

## Mental Health of Parents Having Children with Physical Disabilities

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**Background:** Parents of children with disabilities play an essential role in the successful rehabilitation of their children. However, the high level of care required may affect the mental health of the parents and consequently contribute to an unfavorable rehabilitation outcome in their children. The aims of this study are to investigate the mental health of parents of children with physical disabilities and to elucidate the factors affecting parental mental health.

**Method:** This was a cross-sectional study. Ninety-one parents of children with physical disabilities who visited the outpatient rehabilitation clinics of a tertiary hospital were invited to join the study. Data from the parents and children were recorded during face-to-face interviews. Parental-perceived stress was assessed using the simplified Parenting Stress Index (PSI/SF). Parental mental health was evaluated as the main outcome measure using the 12-item version of the Chinese Health Questionnaire (CHQ-12).

**Results:** Forty parents (44%) were categorized as psychiatric cases on the CHQ. Child-related factors that negatively affected parental mental health were poor walking ability ( $p < 0.05$ ), dependency on others to perform activities of daily life (ADL) ( $p < 0.01$ ), and younger age ( $p < 0.05$ ). Parent-related factors that negatively affected parental mental health were low income ( $p < 0.05$ ), no religious beliefs ( $p < 0.01$ ), high level of parental distress ( $p < 0.01$ ), parent-child dysfunctional interaction ( $p < 0.01$ ), and having difficult child ( $p < 0.05$ ). The most significant predictor of overall parental mental health in multivariate analysis was found to be parental distress.

**Conclusions:** Parents of children with physical disabilities were at risk of poor mental health. Perceived parental distress is the most important factor affecting parental mental health. Strategies to reduce parental stress should be developed to prevent deterioration of parental mental health.

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**Key words:** mental health, parents, children, physical disability

In recent years, there has been a shift in the delivery of health care services away from child-centered models toward a family-centered model.<sup>(1-5)</sup> Parents are typically the key members of a family,

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and the role of parents in the rehabilitation of children with physical disabilities is increasingly being recognized. Regular and active participation by parents during all phases of treatment of children with physical disabilities is a vital part of the overall management.<sup>(6)</sup> However, providing a high level of care that is required by a child with long-term functional limitations may affect the psychological health of the parents.<sup>(7-9)</sup> Psychological problems such as depression may limit the role of parents in the management of the child's illness.<sup>(10)</sup> Emotional distress in a parent may contribute to emotional and psychiatric distress in the child and may affect the family's ability to cope with the illness; thus, the illness may have a greater impact on the family.<sup>(11)</sup> Therefore, early identification of parents who are at risk of poor mental health is important because interventions directed at caregivers are likely to be more successful if they target modifiable determinants of parenting burdens and address specific parental needs.

Although there are several studies reporting that parents of children with physical disabilities are at a great risk of poor mental health,<sup>(7,8,12-21)</sup> most have been conducted in western countries. There is still some controversy about factors associated with the mental health of parents having children with physical disabilities.<sup>(14,19-29)</sup> Parental burden may be perceived differently, depending on the regional, societal and cultural norms. Therefore, this study aims to (1) assess the mental health of parents of children with physical disabilities and (2) determine which factors, both child-related and parent-related, are associated with poor mental health in parents and may be used for prediction.

## METHODS

### Sample

Data were collected from pediatric physical medicine and rehabilitation clinics in a hospital. The subjects of this study were parents of children with physical disabilities. The inclusion criteria for the subjects were as follows: having a child who was less than 18 years old with a major diagnosis of physical disability, being the primary caregiver of the child, not having a severe or chronic medical condition (e.g., diabetes mellitus, arthritis, chronic obstructive pulmonary disease) before or after the birth of the physically disabled child, not being diag-

nosed with a severe or chronic psychological disorder before the birth of the physically disabled child, and not seeking any kind of medical support in an inpatient or outpatient clinic within the 3-month period preceding the study. Ninety-one parents met the criteria and were recruited.

### Procedure

We explained the details of the study to all potential participants. After their oral consent was obtained, a questionnaire package which included the Parenting Stress Index-Short Form (PSI/SF), the 12-item version of the Chinese Health Questionnaire (CHQ-12), and a demographic data collection form was distributed to each participant during a face-to-face interview.

### Measures

#### *Characteristics of parents and children*

Information obtained on the parents included gender, age, level of education, occupational status, number of siblings, whether they lived with their parents/parents-in-law, and whether they were religious. The economic status of the family was defined as low income if the parents had low income family certification from the local government.

Information recorded on the children included age, gender, and functional levels. The functional levels of the children were assessed by therapists and were classified on the basis of difficulty in mobility and dependency of the children on others to perform activities of daily living (ADL). The former was graded as mild (little or no difficulty for walking), moderate (aids or a helper required for walking), or severe (unable to walk even with aids or a helper). The latter was graded as totally dependent, partially dependent, or totally independent.

#### *Parenting Stress Index (PSI)*

Perceived stress in the parents was assessed using the PSI/SF.<sup>(30)</sup> The PSI/SF has 3 subdomains, namely, parental distress (PD), parent-children dysfunctional interaction (PCDI), and difficult child (DC) with a total of 36 items. Each item was graded on a 5-point Likert scale. Higher scores indicated higher perceived stress in the parents. One study demonstrated that the Chinese version of the PSI/SF has good reliability (internal consistency coefficient > 0.78) and construct validity (goodness-of-fit of a 3-

factor structure).<sup>(31)</sup>

**Chinese Health Questionnaire (CHQ)**

Parental mental health status was assessed using the CHQ. The CHQ<sup>(32)</sup> is a self-administered screening instrument used to assess psychiatric morbidity in the Chinese community. This questionnaire has been validated, has satisfactory construct validity, and is used to survey psychiatric morbidity in the community.<sup>(33)</sup> The following 4 factors are included in the CHQ: somatic symptoms; anxiety and worrying; sleep problems; and depression and poor family relationships. In this study, the CHQ-12<sup>(34)</sup> was used. A cutoff point of 3/4 was adopted for the distinction between case and non-case, as used in community studies.<sup>(34)</sup>

**Statistical analyses and data collection**

Parental psychiatric morbidity, as assessed by the CHQ-12 scores, was taken as the main outcome variable. The prevalence of parents with psychiatric problems was determined on the basis of the CHQ-12 scores as follows: a cutoff score of 3/4 indicated a psychiatric or non-psychiatric case. Univariate analysis of differences between the psychiatric and non-psychiatric cases was assessed using the  $\chi^2$  test for discrete variables and *t* test for the means of independent variables. Finally, logistic regression analysis was conducted (by applying likelihood ratio estimation) for predicting poor parental mental health. To further explore the confounding effect of child- and parent-related factors, we use Pearson correlation coefficients to evaluate the association between the PD scores and the PCDI and DC scores. ANOVA was used to test the impact of religious beliefs, family income, performance of ADL, and walking ability on the PD scores. A value of  $p < 0.05$  was considered significant. The data were analyzed with the SPSS statistical package, version 11.0 (SPSS Inc., Chicago).

**RESULTS**

**Characteristics of parents and children**

Parents characteristics are summarized in Table 1. The mean age of the parents was 34.6 years; most (88%) were mothers. Fifty-three parents (58%) had completed high school education, and most (74%) were religious. Twelve (13%) families were low-

**Table 1.** Characteristics of Parents

Variable	
Age (y)	34.6 (6.5)
Range	23–49
Religious belief	
Yes	67 (74)
No	24 (26)
Education	
Below high school	18 (20)
High school	53 (58)
College and above	20 (22)
Low income	
Yes	12 (13)
No	78 (87)
Three-generation family	
Yes	41 (45)
No	50 (55)
Number of children in household	
1	25 (28)
2	42 (46)
> 2	24 (26)

**Abbreviation:** y: year.

Continuous data are expressed as mean  $\pm$  SD (range),  
Categorical data are expressed as n (%).

income families, one parent refused to answer this question. Forty-one (45%) families had three generations in the home.

Of the 91 children, 56 were male, and their mean age was 5.09 years (1-17 years). The diagnoses in the disabled children were as follows: cerebral palsy (n = 75, 82%); congenital spinal deformity (n = 2, 2%); congenital joint contracture (n = 6, 7%); and non-progressive peripheral neuropathy (n = 8, 9%). Two (2%) children were independent in ADL, 34 (37%) were partially dependent, and 55 (61%) were totally dependent. Since only 2 children were completely independent, in further statistical analysis we combined the data of these 2 children with those of the partially dependent children to form the partial assistance group (Table 2).

**Parental stress level**

The mean overall PSI score was 97.11 (SD = 20.71) and the mean score for PD was 34.54 (SD = 8.72); PCDI, 30.16 (SD = 7.41); and DC, 32.43 (SD = 7.22).

**Table 2.** Characteristics of Children

Variable	
Age (y)	5.1 (3.7)
Range	1–17
Diagnosis	
CP	75 (82)
Congenital spinal deformity	2 (2)
Congenital joint contracture	6 (7)
Others	8 (9)
Sex	
Male	56 (62)
Female	35 (38)
Walking	
Independent	28 (31)
Uses walker	16 (17)
Unable to walk	47 (52)
Performance of ADL	
Independent	2 (2)
Partial assistance	34 (37)
Complete assistance	55 (61)

**Abbreviations:** y: year; CP: cerebral palsy; others: non-progressive peripheral neuropathy; ADL: activities of daily living. Continuous data are expressed as mean (SD). Categorical data are expressed as n (%).

### Mental health problem rate

Forty (44%) parents were in the psychiatric case category depending on the CHQ-12. Parents were then divided into 2 groups, cases (N = 40) and non-cases (N = 51).

### Factors related to poor mental health (cases)

As shown in Table 3, the findings indicate that parents whose children could not walk or completely dependent in ADL or younger were at a higher risk for poor mental health ( $p < 0.05$ ).

Parent-related factors associated with poor parental mental health included low income family ( $p < 0.05$ ) and no religious beliefs ( $p < 0.01$ ) (Table 4). Parents with mental health problems had statistically higher scores in the PD ( $p < 0.01$ ), a poorer PCDI ( $p < 0.05$ ), and DC ( $p < 0.05$ ) than those of parents without mental health problems (Table 5).

To understand the contributions of child- and parent-related factors in determining parental mental health, multivariate logistic regression analysis was performed. The results are summarized in Table 6; the PD score was the only significant independent determinant of poor parental mental health ( $p < 0.05$ ).

The PD scores had moderate correlation with

**Table 3.** Univariate Analysis of the Association between Children's Characteristics and Parental Mental Health

	CHQ		X <sup>2</sup>	p	Odds ratio	95% CI	p
	Non-cases (N)	Cases (N)					
Sex							
Male	35	21	2.46	0.12	Reference	0.84 – 4.66	0.11
Female	16	19			1.98		
Walking							
Independent	18	10	4.21*	0.04	Reference	0.15 – 1.08	0.07
Uses walker	13	3			0.41		
Unable to walk	20	27			0.21*		
Performance of ADL							
Complete assistance	24	31	8.14†	0.00	Reference	0.11 – 0.70	0.00
Partial assistance	27	9			0.26†		
Child's age (y)			t	p			
	5.8 (3.9)	4.2 (3.1)	2.20*	0.03			

**Abbreviations:** CHQ: Chinese Health Questionnaire; N: number; y: year; ADL: activity of daily living; CI: confidence interval; \*:  $p < 0.05$ ; †:  $p < 0.01$ .

Continuous data are expressed as mean (SD). The  $\chi^2$  test was used for discrete variables and the  $t$  test for the means of independent variables.

**Table 4.** Univariate Analysis of the Association between Parent Characteristics and Parent Mental Health

	CHQ		X <sup>2</sup>	p	Odds ratio	95% CI	p
	Non-cases (N)	Cases (N)					
<b>Religious belief</b>							
No	8	16	6.83*	0.01	Reference	0.10 – 0.75	0.01
Yes	43	24					
<b>Low income</b>							
Yes	3	9	5.24*	0.02	Reference	0.06 – 0.88	0.03
No	47	31					
<b>Three-generation family</b>							
Yes	23	18	0.00	0.99	Reference	0.44 – 2.31	0.99
No	28	22					
<b>Education</b>							
Below high school	12	6	1.16	0.56	Reference	0.13 – 1.86	0.30
High school	29	24					
College and above	10	10					
<b>Number of children in a household</b>							
1	14	11	1.72	0.42	Reference	0.47 – 3.44	0.63
2	21	21					
> 2	16	8					
<b>Parent's age</b>							
	34.8 (6.7)	34.3 (6.5)	t	p			
			0.41	0.68			

**Abbreviations:** CHQ: Chinese Health Questionnaire; N: number; CI: confidence interval; \*:  $p < 0.05$ .

Continuous data are expressed as mean  $\pm$  SD.

The  $\chi^2$  test was used for discrete variables and the  $t$  test for the means of independent variables.

**Table 5.** Comparison of Parental Stress among Parents with and without Psychological Problems

	CHQ		t	p
	Non-cases (N = 51)	Cases (N = 40)		
<b>PSI</b>				
PD	31.0 (6.9)	38.2 (6.7)	-4.25 <sup>†</sup>	0.00
PCDI	28.0 (6.7)	32.2 (7.3)	-2.84*	0.01
DC	28.4 (6.8)	31.5 (7.1)	-2.10*	0.04

**Abbreviations:** CHQ: Chinese Health Questionnaire; PSI: parental stress index; PD: parental distress; PCDI: parent-child dysfunction interaction; DC: difficult child; N: case number; \*:  $p < 0.05$ ; <sup>†</sup>:  $p < 0.01$ .

Continuous data are expressed as mean (SD).

The  $t$  test was used for the means of independent variables.

the subscales of the PCDI ( $r = 0.62, p < 0.01$ ) and DC ( $r = 0.55, p < 0.01$ ). The PD scores were also significantly associated with religious belief ( $F = 6.22, p = 0.01$ ), performance of ADL ( $F = 19.68, p < 0.01$ ) and walking ability ( $F = 7.83, p < 0.01$ ).

## DISCUSSION

We found that 44% parents of children with physical disabilities had poor mental health. This finding is consistent with previous studies.<sup>(7,8,12-17,19,21,35)</sup>

In one study which assessed parental mental health problems, the parents of handicapped children had a significantly higher mean General Health Questionnaire (GHQ) score, which was also above the threshold score of the GHQ, than parents of children with minor ailments.<sup>(12)</sup> In another study, Mobarak et al found that 41.8% of mothers having children with

**Table 6.** Multivariate Logistic Regression Analysis of Mental Health of Parents of Physically Disabled Children

	CHQ-cases		<i>P</i>
	Odds ratio	95% CI	
<b>Sex</b>			
Male	Reference		
Female	3.170	0.950 – 10.578	0.06
<b>Walking</b>			
Independent	Reference		
Uses walker	1.691	0.259 – 11.013	0.58
Unable to walk	0.541	0.069 – 4.225	0.56
<b>Performance of ADL</b>			
Complete assistance	Reference		
Partial assistance	0.334	0.054 – 2.055	0.24
<b>Religious belief</b>			
Yes	Reference		
No	0.326	0.076 – 1.407	0.13
<b>Low income</b>			
Yes	Reference		
No	0.298	0.037 – 2.388	0.25
<b>Three-generation family</b>			
Yes	Reference		
No	1.253	0.384 – 4.087	0.71
<b>Education</b>			
Below high school	Reference		
High school	0.358	0.052 – 2.466	0.30
College and above	0.208	0.040 – 1.087	0.06
<b>Number of children in a household</b>			
1	Reference		
2	3.928	0.783 – 19.701	0.10
> 2	1.849	0.284 – 12.045	0.52
Child's age	0.873	0.714 – 1.066	0.18
Parent's age	0.992	0.881 – 1.117	0.89
<b>PSI</b>			
PD	1.148*	1.018 – 1.295	0.02
PCDI	1.002	0.871 – 1.153	0.98
DC	0.994	0.869 – 1.138	0.94

**Abbreviations:** CHQ: Chinese Health Questionnaire; ADL: activity of daily living; PSI: parental stress index; PD: parental distress; PCDI: parent-child dysfunction interaction; DC: difficult child; CI: confidence interval; \*: *p* < 0.05.

cerebral palsy (CP) were at a risk for psychiatric morbidity,<sup>(16)</sup> a finding which is similar to ours.

In this study, the results of multivariate analysis indicated that the degree of parent-perceived distress, rather than the severity of the child's disability, was the only independent factor associated with overall parental mental health. It has been suggested that greater physical disability in the child does not necessarily lead to worse parental mental health.<sup>(18,20,21,25,26,28,29)</sup> Skok et al studied the factors which affect the well-being of mothers of children with CP and confirmed that the severity of disability was not significantly related to maternal well-being,<sup>(28)</sup> while both stress and perceived social support significantly predicted well-being. Manuel et al also reported a similar finding.<sup>(25)</sup> Florian et al found that parental mental health was related to the degree of distress experienced by the parents.<sup>(14)</sup> These findings suggest that poor motor functionality in children with physical disabilities does not contribute to detrimental effects on the mental health of their parents, but psychosocial stress does.

There are some studies suggesting that poor psychological health in the caregiver is associated with more severe disability in the child.<sup>(22-24,27,36,37)</sup> A child's disability is a potential stressor, and diminished functional independence in the child typically translates into increased care-giving demands on the parents.<sup>(38)</sup> We found both the child's functional independence and walking ability were significantly related to the PD (data were not shown). This may explain why a child's functional independence and walking ability were significantly associated with parental mental health in univariate analyses, but not in multivariate analysis. Both a child's functional independence and walking ability were confounding factors, not independent predictors of the mental health of parents.

Raina et al reported that child behavior is one of the most important predictors for the mental health of caregivers having children with CP.<sup>(17)</sup> Mobarak et al indicated that in developing countries,<sup>(16)</sup> providing advice to mothers of young disabled children on managing common behavior problems in children is an important component of intervention, as it may directly help to relieve stress in these mothers. In our study, the DC and PCDI subdomains were significantly associated with parental mental health in univariate analysis, but not in multivariate analysis.

Using univariate analysis, we found that parents with younger children were at a significantly higher risk for psychiatric morbidity, but the child's age was not an independent factor associated with parental mental health in the multivariate model. Wiegner et al<sup>(21)</sup> found a relationship between younger children and worse parental adaptation only in the CP group and not in the spina bifida or limb deficiency groups. In our study there was insufficient support of child age as an independent predictor variable.

According to stress and coping theory,<sup>(39,40)</sup> the outcome of the relationship between the individual and the stressor is dependent on the availability and utilization of resources and coping strategies. Some studies have found that social support may buffer the effects of PD.<sup>(41)</sup> The family network has been found to contribute positively to a mother's mental health.<sup>(14,20)</sup> We attempted to examine the association between a 3-generation family and parental mental health. The lack of even a weak relationship between the above-mentioned parameters in this study suggests that the grandparents of the children with physical disabilities provided relatively little support.

We found that none of the parents had ever received respite service from formal care-giving systems. We did not evaluate other social support systems or social networks; these may have affected the parents' emotions. Further studies are needed to examine the relationship between the whole social support and social network and the mental health of parents of disabled children.

Religious belief has been reported to be a resource for coping.<sup>(42,43)</sup> A study of 48 parents with young handicapped children determined that positive belief systems were associated with low psychological distress in mothers.<sup>(23)</sup> In our study, religious belief was not an independent predictor of parental mental health.

Evidence in the literature supports a link between socioeconomic status (SES) and parental mental health.<sup>(8,14,17,35,44)</sup> Higher SES has been associated with better mental health in mothers of children with CP.<sup>(14)</sup> Socio-economic disadvantage was related to high levels of psychological distress in parents of children with disabilities.<sup>(8,17,35,44)</sup> We did not find that the current economic status had a direct influence on parental mental health.

A previous study showed that fathers of children with physical disabilities experienced little psycho-

logical distress compared with mothers.<sup>(35)</sup> Most studies have focused only on maternal mental health.<sup>(7,14,15,22,38)</sup> It is increasingly being recognized that the functioning of families requires contributions from both parents. As more families are depending on 2 incomes to maintain their standard of living, fathers will contribute more to child-care than before. Although typically the mothers were the primary caregivers of children with physical disabilities, in our study, we did not find any difference in psychiatric morbidity between fathers and mothers. Therefore, health professionals working in this area should consider the psychological status of both parents.

Certain findings have particular implications for the delivery of health care services to families of children with physical disability. Failure to screen for parental mental problems represents another missed opportunity to enhance the health and well-being of parents. In this study, we used the CHQ as a screening tool to focus on psychological symptoms rather than the clinical diagnosis. We believe that most clinicians are more likely to detect symptoms than render a clinical diagnoses in adults. Simple standardized screening techniques afford an opportunity to identify parents who are at maximum risk for psychiatric morbidity.

### Study limitations

The limitations of this study have to be acknowledged before we can interpret its findings. First, the study was limited by its cross-sectional design, so it is impossible to make a prediction as to directionality. Second, it relied on several self-report measures from the same informant (including the main independent and dependent variable), so a reporting bias may exist. Third, all children had been involved in the rehabilitation process, which limits the generalizability to parents of children who have not participated in rehabilitation. Therefore, replication of this study with a more diverse sample population would be desirable.

### Conclusions

Our study suggests that parents of children with physical disability were at risk for psychiatric disorders. In dealing with the mental health needs of parents having children with physical disabilities, clinicians should take care to evaluate the particular reac-

tions of each parent and provide adequate intervention in cases where negative effects are evident or persist over time. Referral of these parents for treatment may prevent the development of more severe symptoms, which may interfere with effective parenting.

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## 肢障兒童父母之心理健康狀況

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**背景：**肢障兒童的父母對孩子復健成功與否扮演著重要的角色。然而，這些孩子的高度照顧需求可能會對父母的心理健康狀況產生負面影響，因而不利兒童的復健成果。此研究的目的是探討肢障兒童的父母之心理健康狀況，及其相關因素。

**方法：**本研究為一橫斷面的研究。我們邀請到醫學中心復健科門診求診之肢障兒童的父母參與此研究。採面對面訪談的方式記錄父母和兒童的基本資料。使用簡短版的父母壓力指標 (Parenting stress index, PSI/SF) 評估父母的壓力。家長的心理健康則用十二題的華人健康問卷 (12-item version of Chinese Health Questionnaire, CHQ-12) 作為主要的結果測量。

**結果：**91 位家長完成會談及問卷填寫，其中 40 位 (44%) 達到 CHQ-12 中認為有心理問題的標準。與父母心理健康狀況相關的兒童因素包括兒童走路能力 ( $p < .05$ )、兒童日常生活功能的依賴度 ( $p < .01$ ) 和兒童的年齡 ( $p < .05$ )。與父母心理健康狀況相關的家長因素包括低收入 ( $p < .05$ )、信仰狀況 ( $p < .01$ )、父母自覺辛勞的程度 ( $p < .01$ )、親子互動狀況 ( $p < .01$ ) 和有不易教養的孩子 ( $p < .05$ )。多變數分析的結果顯示肢障兒童的父母心理健康狀況最顯著的預測因子為父母自覺辛勞的程度。

**結論：**肢障兒童的父母為心理不健康之高危險群，父母感受辛勞程度是影響父母心理健康最重要的因素。因此，我們應該要研擬出如何減輕肢障兒童其父母辛勞程度的策略，以避免父母心理健康的惡化。

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**關鍵詞：**心理健康，父母，兒童，肢體障礙

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