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Factors Associated with Caregiver Burden in Primary Caregivers of Patients with Adolescent Scoliosis: A Descriptive Cross-Sectional Study

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Background: Primary caregivers for patients with scoliosis suffer from considerable distress and burden. However, a few studies have examined the factors related to burden of caregivers of patients with adolescent scoliosis, particularly in China. Therefore, the present study aimed to identify patient and caregiver characteristics associated with caregiver burden.

Material/Methods: A cross-sectional study was conducted in a sample comprising 87 pairs of patients with adolescent scoliosis and their primary caregivers from July 2014 to October 2016 in Xi'an, China. Patients and their primary caregivers were administered a sociodemographic questionnaire. The caregiver burden, social support, and self-efficacy were assessed using the Chinese version of the Zarit Burden Interview (ZBI), Social Support Rating Scale (SSRS), and General Self-Efficacy Scale (GSE). A multivariate analysis was used to evaluate the factors associated with caregiver burden.

Results: Most primary caregivers observed in this study were female (65.5%), with mothers of the patients accounting for 58.6% of all the caregivers. The ZBI score of primary caregivers was 36.83±13.30, and most caregivers (88.5%) had moderate or severe burden. The factors associated with caregiver burden were Cobb angle of patients, SSRS scores, GSE scores, and monthly household income per capita of the caregiver ($R^2=0.556$; $P<0.001$). The identified significant factors explained nearly 56% of the variance in the caregiver burden.

Conclusions: The data indicated that most primary caregivers for patients with scoliosis had a considerable caregiver burden, and intervention of social support and self-efficacy might be helpful in reducing caregiver burden.

MeSH Keywords: **Caregivers • Cross-Sectional Studies • Scoliosis**

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Background

Scoliosis, one of the most common spinal deformities, is defined as a lateral curve of the spine of more than 10 degrees [1]. Worldwide, the overall prevalence of scoliosis is unknown. In mainland China, the prevalence of scoliosis was 1.02% among primary and middle school students [2]. The main subgroups of scoliosis are idiopathic scoliosis, congenital scoliosis, and neuromuscular scoliosis. Brace treatment and surgical correction are the most common therapeutic methods. Scoliosis is most common in the early teenage years and can progress to severe deformation of the spine, with severe respiratory issues, disability, and pain [3,4]. Further, scoliosis is associated with a decline in participation and intimate relationships, poor self-perception, lower marriage rates, mental disorders, and even attempted suicide [5–7]. Thus, managing scoliosis is a complex health issue and caring for patients with scoliosis requires considerable resources, including long-term medical services and caregiver support.

As a traditional custom of home-based rehabilitation and insufficient health resources in China, family caregivers usually act as primary caregivers, have a critical role in managing scoliosis, and frequently suffer from enormous stress and caregiver burden. Patients with scoliosis and their parents perceive the psychological burden and emotional stress, and parents usually overestimate the assessment of stress levels related to body deformity [8]. Previous studies have shown that the primary caregivers for patients with scoliosis frequently have reduced quality of life and suffer from enormous psychological and financial stress [9–11]. In addition, parents of children with thoracic insufficiency syndrome, including early-onset scoliosis, had higher caregiver burden scores compared with parents of healthy children [12]. However, information regarding the factors related to caregiver burden and a significant predictor of caregiver burden is limited, particularly in China.

Understanding the specific factors and resources linked to the caregiver burden is critically important to help primary caregivers cope with their burden appropriately and effectively and to support the hospital and government to improve current situation against scoliosis. Further, as the caregiver burden is related to caregiver well-being, it is necessary to focus on caregiver burden to enable health care professionals to address the needs of primary caregivers.

Therefore, the aim of the present study was to describe the level of primary caregiver burden and to evaluate the demographic and clinical characteristics of patients and their primary caregivers, which are associated with burden in primary caregivers of patients with scoliosis.

Material and Methods

Participants

This cross-sectional study was conducted from July 2014 to October 2016 at the Department of Spine Surgery, Honghui Hospital, Xi'an Jiaotong University College of Medicine, Xi'an, China. The patients diagnosed with scoliosis treated surgically were consecutively approached to be recruited into the study. Patients were excluded from the study if they had psychiatric diseases that made it impossible to complete the study questionnaire, or if they did not provide informed consent. The caregiver had to be the patient's family primary caregiver, one for each patient, and the age was 20–65 years. A total of 95 pairs of patients and their primary caregivers were investigated, and 8 pairs refused to participate. Thus, 87 pairs of patients and caregivers consented to take part in the study. This study was approved by the Ethics and Research Committee of Xi'an Honghui Hospital, Xi'an, Shannxi. The study conformed to the recommendations of the Declaration of Helsinki.

Data collection

Patients and their primary caregivers were administered a sociodemographic questionnaire. The demographic data collected from the patients included age, gender, and educational level. The demographic data collected from the primary caregivers were age, gender, education level, place of residence, relationship with the patient, employment status, care for other families, duration of caregiving, and monthly household income per capita (monthly income). Clinical diagnoses of patients, such as scoliosis type, curve location, and Cobb angle, were obtained from the medical records.

Caregivers were also asked to complete 3 instruments to assess their burden, social support, and self-efficacy. Versions of these instruments having adequate reliability and validity among Chinese people were used.

The caregiver burden in the study was evaluated using a self-administered 22-item Zarit Burden Interview (ZBI) [13]. The Chinese version of the ZBI is reliable and valid for use among Chinese caregivers [14]. The ZBI used a 5-item response set, with a range from "never" to "nearly always." The total score of caregiver burden could be divided into 3 levels: 0–20 points indicated little or no burden; 21–39 points indicated moderate burden; and 40–88 points indicated severe burden.

The social support was measured using the Social Support Rating Scale (SSRS) [15]. It is a 3-subscale measure with 10 items: 3 items for evaluating objective support, 4 for subjective support, and 3 for social support availability. Higher scores indicated a higher level of social support.

The 10-item version of the General Self-Efficacy Scale (GSE) was used to measure the self-efficacy of caregivers [16]. The GSE used a four-item response set, with a range from "completely wrong" to "totally right." Higher scores indicated a higher level of self-efficacy.

Data analysis

Descriptive statistics of sociodemographic variables and scales were calculated using means ± standard deviation (SD) for continuous variables and percentages for categorical variables. The differences were assessed using the *t* test for 2 groups and analysis of variance for multiple groups. Spearman's rank correlation coefficient was used to calculate the correlations. The significant factors in univariate and correlation analyses were thereafter entered into stepwise multiple linear regression, with the caregiver burden as the dependent variable. For all tests, a 2-sided *P* value less than 0.05 was considered significant. Data analyses were performed using the Statistical Package for Social Sciences (SPSS) 17.0 software (SPSS, IL, USA).

Results

Subject characteristics

A total of 87 patients with scoliosis and their family primary caregivers were recruited into the study. The mean age of the 87 caregivers was 39.22±5.61 years. Most caregivers were female (65.5%), with mothers of the patients accounting for 58.6% of all the caregivers. The majority lived in rural areas (55.2%) and had a monthly income of less than US$500 (72.4%). Most caregivers had a primary school education or below (63.2%). Further, 55.2% had cared for other families and 80.5% had cared for the patients for more than 1 year (Table 1).

The mean age of the patients was 12.46±5.00 years, and 49.4% were female. The majority (71.3%) had a primary school education or below. The types of scoliosis in this study were idiopathic scoliosis (64.4%), congenital scoliosis (14.9%), and neuromuscular scoliosis (20.7%). The curve location of the scoliosis was defined as previously reported [17]: thoracic (13.8%), lumbar (24.1%), thoracolumbar (40.2%), and S-shaped (21.8%). The average Cobb angle of patients was 61.84±11.57 (Table 1).

Caregiver burden in caregivers

The mean ZBI score of family primary caregivers was 36.83±13.30. Moreover, 10.3% of caregivers had a ZBI score of 0–20 (little or no burden), 52.9% had a score of 21–39 (moderate burden), while 36.8% had a score of 40–88 (severe burden).

Correlations of caregiver burden with SSRS and GSE

The mean SSRS score of primary caregivers was 39.95±7.51, and the mean GSE score was 21.67±7.65. The correlation between ZBI, SSRS, and GSE scores was analyzed to assess the relationship between caregiver burden, self-efficacy, and social support. The correlation analysis showed that the ZBI scores were negatively correlated with SSRS ($r=-0.577$; $P<0.001$) and GSE scores ($r=-0.460$; $P<0.001$).

Univariate analysis of the factors associated with caregiver burden

As shown in Table 2, the univariate factor analysis showed no significant relationships between the caregiver burden and patient characteristics, including age, gender, education level, scoliosis type, and curve location. However, the Cobb angle of patients was associated with caregiver burden ($F=14.690$; $P<0.001$). In addition, the levels of Cobb angle were positively correlated with caregiver burden ($r=-0.559$, $P<0.001$).

As shown in Table 3, the univariate factor analysis showed no significant relationships between the caregiver burden and caregiver characteristics, including age, gender, education level, relationship with the patient, and employment status. However, among the caregivers, the place of residence, care for other families, duration of caregiving, and monthly income were significantly associated with caregiver burden.

Multivariate regression analysis for factors associated with caregiver burden

A stepwise multiple linear regression analysis was then used to detect variables associated with the caregiver burden. The study focused on variables shown to be associated with caregiver burden. In this respect, significant variables from the univariate and correlation analysis were selected. Indeed, the multivariate analysis demonstrated that the Cobb angle of patients, GSE scores, SSRS scores, and monthly income were significantly correlated with the caregiver burden (Table 4). The identified significant factors could explain nearly 56% of the variance in the caregiver burden.

Discussion

This study revealed that the majority of primary caregivers for patients with scoliosis had a considerable caregiver burden in China. The factors related to caregiver burden included the Cobb angle of patients, monthly income, self-efficacy of caregiver, and social support.

Table 1. Demographic and clinical characteristics of patients and caregivers.

Variable	Patients (n=87)		Caregivers (n=87)	
Age (mean ±SD, years)	12.46±5.00		39.22±5.61	
Gender, n (%)				
Female	43	(49.4)	57	(65.5)
Male	44	(50.6)	30	(34.5)
Education, n (%)				
≤Primary	62	(71.3)	55	(63.2)
≥Secondary	25	(28.7)	32	(36.8)
Place of residence, n (%)				
Rural	NA		48	(55.2)
Urban	NA		39	(44.8)
Relationship, n (%)				
Mothers	NA		51	(58.6)
Others	NA		36	(41.4)
Employed, n (%)				
Yes	NA		40	(46.0)
No	NA		47	(54.0)
Care for other families, n (%)				
Yes	NA		48	(55.2)
No	NA		39	(44.8)
Duration of caregiving, n (%)				
<1 year	NA		17	(19.5)
≥1 year	NA		70	(80.5)
Monthly income, n (%)				
<200 US$	NA		25	(28.7)
200–500 US$	NA		38	(43.8)
>500 US$	NA		24	(27.6)
Scoliosis type, n (%)				
Idiopathic	56	(64.4)	NA	
Congenital	13	(14.9)	NA	
Neuromuscular	18	(20.7)	NA	
Curve location, n (%)				
Thoracic	12	(13.8)	NA	
Lumbar	21	(24.1)	NA	
Thoracolumbar	35	(40.2)	NA	
S-shaped	19	(21.8)	NA	
Cobb angle (mean ±SD, degrees)	61.84±11.57		NA	

Data are presented as mean ±SD or number (percentage). NA – not applicable.

Table 2. Comparison of caregiver burden with patient variables.

Variable	Little/no		Moderate		Severe		Difference
Age	13.00±4.30		12.26±4.88		12.59±5.48		*F*=0.098
(mean ±SD, years)							df=86
							P=0.907
Gender, n (%)							χ^2=1.462
Female	3	(33.33)	25	(54.35)	15	(46.88)	df=2
Male	6	(66.67)	21	(45.65)	17	(53.12)	*P*=0.482
Education, n (%)							χ^2=1.706
≤Primary	5	(55.56)	35	(76.09)	22	(68.75)	df=2
≥Secondary	4	(44.44)	11	(23.91)	10	(31.25)	*P*=0.426
Scoliosis type, n (%)							χ^2=2.592
Idiopathic6	7	(77.78)	29	(63.04)	20	(62.50)	df=2
Others	2	(22.22)	17	(36.96)	12	(37.50)	*P*=0.274
Curve location, n (%)							χ^2=0.092
Thoracolumbar	4	(44.44)	18	(39.13)	13	(40.63)	df=2
Others	5	(55.56)	28	(60.87)	19	(59.37)	*P*=0.955
Cobb angle	52.00±7.84		58.74±8.82		69.06±12.09		*F*=14.690
(mean ±SD, degrees)							df=86
							P<0.001

The findings of this study showed that the characteristics of patients with scoliosis did not significantly impact caregiver burden, except that the Cobb angle of patients was positively correlated with caregiver burden, indicating that patients with scoliosis required increasing supervision and personal care depending on their functional ability. In particular, large curves increased the risk of health problems such as pain, respiratory issues, and disability [3,18]. Spinal surgical treatment is now generally recommended for patients with scoliosis and is widely performed to correct the deformity, with better functional outcomes [19–21]. Therefore, surgical intervention to help correct Cobb angle in patients with scoliosis may be an effective way to decrease caregiver burden.

Most caregivers observed in this study were females, and the majority of the caregivers were mothers of the patients. This highlighted the challenges faced by mothers. As reported previously, parents of patients with a long-term illness and subsequent hospitalization commonly experience stress, fear, anger, and anxiety [22,23], which can disrupt the roles of parents in assisting and supervising patients. However, the present data showed that gender and relationship with the patient, which impact the burden in an adult population [24], were not significantly correlated with caregiver burden. In addition, the level of education and age of caregivers were also not associated with the burden of care.

In this study, the majority of primary caregivers were in their early 40s and patients were in their early 20s. Therefore, most primary caregivers had additional responsibilities in the family, such as care for their aged parents and other family members, due to the influence of filial piety in China, which might be different from the culture of Western countries. Previous studies reported that adult caregivers suffered higher levels of caregiver burden due to the conflicts between their caregiving tasks, careers, and nuclear families [25]. Further, primary caregivers of patients with chronic disorders were more likely than other parents to reduce their work hours, quit work, and lose economic opportunities [26,27]. Consistently, the findings showed that the majority of caregivers had a monthly income of less than US $500, and a lower monthly income indicated a higher level of caregiver burden. Therefore, special strategies and policy support are necessary to reduce the caregiver burden on low-income families, including increased government financial support, expanded coverage of health insurance, and more information and resources.

Table 3. Comparison of caregiver burden with caregiver variables.

Variable	Little/no	Moderate	Severe	Difference
Age	40.67±2.92	39.13±5.63	38.94±6.20	F=0.340
(mean ±SD, years)				df=86
				P=0.713
Gender, n (%)				χ^2=0.467
Female	5 (55.56)	31 (67.39)	21 (65.63)	df=2
Male	4 (44.44)	15 (32.61)	11 (34.37)	*P*=0.792
Education, n (%)				χ^2=0.991
≤Primary	5 (55.56)	27 (58.70)	22 (68.75)	df=2
≥Secondary	4 (44.44)	19 (41.30)	10 (31.25)	*P*=0.609
Place of residence, n (%)				χ^2=12.720
Rural	0 (0.00)	27 (58.70)	21 (65.63)	df=2
Urban	9 (100.00)	19 (41.30)	11 (34.37)	*P*=0.002
Relationship, n (%)				χ^2=0.042
Mothers	5 (55.56)	27 (58.70)	19 (59.38)	df=2
Others	4 (44.44)	19 (41.30)	13 (40.62)	*P*=0.979
Employed, n (%)				χ^2=5.462
Yes	7 (77.78)	22 (47.83)	11 (34.37)	df=2
No	2 (22.22)	24 (52.17)	21 (65.63)	*P*=0.065
Care for other families, n (%)				χ^2=8.512
Yes	1 (11.11)	26 (56.52)	21 (65.63)	df=2
No	8 (88.89)	20 (43,48)	11 (34.37)	*P*=0.014
Duration of caregiving, n (%)				χ^2=7.806
<1 year	1 (11.11)	5 (10.87)	11 (34.37)	df=2
≥1 year	8 (88.89)	41 (89.13)	21 (65.63)	*P*=0.029
Monthly income, n (%)				χ^2=10.710
≤500 US$	3 (33.33)	32 (69.57)	28 (87.50)	df=2
>500 US$	6 (66.67)	14 (30.43)	4 (12.50)	*P*=0.005

Table 4. Variables related to caregiver burden in the multivariate regression analysis.

Variable	β	SE	Standardized coefficient, β	*t*	*P*
Cobb angle	0.282	0.100	0.245	2.830	0.006
GSE scores	−0.459	0.136	−0.264	−3.367	0.001
SSRS scores	−0.471	0.162	−0.266	−2.902	0.005
Monthly income	−4.493	1.449	−0.255	−3.100	0.003

Adjusted R^2=0.556; *P*<0.001. GSE – General Self-Efficacy Scale; SE – standard error; SSRS – Social Support Rating Scale.

As reported in the literature, social support and self-efficacy of caregivers, as main available resources to meet care demands, are effective to reduce the caregiver burden [28,29]. Indeed, the present study found that social support was negatively related to caregiver burden, which was in agreement with the findings of other studies [30,31]. The main supports for caregivers were from other family members owing to cultural norms and insufficient available services in China. Moreover, social support from families and professional institutes made it easier for caregivers to care for patients and themselves, cope with the stress, and minimize the caregiver burden [32,33]. Thus, more social support from health care professionals is needed to help minimize the caregiver burden, such as providing appropriate information and support from medical staff and strengthening home-care services for caregivers.

Additionally, self-efficacy is considered a mediator to lower the caregiver burden [25], leading to more positive emotions and better physical health [29,34]. Consistently, the data showed that self-efficacy was negatively associated with caregiver burden, implying that the primary caregivers with high self-efficacy were likely to better handle the caregiving stress and tasks. As a result, interventions to improve self-efficacy, including peer training, follow-up, and support institutions, are necessary for caregivers to lessen their burden of caregiving.

This study had several limitations. We study included a relatively limited sample size and involved only 1 center within China. Given the cross-sectional nature of this study, we could not draw conclusions about causality. Thus, a longitudinal study is recommended to assess the predictors related to caregiver burden. Furthermore, selection bias was inevitable, as nonsurgically treated patients were not included. Finally, data on postoperative patients were not examined. Therefore, further investigations, including studies with a larger sample sizes, comprehensive sample populations, and follow-up observations, are needed to confirm and extend the results of the present study.

Conclusions

In conclusion, the present study provides much-needed information on the burden for primary caregivers of patients with scoliosis in China. We found that the Cobb angle, financial burden, social support, and self-efficacy of patients were factors directly associated with caregiver burden. More attention and support, such as providing professional information, increasing government financial and policy support, and strengthening low-cost and effective care services, should be provided to primary caregivers of patients with scoliosis to increase parental competence and satisfaction and, in turn, patient outcomes.

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Conflicts of interest

None.

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