

Study on Family Burden of Parents with Children with Autism Spectrum Disorder

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Keywords: Autism Spectrum Disorder (ASD), Parents, Mental Burden.

Abstract. In this study, we evaluate mental burden of parents with children with autism spectrum disorders by using Self-compiled personal questionnaire composed by demographic and household data, Hospital Anxiety and Depression Scale (HADS) and the Parenting Locus of Control Scale (PLOC). And we use logistic regression analysis to explore the influencing factors of parents' mental burden. In conclusions, parents with children with ASD have much more mental burden than ordinary parents. More than half of them are in abnormal anxiety and depression. And those parents have some abnormal performances in educating their autistic children in the dimensions of educational effectiveness, children's control, and parental control, which is caused mainly by the proportion of treatment costs, the implementation of rehabilitation training program, as well as their degree of anxiety and depression.

Introduction

Looking after children with autism spectrum disorder (ASD) may pose challenges for families due to the nature of the core symptoms of the disorder, including impairments in social-communication and restrictive or stereotyped behaviors and interests [1], as well as additional functional impairments, co-occurring physical and mental health conditions, and challenging behavior problems.[2] Across the lifespan of individuals with ASD, family caregivers play an important role in supporting them. The wellbeing of families of individuals with ASD, however, rarely takes center stage in research and policy arenas alike. [3] Mostly, researchers pay attention to how to diagnose and treat ASD. In order to care family members with ASD, many family caregivers reduce their work hours while facing high out-of-pocket costs of care.[4]Due to their often-challenging behavior, many individuals with ASD require ongoing monitoring, thus limiting families' abilities to participate in social activities and contributing to their sense of social isolation.[5] For a whole family, it's a kind of burden and even a disaster sometimes. Family care giving is an emerging public health concern with multifaceted psychological, social, and economic implications.[6] ASD affects approximately 1 in every 68 children in the United States.[7] We can imagine the large number of autistic families in the world. Besides, for families with children with ASD, parents need to pay more time and money not only to care them but also to educate them.

The objectives of this study are using questionnaires to explore the factors which influence parental abnormal education with autistic children which can be regarded as a kind of burden for a family.

Methods

We conducted a cross-sectional survey study of 420 families with children with ASD who participated in Sino-American Autism Research Expert Experience Exchange Conference held in the Zhejiang University of Technology in 2016.

The survey domains included Self-compiled personal questionnaire composed by demographic and household data, Hospital Anxiety and Depression Scale (HADS) and The Parenting Locus of Control Scale (PLOC).

HADS has two dimensions, including anxiety and depression. According to its Chinese version compiled by Wei-fei Ye and Jun-mian Xu (1993), we use 9 points as a criterion to distinguish normal and abnormal.

PLOC has four dimensions, including educational effectiveness, parental responsibility, children's control, and parental control. Convergent validity studies showed that parents who had problems in educating their children had a higher score on external control in the dimensions of educational effectiveness, children's control, and parental control ($p < .02$). Further studies had shown that there was a high correlation between whether there was a problem in education for parents and the score of PLOC ($p < .0002$). In this study, we use its norms of subscales as criteria to distinguish abnormal and normal education for parents with autistic children.

We show descriptive data including means and standard deviations and percentages. We further computed logistic regression models exploring the factors which influence parental abnormal education by using SPSS 22.0.

Results

Of the 420 surveys sent, we received 399 available questionnaires. There were 341 boys and 58 girls aged from 1 to 22 years old ($M = 5.41$, $SD = 2.66$). The age of onset of symptom ranged from 0 to 60 months ($M = 23.63$, $SD = 9.51$) and the age of diagnosis ranged from 0 to 97 months ($M = 33.94$, $SD = 12.66$). For all the autistic children surveyed, the only child took up 73.2% and 94% of families with children with ASD were from towns and cities. Besides, more than half of autistic children (53.5%) attended ordinary schools and the rest of them accepted education in special education institutions or even couldn't accept any education and just stayed at home. What's more, only 25.3% parents got disabled cards for their children. And almost 93.7% of children tried training program about corresponding rehabilitation, but only 20.6% of children persisted the plan.

For households with children with ASD, the majority of respondents were female ($n = 334$) with at least a college education (59.6%). The age of parents ranged from 22 to 57 years old ($M = 35.72$, $SD = 4.70$). And approximately 67.2% of parents spent more

than 6 hours to accompany their children everyday. In 57.1% of families, the cost of treatment accounted for more than 30% of total household consumption.

The result of HADS revealed that 56.9% of parents were in abnormal anxiety (for all parents, $M = 17.37$, $SD = 3.66$), and about 54.6% of them were in abnormal depression (for all parents, $M = 16.99$, $SD = 3.70$).

We used the independent samples t-test to analyze the result of PLOC and found that compared with their norms, the scores of educational effectiveness ($t = 26.60$, $p < .001$), parental responsibility ($t = -10.13$, $p < .001$), children's control ($t = 29.91$, $p < .001$), and parental control ($t = 21.15$, $p < .001$) show significant differences and except the mean score of parental responsibility, the mean scores of rest dimensions are higher than their norms. And when we used its norms of subscales as criteria to distinguish abnormal and normal education for parents with autistic children, we found it showed significant difference between two groups in all dimensions ($p < .001$).

In order to explore the influencing factors of those dimensions which showed parental abnormal education, we computed logistic regression models for the three dimensions of educational effectiveness, children's control, and parental control. The dependent variable is the classification of parental abnormal and normal education. The screening variable consists of 13 variables, including the gender of children, the growth environment, the implementation of rehabilitation training program, the time spent with children everyday, the proportion of treatment costs, the degree of parents' anxiety and depression, and other variables. Then we carried out multiple-factor analysis by Logistic backward stepwise regression.

In the subscale of educational effectiveness, there were 342 parents (85.7%) classified into abnormal group and three variables into the model, i.e. the gender of children, the information of rehabilitation training program, and the degree of parents' depression. Then we carried out chi-square test on the regression model, and $\chi^2 = 21.298$, $p < .01$, which showed statistical significance. The results of logistic regression are shown in Table 1. The degree of parents' depression was a positive predictor for parental abnormal performance in the dimension of educational effectiveness. Besides, compared to 'have a detailed plan and insist on it', 'have a plan but not detailed' and 'had a detailed plan but not insisted on it' were positive predictors for parental abnormal performance from the implementation about rehabilitation training program.

In the subscale of parental control, there were 321 parents (80.5%) classified into abnormal group and three variables into the model, i.e. the implementation of rehabilitation training program, the proportion of treatment costs, and the degree of anxiety. Then we carried out chi-square test on the regression model, and $\chi^2 = 44.517$, $p < .001$, which showed statistical significance. The results of logistic regression are shown in Table 2. The degree of parents' anxiety was a positive predictor for parental abnormal performance in the dimension of children's control. Compared to 'have a detailed plan and insist on it', 'never have a plan', 'have a plan but not detailed' and

‘had a detailed plan but not insisted on it’ were positive predictors for parental abnormal performance from the implementation of rehabilitation training program.

Table 1 Logistic regression analysis results of factors of the educational effectiveness dimension

Screening variable	B	Wald	P	OR
the degree of depression	0.120	7.987	0.005	1.127(1.037,1.225)*
the implementation about rehabilitation training program [^]		7.296	0.063	
never have a plan	0.644	0.904	0.342	1.903(0.505,7.173)
have a plan but not detailed	0.663	4.012	0.045	1.941(1.014,3.713)*
had a detailed plan but not insisted on it	1.405	5.758	0.016	4.074(1.293,12.829)*
the gender of children	-1.005	3.347	0.067	0.366(0.125,1.074)

*Statistically significant at 0.05 or less.

[^]BaseN ‘have a detailed plan and insist on it’ = 82.

Table 2 Logistic regression analysis results of factors of the parental control dimension

Screening variable	B	Wald	P	OR
the degree of anxiety	0.146	13.240	0.000	1.158(1.070,1.253)*
the proportion of treatment costs [^]		8.598	0.072	
under 10%	-0.587	2.126	0.145	0.556(0.252,1.224)
10%~20%	0.332	0.577	0.447	1.394(0.592,3.285)
20%~30%	0.840	3.638	0.056	2.317(0.977,5.494)
30%~40%	0.220	0.327	0.567	1.246(0.587,2.642)
the implementation about rehabilitation training program [^]		17.474	0.001	
never have a plan	1.511	4.813	0.028	4.530(1.175,17.470)*
have a plan but not detailed	1.221	15.740	0.000	3.389(1.854,6.194)*
had a detailed plan but not insisted on it	1.075	5.846	0.016	2.930(1.226,7.002)*

*Statistically significant at 0.05 or less.

[^]Base N ‘have a detailed plan and insist on it’ = 82 and ‘over 40%’ = 152.

In the subscale of children’s control, there were 351 parents (88.0%) classified into abnormal group and three variables into the model, i.e. the gender of children, the proportion of treatment costs, and the degree of anxiety. Then we carried out chi-square test on the regression model, and $\chi^2 = 50.915$, $p < .001$, which showed statistical significance. The results of logistic regression are shown in Table 3. The degree of parents’ anxiety was a positive predictor for parental abnormal performance in the dimension of children’s control. Compared to ‘over 40%’, ‘10%~20%’ was a negative predictor for parental abnormal performance in the proportion of treatment costs.

Table 3. Logistic regression analysis results of factors of the children's control dimension

Screening variable	B	Wald	P	OR
the degree of anxiety	0.311	29.383	0.000	1.365(1.220,1.528)*
the proportion of treatment costs [^]		10.303	0.036	
under 10%	-0.774	2.172	0.141	0.461(0.165,1.291)
10%~20%	-1.376	8.273	0.004	0.253(0.099,0.645)*
20%~30%	-0.094	0.032	0.859	0.910(0.323,2.567)
30%~40%	-0.221	0.187	0.665	0.802(0.295,2.179)
the gender of children	-1.131	3.670	0.055	0.323(0.101,1.026)

*Statistically significant at 0.05 or less.

[^]Base N 'over 40%' = 152.

Discussion

Among a sample of parents of children with ASD in China, we can see a picture which is not very optimistic. There are almost 10 months between the onset of symptoms and the diagnosis. However, the sooner autistic children are diagnosed and intervened, the better their prognosis can be. What's more, the majority of parents we surveyed have the only child. So it's very important to make a quick and accurate diagnosis to release parents' mental burden. In our research, in order not to increase parents' own pressures and the hurt their children suffered from schools, more than two thirds of parents don't get disabled cards for their children and a third of parents don't let their children go to school. All parents love their children, although they are with ASD. Most parents tried training program about corresponding rehabilitation for their children. Nearly a third of parents gave up their job to look after their children all the day, but more than half of parents reported that the proportion of treatment costs is more than 30%, which confirm the conclusion of other researches that many family caregivers reduce their work hours while facing high out-of-pocket costs of care. [4] More than half of parents are in abnormal anxiety and depression, which show their great pressure and mental burden directly.

From the results of PLOC, we can found that parents have abnormal performance in educating their children with ASD in the dimensions of educational effectiveness, children's control, and parental control. And in following regression analysis, we can see that parents who are more anxious would feel children's control even stronger and control their children even stronger at the same time. For parents who are more depressed, they would feel less educational effectiveness and show a deep sense of hopelessness and helplessness. Compared to 'have a detailed plan and insist on it', the situation of 'have a plan but not detailed' and 'had a detailed plan but not insisted on it' would bring parents more helpless in educational effectiveness. But all the decisions of parents about rehabilitation training program represent a sense of control on their children with ASD. In the proportion of treatment costs, compared to 'over 40%', parents who reported '10%~20%' would be in a more unstrained atmosphere

from children's control.

Conclusions

Above all, we can conclude that parents with children with ASD have much more mental burden than ordinary parents. More than half of them are in abnormal anxiety and depression. And those parents have some abnormal performance in educating their autistic children in the dimensions of educational effectiveness, children's control, and parental control, which is caused mainly by the proportion of treatment costs, the implementation of rehabilitation training program, as well as their degree of anxiety and depression.

Acknowledgement

This research was financially supported by the National Social Science Major Project, interdisciplinary research on early detection, intervention and education of autistic children (12&ZD229).

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