

Parenting Stress and Related Factors in Parents of Children With Tourette Syndrome

Mei-Yin Lee • Yueh-Chih Chen* • Huei-Shyong Wang** • Duan-Rung Chen***

ABSTRACT: The objective of this study was to assess the stress of parents and its influencing factors in caring for children with Tourette syndrome. A total of 150 subjects, either fathers or mothers of children diagnosed with Tourette syndrome between the ages of 6 and 12, were recruited by purposive sampling from the membership roster of the Taiwan Tourette Family Association. Study tools included a Parenting Stress Index Form and Social Support Index Form. The standardized score for parent perception of parenting stress was 83.5. The main stressor of parents of children with Tourette syndrome was found to be child care difficulties. A correlation was found between parenting stress and child gender, age, school situation and disease severity; parent age and family income. A significant negative correlation ($r = -.459, p < .01$) was found between social support and parenting stress. It was revealed that social support had a significant effect on parenting stress in this study. Multiple linear regression analysis found disease severity and family income to be the variables with the greatest predictive power for parenting stress, explaining 42% of total variance. Results showed that factors affecting parenting stress included family income and disease severity. These findings should help clinical professionals develop more effective health care strategies to address the needs of children with Tourette syndrome and their parents.

Key Words: Tourette syndrome, parenting stress, social support.

Introduction

Tourette syndrome, a chronic neuropsychiatric disorder of childhood, has a prevalence rate of 4.28 in every 10,000 people and a male-to-female ratio of 3–4:1 (Golden & Hood, 1982). Onset of the disorder in Taiwan occurs before the tenth birthday in 84% of cases – a rate similar to that of other countries. The first study of Tourette syndrome in Taiwan included 32 children, seven of whom had a family history of single or multiple tics (Wang & Sung, 1984).

Motor and vocal tics represent the main symptoms of Tourette syndrome. Onset of the disorder usually takes place between ages 2–18, with a mean onset age of 7 (Wang, 2001a). Hyperactivity, compulsive and learning disorders often occur in combination with Tourette syndrome, which may affect sufferers' development of social

relationship skills (Lin, 1997; Peng, 2001; Wang, 1999; Wang, 2001b).

Although Tourette syndrome is considered a neurological rather than a psychiatric problem, its pathogenetic mechanism is not yet understood. Many scientists believe hyper-responsiveness of post-synaptic dopamine receptors affects the basal ganglia and the connected motor cortex (Scahill, 1996; Wang, 2001a). After establishing a diagnosis of Tourette syndrome, assisting children, parents and those with whom they interact in society to understand and accept the disorder is more important than drug therapy. It is also important not to overlook other coexisting emotional problems, such as comorbid disorders (Harlan, 1996; Wang, 2001b). Nurses provide a very important link between families, doctors and teachers, and must be able to assess symptoms and related behavior. Regardless of sym-

RN, MSN, Doctoral Student, Institute and Faculty of Nursing, School of Nursing, National Yang Ming University; *RN, PhD, Professor, School of Nursing, College of Medicine, National Taiwan University; **MD, Visiting Staff, Division of Pediatric Neurology, Chang Gung Children's Hospital & Associate Professor, College of Medicine, Chang Gung University; ***PhD, Associate Professor, Institute of Health Care Organization Administration, College of Public Health, National Taiwan University.

Received: July 6, 2006 **Revised:** March 1, 2007 **Accepted:** July 19, 2007

Address correspondence to: Yueh-Chih Chen, No. 1, Ren Ai Rd. Sec. 1, Taipei 10051, Taiwan, ROC.

Tel: 886(2)2312-3456 ext. 8423; Fax: 886(2)2321-9913; E-mail: ychichen@ntu.edu.tw



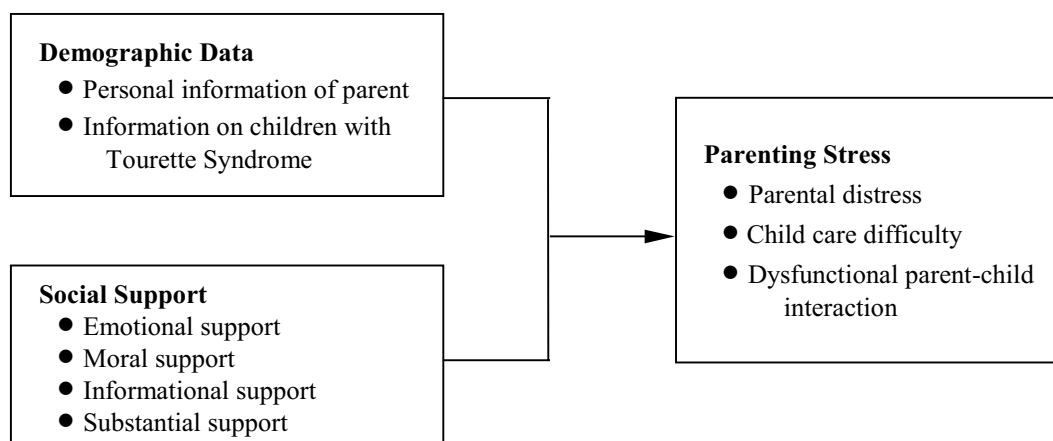


Figure 1. The relationship between demographic data, social support, and parenting stress.

ptom severity or complexity, sufferers must be cared for and referred appropriately (Adkins, 1989).

Study of Tourette syndrome has been very limited in Taiwan. Wang and Wei (2006) found that children with this disorder have received a great deal of attention in special education in recent years. However, children with Tourette syndrome, who must learn to live with their disease, remain short of such resources and support. The stress and frustration they and their family face are beyond our imagination (Hsieh & Wang, 2002).

Parenting stress is the pressure experienced by parents rooted in their interactions with their children (Abidin, 1990). Fuller and Rankin (1994) indicated that parenting stress levels are higher in mothers whose children receive special education than in those with children enrolled in the normal school curriculum. The mental, physical, and growing problems of children place pressure on parents. If parents cannot adapt, handle the situation, or deal appropriately with their children's behavior, they lose confidence, which can devolve in to teaching pressure that can cause them to lose their teaching function as well (Abidin, 1990). Wang and Jong (2004) indicated that parenting stress levels are typically higher in parents of children with cerebral palsy than in those with normal children. Pearson and Chan (1993) stated parenting stress in mothers of Chinese children with a learning disability showed that social support works as a catalyst for building up a greater defense against the effect of unpleasant experiences. Yin (1994) indicated family income to be associated positively with social support and level of parenting stress to have a positive correlation with child abuse. The way parents deal with Tourette syndrome reflects their personal characteristics, ability to

handle stress and uncertainty, and social support and medical care received (Hsieh & Wang, 2002).

In summary, parents of children with health problems face significantly higher levels of pressure and are more likely to feel hopelessness/fear regarding their child's condition and treatment. This research focused on achieving the following three objectives: (1) identify the key behavioral problems, parenting stressors and social support needs related to children with Tourette syndrome; (2) analyze case data and relationships between parenting stress and social support of children with Tourette syndrome; and (3) discuss the main predictive variables influencing parenting stress. The framework of this research is presented in Figure 1.

Methods

Research Subjects and Tools

Subjects in this study consisted of 150 primary caregivers (both fathers and mothers) of children aged 6–12 diagnosed with Tourette syndrome by a pediatric neurologist. Parents of children with concurrent other chronic neuropsychiatric disorders or disabilities were excluded. Subjects were registered with the Taiwan Tourette Family Association. One of the authors of this study joined the Taiwan Tourette Family Association and served as the deputy chief on the Association's volunteer committee in order to better appreciate the pressures and problems faced by research subjects. A structured questionnaire, finalized to reflect expert suggestions and formats recommended in the literature, was distributed to subjects after receiving their written consent. All data acquired were handled anonymously (Abidin, 1995; Cohen, Jankovic, & Goetz, 2001;

Jen, 1995; Yang, 1998). The questionnaire comprised three sections as follows: (1) Demographic data on children and parents (including child's gender, age, education, length of time since Tourette diagnosis and syndrome severity and parent gender, age, number of children, monthly income, and family type); (2) The Parenting Stress Index-Short Form (Abidin, 1995) translated into Chinese by Jen (1995) and including 34 items used to obtain an overall score as well as scores for three subscales (i.e., child care difficulty, parental distress, and dysfunctional parent-child interaction). Each score had a total possible range of between 34 and 170, with score values correlating positively to level of parenting stress. The average expert validity score for the Parenting Stress Index Form was 4.66. Average scores for subscales fell between 4.62 and 4.68. Content validity indexes were all greater than .91 and reliability test results showed a Cronbach α for the Parenting Stress Scale of .91, and .87, .82 and .83, respectively, for the three subscales. This was similar to the reliability found by Jen (1995), Lin and Chung (2002) and Lin (2003); and (3) The Social Support Scale, based on a revision of the scale designed by Yang (1998). This scale comprised 16 items covering the four subscales of informational, emotional, moral, and substantial support. Each score ranged from 16 to 64, with scores correlating positively with level of social support. The average expert validity score was 4.55 for the Social Support Scale and between 4.50 and 4.63 for its subscales. The content validity indexes all exceeded .90. Cronbach's α for the 4 subscales were .86, .72, .88 and .82, respectively, and .94 for the total scale, a finding similar to that of Yang's study (1998). Walkup, Rosenberg, and Brown (1992) reported that the Yale Global Tic Severity Scale (YGTSS) can be employed to assess effectively Tourette syndrome severity with good reliability and validity. The YGTSS consists of separate ratings of severity for motor and phonic tics along the five historical and objective dimensions of number, frequency, intensity, complexity, and interference. Cohen et al. (2001) indicated that the severity of motor and phonic tic behaviors can be evaluated using the YGTSS assessment method. This method is better than any another assessment tool known to the authors.

Data Analysis

The data gathered in this research was analyzed using SPSS/PC for Windows Release 10.0, including descriptive

statistics: percentage and average, and inferential statistics: *t*-test, ANOVA, Pearson's product-moment correlation coefficient, and multiple linear regression.

Results

Demographic Characteristics

The 150 subjects in this study included 115 females and 35 males. Mean age was 39.3 ($SD = 4.5$); 91 (60.7%) subjects had two children; 25 (16.7%) had a monthly income of less than NTD \$40,000; and 102 (68%) subjects lived in a family format in which parents and children lived together. Of children with Tourette syndrome, 132 (88%) were male and 18 (12%) female; mean age was 9.3 ($SD = 1.8$) and 60 (40%) were second-born. Slightly over one-third (35.4%) were in the third or fourth grade of elementary school. Less than a year had passed since Tourette syndrome diagnosis was made in 51 (34%) children. Mean score for disease severity was 16.7 ($SD = 10.2$) (Table 1).

Score Ranges for Parenting Stress and Social Support

The mean parenting stress level score was 83.5 ($SD = 18.3$). Analysis of the mean item scores of the three subscales revealed that the level of parenting stress was highest for "child care difficulty" and lowest for "dysfunctional parentchild interaction". The mean score for the level of social support was 40 ($SD = 10.6$). Further analysis of the social support subscales revealed that mean item scores were highest for emotional support and lowest for substantial support (Table 2).

Relationships Between Parenting Stress and Related Factors

Parenting stress (subscales) was greater in cases where the child was a male or in the first grade of junior high school. Subjects under 30 years of age or earning a monthly family income of less than NTD 40,000 showed a relatively high level of overall parenting stress. Further analysis of the three parenting stress subscales showed that parents under the age of 30 or earning a monthly family income of less than NTD 40,000 had a comparatively high level of parental distress (Table 3). A Pearson correlation test revealed that child age and syndrome severity to be significantly associated with level of parenting stress. A significant positive correlation was found between the syndrome severity and overall parenting stress ($r = .224$,

Table 1.
Demographic Characteristics of Study Sample (N = 150)

Variables	n	%	M ± SD	Min-Max
Patient Characteristics				
Gender				
Male	132	88		
Female	18	12		
Age			9.31 ± 1.8	6–12
Education				
Kindergarten	13	8.7		
Elementary school 1st and 2nd grade	42	28		
Elementary school 3rd and 4th grade	53	35.4		
Elementary school 5th and 6th grade	37	24.6		
Junior high school 1st grade	5	3.3		
Duration of Diagnosis with TS				
< 1 year	51	34		
1 year to > 2 years	43	28.7		
2 year to > 3 years	29	19.3		
3 year to > 4 years	10	6.7		
> 4 years	17	11.3		
Severity of TS			16.7 ± 10.2	2–47
Parent Characteristics				
Gender				
Male	35	23.4		
Female	115	76.6		
Age			39.3 ± 4.5	30–51
< 30	4	2.7		
31–40	86	57.3		
> 41	60	40		
Number of Children				
1	19	12.7		
2	91	60.7		
≥ 3	40	26.6		
Monthly Income				
Less than 40,000	25	16.7		
40,001–60,000	45	30		
60,001–100,000	46	30.7		
100,001 or above	34	22.7		
Family Structure				
Parents and children live together	102	68		
Other	48	32		

Note. TS = Tourette syndrome.

Table 2.
Scores on the Overall Scale and Sub-Scales for Parenting Stress and Social Support (N = 150)

Item	Range	M ± SD	Mean item score
Overall parenting stress	34–170	83.5 ± 18.3	2.5
Subscales			
Child care difficulty	13– 65	37.3 ± 9.0	2.9
Parental distress	11– 55	25.3 ± 6.6	2.3
Dysfunctional parent-child interaction	10– 50	20.8 ± 6.7	2.1
Overall social support	16– 64	40.0 ± 10.6	2.5
Subscales			
Informational support	5– 20	12.2 ± 3.7	2.4
Emotional support	4– 16	10.7 ± 2.9	2.7
Moral support	3– 12	7.9 ± 2.2	2.6
Substantial support	4– 16	9.8 ± 3.1	2.4

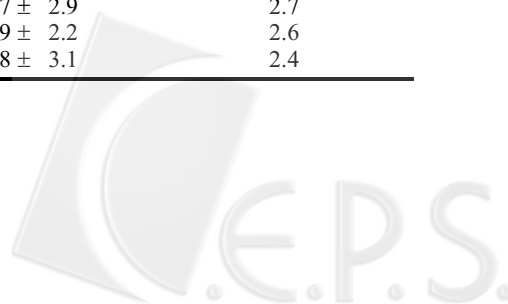


Table 3.
Difference Between Demographic Characteristics and Parenting Stress (N = 150)

Variables	Parental distress subscale	Dysfunctional parent-child interaction subscale	Child care difficulty subscale	Overall parenting stress
	<i>M ± SD</i>	<i>M ± SD</i>	<i>M ± SD</i>	<i>M ± SD</i>
Patient Characteristics				
Gender				
Male	25.62 ± 6.58	21.13 ± 6.77	37.57 ± 8.48	84.32 ± 17.49
Female	23.28 ± 8.93	18.22 ± 6.08	35.56 ± 12.37	77.06 ± 23.17
<i>t</i> value	-2.265*	-1.710	-.7779	-1.449
Education				
① Kindergarten	27.54 ± 5.65	18.92 ± 4.48	36.69 ± 8.79	83.15 ± 14.30
② Elementary school 1st and 2nd grade	25.62 ± 6.51	19.81 ± 7.28	35.95 ± 9.60	81.38 ± 19.14
③ Elementary school 3rd and 4th grade	26.23 ± 7.60	20.77 ± 6.43	38.94 ± 7.58	85.94 ± 16.92
④ Elementary school 5th and 6th grade	22.68 ± 6.04	21.95 ± 7.09	36.54 ± 9.62	81.16 ± 19.58
⑤ Junior high school 1st grade	27.60 ± 8.20	25.20 ± 6.34	39.20 ± 14.04	92.00 ± 26.58
<i>F</i> value	9.104*	6.668	3.833	4.271
Scheffe	⑤ > ① > ③			
Duration of Diagnosis with TS				
< 1 year	25.53 ± 7.06	19.47 ± 5.57	36.82 ± 8.31	81.82 ± 16.04
1 year to > 2 years	24.81 ± 7.32	21.05 ± 7.77	36.84 ± 9.27	82.7 ± 20.44
2 year to > 3 years	26.55 ± 6.82	21.79 ± 7.07	39.62 ± 9.04	87.97 ± 18.93
3 year to > 4 years	22.7 ± 6.82	19.4 ± 5.78	36.1 ± 9.17	78.2 ± 19.66
> 4 years	25.59 ± 5.69	23.12 ± 6.85	36.88 ± 10.53	85.59 ± 17.69
<i>F</i> value	2.808	4.231	2.834	3.884
Parent Characteristics				
Gender				
Male	24.2 ± 5.52	20.34 ± 6.31	35.40 ± 8.12	79.94 ± 14.51
Female	25.69 ± 7.26	20.91 ± 6.88	37.91 ± 9.21	84.51 ± 19.27
<i>t</i> value	-.875	-.209	-1.726	-1.318
Age				
① < 30	35.25 ± 9.60	27.25 ± 9.64	42.00 ± 1.83	104.5 ± 18.48
② 31-40	25.98 ± 7.04	20.86 ± 6.92	37.87 ± 1.83	80.23 ± 18.74
③ > 41	23.77 ± 5.88	20.23 ± 6.15	36.23 ± 9.36	83.45 ± 16.8
<i>F</i> value	8.368*	2.272	2.802	6.930
Scheffe	① > ② > ③			
Number of Children				
1	25.5 ± 6.81	21.35 ± 5.71	38.75 ± 10.88	85.60 ± 19.20
2	24.85 ± 6.52	20.24 ± 6.28	36.99 ± 7.77	82.09 ± 16.23
≥ 3	26.35 ± 7.81	21.70 ± 8.11	37.38 ± 10.62	85.43 ± 22.17
<i>F</i> value	1.872	1.581	1.432	1.914
Monthly Income				
① Less than 40,000	28.00 ± 8.33	22.88 ± 7.61	40.36 ± 8.62	91.84 ± 20.48
② 40,001-60,000	26.29 ± 6.68	20.60 ± 6.40	36.07 ± 9.35	82.96 ± 17.21
③ 60,001-100,000	24.52 ± 6.07	20.85 ± 6.49	38.89 ± 7.43	84.26 ± 16.69
④ 100,001 or above	22.79 ± 6.19	19.38 ± 6.74	34.65 ± 10.01	76.82 ± 18.35
<i>F</i> value	9.180*	3.765	6.200	8.286*
Scheffe	① > ② > ③			① > ③ > ②

**p* < .05.

p < .01), the parental distress subscale (*r* = .171, *p* < .05) and the child care difficulty subscale (*r* = .252, *p* < .01). This means the greater the severity of the syndrome, the more parenting stress that parents suffered. Another significant positive correlation was found between child age and the parent-child interaction subscale (*r* = .196, *p* < .05) (Table 4).

Individuals who provided the most social support to subjects were, respectively, the spouse, parents, other relatives and friends (including other families of children with Tourette syndrome and teachers). A significant negative correlation was found between overall social support and overall parenting stress (*r* = -.459, *p* < .01), the parental

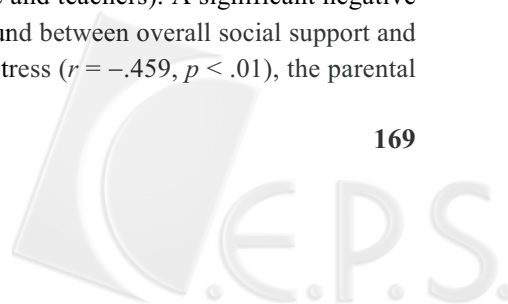


Table 4.
Correlation Analysis for Demographic Characteristics and Parenting Stress (N = 150)

Variables	Parental distress subscale	Dysfunctional parent-child interaction subscale	Child care difficulty subscale	Overall parenting stress
Patient age	-.106	.196*	.016	.033
Severity of TS	.171*	.134	.252**	.244**

* $p < .05$. ** $p < .01$.

Table 5.
Correlation Analysis of Social Support and Parenting Stress (N = 150)

Variables	Parental distress subscale	Dysfunctional parent-child interaction subscale	Child care difficulty subscale	Overall parenting stress
Emotional support subscale	-.318	-.327	-.315	-.390
Moral support subscale	-.332	-.327	-.408	-.438
Informational support subscale	-.369	-.263	-.349	-.403
Substantial support subscale	-.353	-.273	-.369	-.414
Overall social support	-.374**	-.273**	-.406**	-.459**

** $p < .01$.

Table 6.
Multiple Linear Regression on the Parenting Stress (N = 150)

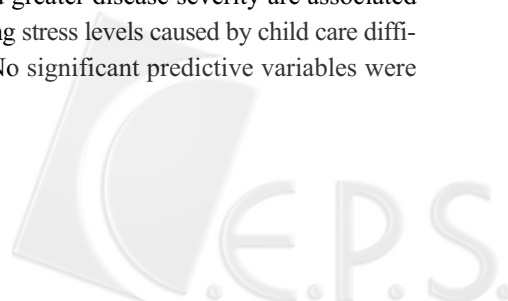
Variable	Overall parenting stress			Parental distress (subscale)			Child care difficulty (subscale)		
	B	Beta	R ² /F	B	Beta	R ² /F	B	Beta	R ² /F
(Constant)	105.03		.42/6.012**						
Family income	-2.72	-.15							
Disease severity	0.32	.18							
(Constant)				39.46		.34/4.283**			
Family income				-1.51	-.22				
(Constant)							43.23		.366/4.802**
Child age							-1.59	-.32	
Disease severity							0.2	.23	
School situation							2.78	.30	

** $p < .01$.

distress subscale ($r = -.374, p < .01$), the dysfunctional parent-child interaction subscale ($r = -.273, p < .01$), and the child care difficulty subscale ($r = -.406, p < .01$) (Table 5).

Multiple linear regression was used to identify predictors of parenting stress. The parenting stress total and 3 subscales were designated as dependent variables. These variables showed a either correlation or significant difference with parenting stress under univariate analysis when child gender, age, education, severity of Tourette syndrome, family income, social support independent variables. Results also showed disease severity and family income to be significant predictive variables ($F = 6.012, p < .01$) for overall parenting stress, explaining 42% of total variance. Results further indi-

cate that overall parenting stress correlates positively with disease severity and negatively with family income. Family income was a significant predictive variable ($F = 4.283, p < .01$) for the parental distress subscale, explaining 34% of the total variance and indicating lower family income to be associated with higher parenting stress resulting from parental distress. Child age, disease severity and school situation were significant predictive variables ($F = 4.802, p < .01$) for the child care difficulty subscale, explaining 36.6% of total variance. This finding means that, for younger children, a higher education level and greater disease severity are associated with higher parenting stress levels caused by child care difficulties (Table 6). No significant predictive variables were



identified in this study for the dysfunctional parent-child interaction subscale.

Discussion

The mean score for overall parenting stress in subjects participating in this study was 83.5. Child care difficulties represented the main parenting stressor. These results were similar to studies on parenting stress in parents of children with attention deficit hyperactive disorder and other diseases using the Parenting Stress Index-Short Form (Lai, 1998; Lin & Chung, 2002). There is a 50% to 90% chance that hyperactivity will occur in combination with Tourette syndrome. Attention Deficit Hyperactivity Disorder (ADHD) and compulsive and learning disorders also occur often in combination with Tourette syndrome (Cohen et al., 2001). Certain characteristics and temperaments of children with Tourette syndrome can be sources of trouble to parents, causing problems with adaptability, emotional states, needs, activity level and problem behavior (Abidin, 1990). It is therefore imperative to identify methods to deal constructively and correctly with those characteristics that make caring for children with Tourette syndrome so difficult.

No significant difference in overall parenting stress was found between families of female and male children with Tourette syndrome. This is similar to the findings of studies that used questionnaires similar to the one used in this study to measure parenting stress in parents of children with different diseases (Jen, 1995; Lin & Chung, 2002; Lin, 2003; Yu & Kuo, 2001). Stress caused by parent distress was greater in male than female children with Tourette syndrome; a finding similar to that of a previous study (Lin & Chung, 2002). This may be related to the relatively greater severity of the disease in males as compared to females and the greater likelihood of boys to be adventurous and lively. Older children tended to have relatively higher stress level due to dysfunctional parent-child interaction, and the levels of parenting stress caused by parental distress measured relatively high in parents of children in their first year of junior high school.

Symptoms of Tourette syndrome are easily perceived, becoming increasingly severe through the early stages of adolescence and potentially lessening somewhat during mid- to late-adolescence. When Tourette syndrome is diagnosed, or when symptoms become more severe and problems appear at school or in the child's behavior, family therapy can be applied to assist family members to cope

with the situation (Barbara, 1999). Children in the first year of junior high school are in early adolescence, a time of physiological change, the formation of peer groups and self-identification, and attempts to reduce their parents' authority in their lives. Strains and disagreements in the parent-child relationship may further lead to increased parenting stress. Increased Tourette syndrome severity is associated with greater overall parenting stress and stress in the three parenting stress subscales. One mother participating in this study noted: *"When I'm at home and think that the symptoms are very severe, I feel extremely stressed. But when I'm at the outpatient department and see children with symptoms far more severe than our child's -- children that jump and shout, I think that others may be even more stressed than we are."*

Overall stress was greater in subjects below the age of 30; a finding consistent with those of previous studies (Jen, 1995; Tseng & Chou, 2006). Parenting stress attributable to distress was also greater in subjects below the age of 30; a finding also consistent with those of previous studies (Lin & Chung, 2002). This may have to do with the fact that younger parents have relatively little experience in their roles as parents and that, as Tourette syndrome is a complicated problem, these parents lack confidence. Our finding showing that overall parenting stress and parental distress subscale were greater in parents earning a monthly family income of less than NT 40,000 was consistent with several previous studies (Jen, 1995; Lo, 1997; Yin, 1994). Medical visit frequencies will be affected by a family's economic condition, with lower income families likely to take their children with Tourette syndrome less frequently than those in better economic straits. Consequently, illness and problem behaviors associated with the disease are more likely to increase parent stress.

Lower levels of social support were associated with higher parenting stress (including overall and for all three subscales), a finding similar to the results of previous studies of parents and their children (Lai, 1998; Lin, 2003; Lo, 1997; Pearson & Chan, 1993; Yin, 1994). Also similar to previous studies was the finding that "emotional support" earned the highest mean item score (Chuang, 2000; Lo, 1997; Yang, 1998). Subjects most often received social support from their spouse, a finding also consistent with previous studies (Chuang, 2000; Pearson & Chan, 1993). It is very important to deal with children suffering from Tourette syndrome in a correct and proper manner. Social support can alleviate parents' pressure. Support group partici-

pation can help parents to obtain more useful resources. Therefore, nursing staff can try to develop parent training groups in order to relieve parenting stress.

Conclusions and Suggestions

The standardized score for parent perception of parenting stress was 83.5. The main stressor for parents of children with Tourette syndrome was attributed to child care difficulties. A correlation was found between parenting stress and their child's gender, age, school situation, disease severity, parent age and family income. Results showed that factors affecting parenting stress included family income and disease severity. In addition to motor and vocal tics, Tourette syndrome can cause problem behaviors such as obsessive compulsive disorder, attention deficit hyperactivity disorder and self injury behavior. In addition, syndrome severity tends to be erratic and unpredictable, which makes parents worry even more about their child's condition and the further elevate the level of pressure perceived by parents. Family support and encouragement, the sharing of experiences between parents of children with Tourette syndrome, and intervention by and assistance from the Taiwan Tourette Family Association can all play a positive role in reducing parenting stress. However, 5.5% to 15.83% of subjects reported not receiving functional social support as categorized by the four types. Further evaluation of the reasons underlying this lack of a social resource network is needed, as is increased understanding of Tourette syndrome by health professionals. This research only studied parents who are members of the Taiwan Tourette Family Association. Further research should study the parents of children with Tourette syndrome island-wide in order to obtain a better understanding of the current situation in Taiwan as a whole. As disease onset mostly takes place while children are in early school age, programs to increase school nurse sensitivity to Tourette syndrome and to encourage adequate referrals for special care are important. Furthermore, programs which result in increased public understanding and tolerance of Tourette syndrome sufferers are needed. Giving more support to parents of children with Tourette syndrome may also lead to decreased parenting stress and improved quality of life.

Acknowledgment

This study could not have been completed without the expert assistance of Wang-Zuo Li, Shu-Hui Li, Xu-Fang

Li, Bih-Shya Gau and Shi-Jie Zeng, who reviewed the questionnaires and provided valuable clinical experience. We are also indebted to the 150 parents of children with Tourette syndrome who participated enthusiastically in the study. Special thanks also go to the Taiwan Tourette Family Association for their full support.

References

- Abidin, R. R. (1990). Introduction to the special issue: The stresses of parenting. *Journal of Clinical Child Psychology, 19*, 298–301.
- Abidin, R. R. (1995). *Parenting stress index-test manual* (3rd ed.). Charlottesville, VA: Pediatric Psychological Press.
- Adkins, A. S. (1989). Helping your patient cope with Tourette syndrome. *Pediatric Nursing, 15*, 135–137.
- Barbara, M. (1999). *Coping with Tourette syndrome and Tic disorder*. New York: Rosen.
- Chuang, H. L. (2000). *The perceived stress and psychological distress of parents with premature infants in the PNICU*. Unpublished master's thesis, Chang Gung University, Taoyuan, Taiwan, ROC.
- Cohen, D. J., Jankovic, J., & Goetz, C. G. (2001). *Advances in neurology Vol. 85 Tourette syndrome*. New York: Lippincott Williams & Wilkins.
- Fuller, G. B., & Rankin, R. E. (1994). Differences in levels of parenting stress among mothers of learning disabled, emotionally impaired, and regular school children. *Perceptual and Motor Skills, 78*, 583–592.
- Golden, G., & Hood, O. (1982). Tics and tremors. *Pediatric Clinics of North American, 29*, 95–103.
- Jen, W. S. (1995). *Parenting stress, coping strategy and satisfaction of parent-child relations*. Unpublished master's thesis, National Taiwan Normal University, Taipei, Taiwan, ROC.
- Harlan, C. (1996). The child with Tourette syndrome. *Canadian Nurse, 92*, 27–30.
- Hsieh, Y. L., & Wang, H. S. (2002). Explore the influence on quality of life with Tourette syndrome children. *Taiwan Medical Journal, 45*(8), 16–20.
- Lai, Y. C. (1998). *Family need welfare, social support and parenting stress in relation of children with attention-deficit hyperactive disorder*. Unpublished master's thesis, Chinese Culture University, Taipei, Taiwan, ROC.
- Lin, P. Y. (2003). *A comparative study of parental stress and quality of life between congenital heart disease and healthy children's mother*. Unpublished master's thesis, National Taiwan University, Taipei, Taiwan, ROC.

- Lin, K. C. (1997). Tourette syndrome. *Medical Digest*, 24(1), 79–83.
- Lin, Y. F., & Chung, H. H. (2002). Parenting stress and parents' willingness to accept treatment in relation to behavioral problems of children with attention-deficit hyperactive disorder. *The Journal of Nursing Research*, 10(1), 43–56.
- Lo, K. W. (1997). *A study on social support and mother parenting stress from daily care for school-aged child of end-stage renal failure*. Unpublished master's thesis, National Defense University, Taipei, Taiwan, ROC.
- Pearson, V., & Chan, T. W. L. (1993). The relationship between parenting stress and social support in mothers of children with learning disabilities: A Chinese experience. *Social Science Medicine*, 37(2), 267–274.
- Peng, S. L. (2001). Comorbid conditions and disorder associated with Tourette's disorder. *ACTA Paediatrica Taiwanica*, 42(suppl.), 13–18.
- Scahill, L. (1996). Contemporary approaches to pharmacotherapy in Tourette's syndrome and obsessive – compulsive disorder. *Journal of Child & Adolescent Psychiatric Nursing*, 9, 27–43.
- Tseng, T. J., & Chou, C. C. (2006). Parental stress in mothers of children with asthma. *The Journal of Nursing*, 53(4), 31–41.
- Walkup, J. T., Rosenberg, L. A., & Brown, J. (1992). The validity instrument measuring Tic severity in Tourette's syndrome. *Journal of the American Academy of Child & Adolescent Psychiatry*, 31, 472–477.
- Wang, H. S. (1999). *Trembling and shouting – The fight against Tourette syndrome* (1st ed.). Taipei: Cindi.
- Wang, H. S. (2001a). Clinical diagnosis and management of Tourette syndrome. *ACTA Neurological Taiwanica*, 10(3), 219–228.
- Wang, H. S. (2001b). An introduction of Tourette syndrome. *ACTA Paediatrica Taiwanica*, 42(suppl.), 8–12.
- Wang, H. S., & Wei, M. H. (2006). The study of the children with Tourette's syndrome: Their related learning and adjustment problems. *Special Education Quarterly*, 99, 19–23.
- Wang, H. Y., & Jong, Y. J. (2004). Parental stress and related factors in parents of children with cerebral palsy. *The Kaohsiung Journal of Medical Sciences*, 20(7), 334–340.
- Wang, X. Y., & Sung, W. C. (1984). Gilles de la Tourette syndrome: Clinical manifestation in Chinese patients. *Journal of the Formosan Medical Association*, 83, 119–126.
- Yang, Y. S. (1998). *Social support and well-being in patients with epilepsy*. Unpublished master's thesis, National Yang Ming University, Taipei, Taiwan, ROC.
- Yin, Y. J. (1994). *Social support, parenting stress and child abuse potential in abused and nonabused parents*. Unpublished master's thesis, Chinese Culture University, Taipei, Taiwan, ROC.
- Yu, Y. C., & Kuo, B. J. (2001). Parenting stress in women who conceived using assisted reproductive technology. *Nursing Research*, 9(3), 344–353.

妥瑞症患童父母親職壓力及其相關因素之探討

李美銀 陳月枝* 王輝雄** 陳端容***

摘要：本研究目的為探討妥瑞症患童父母親職壓力及其相關影響因素。為一相關性研究，採立意取樣，運用結構式問卷，以台灣妥瑞症協會 6-12 足歲罹患妥瑞症患童的父母 150 位為研究對象。研究工具包括「親職壓力量表」及「社會支持量表」。結果顯示父母感受親職壓力標準化得分為 83.5 分，感到最主要的親職壓力來源是孩子難養育的行為特質。患童性別、年齡、就學情形、疾病嚴重度、父母年齡、家庭收入與親職壓力有顯著相關。社會支持程度與親職壓力呈顯著負相關 ($r = -.459, p < .01$)，顯示社會支持對研究對象的親職壓力有相當大的影響。複迴歸分析發現，妥瑞症患童父母對於整體親職壓力最具預測力變項為疾病嚴重度及家庭收入，兩變項可解釋 42% 的總變異量。當家庭收入愈低、孩童妥瑞症症狀嚴重度愈高，父母的親職壓力愈大。本研究結果可提供臨床、學校及社區的相關人員對妥瑞症孩童護理周延性之參考。

關鍵詞：妥瑞症、親職壓力、社會支持。

國立陽明大學護理學系暨研究所博士生 *國立台灣大學護理學系教授 **長庚兒童醫院小兒神經科主治醫師兼
長庚大學醫學院副教授 ***國立台灣大學公共衛生學院醫療機構管理研究所副教授
受文日期：95 年 7 月 6 日 修改日期：96 年 3 月 1 日 接受刊載：96 年 7 月 19 日
通訊作者地址：陳月枝 10051 台北市仁愛路一段 1 號