with more severe disability (severe and very severe) than in children with milder disabilities. However, the difference was not statistically significant for field 1 (p>0.05).

Table 4. Multivariable linear regression model to investigate the relationship between age and level of disability with stress status of the mothers (n=55)

PSI score	Univariable			Multivariable [a,b]		
	Coefficient	S. Error	95% CI	Coefficient	S. Error	95% CI
Children gender	-6.4	6.0	-18.4 - 5.6	-4.7	6.0	-16.9 - 7.4
Time of continuous care (Children's age) group	**19.8 ****	**6.2**	**7.4 - 32.2**	**15.5 ***	**7.1**	**1.2 - 29.9**
Children's Birth order	-3.0	5.6	-14.2 - 8.3	-1.0	5.3	-11.8 - 9.8
Additional children with disability in the family	10.2	8.8	-7.5 - 27.9	-1.4	10.3	-22.1 - 19.3
Mother's occupation	-2.4	6.0	-14.5 - 9.7	-3.4	6.1	-15.6 - 8.9

PSI score	Univariable			Multivariable [a,b]		
	Coefficient	S. Error	95% CI	Coefficient	S. Error	95% CI
Level of disability of the children	**14.4 ***	**6.7**	**1.05 - 27.9**	8.6	8.5	-8.4 - 25.7

a. R-squared = 0.1941, Adj R-squared = 0.0933

b. Intercept = 66.83

*c. * $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$*

Prior to model building, we conducted tests to ensure the validity and reliability of the analysis. Firstly, we examined the linearity assumption through scatter plots of the PSI scores against the independent variables. Next, we checked homoscedasticity by inspecting the scatter plot of residuals against the fitted values. Finally, to assess the normality of residuals, we generated histograms for comparison with the standard normal distribution. Based on the results of these tests, we confirm that the assumptions of linearity, homoscedasticity, and normality have been met in our model. Conducting these checks has been crucial in ensuring the accuracy and reliability of our multiple linear regression model.

The model showed that the mother in group >6 – 9 years of continuous care for children with developmental disabilities had 15.5 PSI scores significantly higher than the mother in group 4-6 years (95%CI 1.2 – 29.9). More and more year the mother lives with children.

The level of child disability was associated with maternal stress in univariate analysis (14.4; 95%CI 1.05 – 27.9) but not statistically significant in control multivariate analysis with all other factors.

DISCUSSION

Medical literature around the world shows that the level of stress on parenting of mothers with children with disabilities is often higher than that of mothers with normal children. In our study, the mean score of total pressure in two areas (1-Parent's distress and 2-The interaction between parents and children is difficult) was 64.6 (34-102, standard deviation 13.6) compared with 58.7 (29-98, standard deviation 10.5) in a study conducted on fathers with normal children in Chi Linh, Hai Duong (38). In a study in Malaysia (40) the mean total PSI score of both fathers and mothers of children with learning difficulties was 122.44 (SD=10,603), among mothers in Iran of children aged 6-12 years with chronic physical disease, psychological disturbances, or sensory-motor or mental problems (27) was 107.25 (SD = 10.18) and higher than the total PSI score in our study of 97.2 (SD=9.6). Differences in stress levels can be attributed to different ages and types of disabilities of children, so the stress level of mothers in caring for their children varies without consideringother possible family and social aspects, can indirectly increase mothers's stress in the care of children with disabilities. In our study, the results of univariate analysis showed that maternal stress is positively related to the child's disability level. Similar to the study by Ritzema et al. (32) maternal stress levels are related to the behavior of children with disabilities and change over time. Stress in caring for children with disabilities accumulates over time and is caused by many factors (14), the long-term investment of time and continuous care of children and the change in behavior of children with disabilities according to time is also related to maternal stress levels (18, 21, 32). In our study, the stress in caring for children with disabilities was related to the age of the children in both univariate and multivariate

linear regression analyzes controlled for the level of disability and the child's gender. Because the child's disability cannot change rapidly or may not change, the child grows up with his or her disability, so the disability is age related (3). The study by Feldman et al that examined the stress status of mothers of children with intellectual disabilities found that, stress level of mothers of school-age children is significantly higher than that of infants/toddlers and preschoolers. The results of the hierarchical multivariate regression analysis also showed that the child's age was one of the statistically significant predictors of parental stress (24). Similarly in the study of Orr et al (4) also showed that the stress level of mothers with children in the age group of 7-10 years is higher than that of mothers with children in the younger age group (2-6 years old). In the care of children with neurological disabilities(25) mothers of older children with disabilities (6-12) also reported higher levels of stress-related concerns for their children than mothers of younger children with disabilities (<6 years old).

The study encountered common challenges in studies of disability and special education: the small sample size and narrow age range, mainly in the pre-school age group, making the mean measurement less accurate and leading to limitation in summary of research results. In addition, because of the small sample size, the differences found may affect the p-values obtained in comparative tests.

CONCLUSION

Maternal stress in caring for children with intellectual disabilities is related to children's severity of disability type and time of continuous care. The mothers invested more time of continuous care for children with disability have more risk to get maternal stress. This finding needs to be further confirmed in studies with larger sample sizes. However, the findings from our study, together with the results from other studies, are good suggestions for developing an intervention program that focuses more on the group of older children and/or with severe disability; and also can help to reduce stress of mothers.

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