Analysis on Factors Related to Family Caregivers Burden for Elderly Patients with Spinal Tumors in Northwest China

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Abstract

Background Primary caregivers of elderly patients with spinal tumors suffer considerable pain and burden during the care process. This study aims to investigate the factors associated with caregiver burden in elderly patients with spinal tumors. Methods A total of 220 elderly patients with spinal tumors (age, ≥ 65 years) hospitalized in the spine center of our hospital from January 2015 to December 2017 and their primary caregivers were selected in this cross-sectional study. Patients and their primary caregivers were all investigated through the sociodemographic questionnaire. The caregiver burden, social support and self-efficacy were assessed by the Chinese version of the Zarit Burden Interview (ZBI), Social Support Rating Scale (SSRS) and General Self-Efficacy Scale (GSE), respectively. The related factors of caregiver burden were analyzed by multivariate analysis. $P < 0.05$ was considered as statistically significant. Results The 216 elderly patients with spinal tumors aged (71.59 ± 8.49) years, and their caregivers aged (70.46 ± 9.13) years. 170 patients were cared for by spouses, accounting for 78.7% of all caregivers. ZBI score of primary caregivers was 35.5 ± 7.5, and most caregivers (84.5%) showed moderate or heavy burden. The factors related to caregiver burden included patients' paralysis and pain scores and caregivers' SSRS scores, GSE scores and monthly income. Conclusions Most primary caregivers of elderly patients with spinal tumors have considerable caregiver burden. The intervention of social support and self-efficacy is helpful to reduce caregiver burden.

Background

The spine is a common site of bone metastases in malignant tumors, accounting for 5%~10% of all bone metastases [1,2]. With the aging of the population and the extension of average life expectancy, the incidence of spinal tumors in the elderly has increased significantly in recent years, which has become one of a major chronic disease with high mortality, disability, medical risk and medical cost in China seriously affecting the physical and mental health of the elderly. Surgical treatment can significantly alleviate pain, rebuild spinal stability and relieve spinal cord compression [3,4]. The management of malignant spinal tumors is a complex health problem. Care for patients with malignant spinal tumors requires considerable resources, including long-term medical services and caregiver support.

In China, especially in northwest China, due to the limited public medical resources, many patients with spinal tumors need to be cared for at home. In addition, there are traditional customs of family rehabilitation in our country, so family caregivers are usually the primary caregivers of patients. Family caregivers play a key role in the management of patients with spinal tumors and often suffer from tremendous pressure and burden of care. Patients with spinal tumors and their caregivers suffer from psychological and emotional stress. Previous studies have shown that the primary caregivers of patients with spinal tumors often suffer from poor quality of life and immense psychological and economic stress [5,6]. In China, little information is available on the factors related to caregiver burden for patients with spinal tumors.

Understanding the specific factors of caregiver burden plays an important role in helping the primary caregivers deal with the burden, and can support hospitals and governments to improve the current situation of care for patients with spinal tumors. Moreover, because of the correlation of caregiver burden with the well-being of caregivers, it is necessary to pay attention to caregiver burden so that health care professionals can meet the needs of primary caregivers. Therefore, this study aims to investigate the factors related to the burden of primary caregivers for elderly patients with spinal tumors, and to assess the demographic and clinical characteristics of patients and their primary caregivers.

Methods

Study participants

The clinical data of 220 elderly patients with spinal tumors (primary or metastatic) undergoing surgery in the spine center of our hospital from January 2015 to December 2017 and their primary caregivers were selected in this cross-sectional study. Spinal tumors were diagnosed based on clinical manifestations, imaging examinations (X-ray, CT, MRI), and postoperative pathological examination. The other inclusion criteria included that the primary caregivers must be patients' family members, age ranged from 20 to 75 years, and patients lived in Northwest China. The exclusion criteria were as follows: 1) had mental illness, 2) did not sign informed consent, 3) not able to understand the questions, 4) less than two months as caregivers, 5) refusal or withdrawal from participation. The Ethics Committee of the Honghui Hospital, Xi'an Jiaotong University College of Medicine approved the study protocol. All the patients and caregivers provided written informed consent for the use and publication of data for research purposes.

Data collection

The patients and their primary caregivers were investigated by sociodemographic questionnaire. Demographic statistics collected from the patients included age, gender and educational level. Demographic statistics collected from the primary caregivers included age, gender, education level, place of residence, relationship with patients, duration of care and monthly income per person. Clinical diagnosis of the patients was obtained from medical records, such as the site of spinal tumors, paraplegia and degree of pain. After explaining the objectives, methods, benefits and potential risks of this study, the consenting caregivers signed the informed consent and then subjected to face-to-face interviews. Data were collected in the patients' home and the patients were not allowed to be present during the interviews to ensure the confidentiality of information.

Evaluation Standard

Caregivers were also asked to complete three tools to determine their burden, social support and self-efficacy. Caregiver burden in the study was assessed by means of self-managed 22-item Zarit Burden

Interview (ZBI) [7]. The Chinese version of ZBI is reliable and effective for Chinese caregivers [8,9]. A five-point Likert-type scale ranging from 0 to 4 was applied to score responses. For item 1–21, respondents indicated their endorsement for each statement (0-never; 1-rarely; 2-sometimes, 3-quite frequently, and 4-nearly always). For the last item, respondents rated how overwhelmed they feel as a caregiver (0-not at all; 1-a little, 2-moderately, 3-quite a bit, 4-extremely). The total score of care burden was divided into three grades: 0-20, little or no burden; 21-39, moderate burden; 40-88, heavy burden.

Social support was evaluated by the Social Support Rating Scale (SSRS) [10]. It is a 3-subscale measure with 10 items, including 3 items for evaluating objective support, 4 for subjective support, and 3 for social support. High scores presented a high level of social support.

The self-efficacy of caregivers was measured using the 10-item version of the General Self-Efficacy Scale (GSE) [11]. A four-item response set was used in the GSE, with a range from "completely wrong" to "totally right." High scores indicated a high level of self-efficacy.

Statistical analysis

Data were statistically processed with SPSS 19.0. The measurement data were expressed as "x ± s" and analyzed by the t-test. The enumeration data were expressed as percentage (%). The differences between two groups were analyzed by the t-test and among multiple groups by the analysis of variance. Correlations were calculated through Spearman's rank correlation coefficient. After that, the important factors in univariate and correlation analysis were included into multivariate linear stepwise regression, in which caregiver burden was used as a dependent variable. For all tests, $P < 0.05$ was considered as statistically significant.

Results

A total of 220 caregivers were recruited in the study, among whom 4 were excluded, including 2 who refused to participate and 2 who quit halfway. The final sample size was 216 (response rate, 98.18%).

Characteristics

The 216 caregivers all were family members of the patients [126 males and 90 females; mean age ± standard deviation (SD): 70.46 ± 9.13 years (range, 20-75)], including 170 spouse caregivers (78.7%). Most caregivers lived in rural areas (60.6%). Most caregivers received primary or lower education (70.4%). The monthly income of 74.5% caregivers was less than 500 dollars and 30.6% caregivers cared for the patients for more than six months (Table 1).

The 216 patients with spinal tumors aged (71.59 ± 8.49) years, including 53.3% females. Among them, 67.1% patients received primary or lower education, 34.7% had paralysis and 78.7% had moderate to severe pain (Table 1).

Caregiver burden

The average ZBI score of the primary family caregivers was 35.5 ± 7.5. In addition, 15.4% caregivers presented little or no burden in ZBI grade, 60.5% showed moderate burden and 24.1% had heavy burden.

Correlations of caregiver burden between SSRS and GSE

In this study, the relationship between caregiver burden, self-efficacy and social competence were assessed based on the analysis of correlations among ZBI, SSRS and GSE scores. The average SSRS score and GSE score of the primary caregivers were 43.5 ± 6.4 and 24.6 ± 5.8, respectively. The results demonstrated that high ZBI score was correlated with low SSRS and GSE scores, suggesting a negative correlation.

Factors associated with caregiver burden

Univariate analysis showed that the care burden was not related to patients' age, gender, education level and tumor site (Table 2), but patients' degree of pain and paralysis were positively correlated with the burden of care.

Univariate analysis also revealed that the care burden was not linked to caregivers' age, gender, education level and relationship with the patients (Table 3), but significant correlations were found of the caregivers' residence, care time and monthly income with the burden of care.

Multivariate analysis for factors associated with caregiver burden

All variables with P value < 0.10 in the univariate analysis and caregivers' gender were included in a multiple regression model for control of potential confounders. Multivariate analysis showed that patients' paralysis, pain score, GSE score, SSRS score and monthly income were significantly correlated with the burden of care. These clear and key factors could explain about 52% variables of care burden.

Discussion

This study analyzed the factors related to caregiver burden for patients with spinal tumors, thus helping to understand the care burden of caregivers in this region of China. This study showed that most primary caregivers of patients with spinal tumors carried a considerable care burden in China. Analysis of caregiver burden demonstrated that the average ZBI score was 35.5 ± 7.5. The factors significantly

related to the burden of care included patients' paralysis, pain score, GSE score, SSRS score and monthly income.

In this study, the sociodemographic characteristics of caregivers revealed that the primary caregivers were spouses of the patients with low educational level and age at about 70 years. However, these demographic characteristics did not increase caregiver burden. The patients' degree of pain was positively correlated with the burden of care. Severe pain affected the quality of life of the patients. Pain required continuous analgesic treatment, which raised the workload and expenditure of caregivers, ultimately increasing the burden of care. Patients' paralysis was positively correlated with caregiver burden, indicating that patients with spinal tumors needed more and more supervision and personal care, which increased the burden of care. In this study, most primary caregivers earned less than 500 dollars a month. Low monthly income represented high caregiver burden. Therefore, specific strategies and policies are needed to reduce the burden of care for elderly caregivers and low-income families, such as the government increasing support for the elderly, increasing government financial support, expanding medical insurance coverage, and strengthening low-cost and effective nursing services.

As the main available resources to meet the needs of care, social support and self-efficacy of caregivers can effectively reduce caregiver burden [12,13]. This study found that social support was negatively correlated with caregiver burden, which was consistent with the findings of other parallel studies [14,15]. For caregivers in our country, due to the lack of traditional culture and available services, they usually cannot receive the main support from other members of the family. Additionally, social support from other families and professional institutions makes it easier for caregivers to take care of patients and themselves, to cope with stress and possibly minimize caregiver burden [16,17]. Aiming to reduce caregiver burden, more social support from professional health care institutions and personnel is needed, such as providing appropriate information and support by medical staff and strengthening family care services for caregivers. Moreover, self-efficacy can reduce caregiver burden [18,19], guide more positive emotions and contribute to better physical health [20,21]. Our previous studies have also confirmed that self-efficacy reduces the burden of care for caregivers, and at the same time leads to more positive emotions and better physical health [22]. The results of this investigation are consistent with the above results. This investigation showed that self-efficacy is negatively correlated with caregiver burden indicating that the primary caregivers with high self-efficacy can better deal with care stress. More attention and support should be provided to the primary caregivers of spinal tumors patients on how to improve self-efficacy, such as vocational training so as to reduce the caregiver burden.

There are some limitations in this study. The sample size of this study was relatively small and only a spine center in Western China was involved. Considering the cross-sectional nature of this study, we cannot draw conclusions about the causal relationship. Therefore, longitudinal studies are recommended to assess the factors related to caregiver burden. Despite these limitations, this study identifies the factors closely related to caregiver burden, and proposes improvement strategies and interventions to reduce the caregiver burden for patients with spinal tumors.

Conclusions

This study provides information on the care burden of primary caregivers for patients with spinal tumors. This study reveals that the patients' paralysis, pain scores, GSE score, SSRS score and monthly income are directly correlated with caregiver burden. These findings may cause discussions and actions that may be beneficial to reduce the burden of primary caregivers for patients with spinal tumors in the short or medium term.

Abbreviations

Social Support Rating Scale: SSRS; Zarit Burden Interview: ZBI; General Self-Efficacy Scale :GSE; standard deviation: SD; Visual analogue scale:VAS.

Declarations

Ethics approval and consent to participate

Ethical approval from the Ethics Committee of the Honghui Hospital, Xi'an Jiaotong University College of Medicine, was obtained for this study. Each author certifies that all investigations were conducted in conformity with ethical principles. Written informed consent was obtained from all patients included in the study.

Consent for publication

All patients signed informed consent to publish their personal details in this article.

Availability of data and material

The datasets supporting the conclusions of this article are included within the article. The raw data can be requested from the corresponding author on reasonable request.

Competing interests

The authors declare that they have no competing interests.

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Authors' contribution

JL, HL and JH participated in the recruitment, data collection and analysis. All authors contributed to the study design and drafting of the manuscript. All authors read and approved the final manuscript.

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Tables

Table 1. Demographic and clinical characteristics of patients and caregivers

Variable	Patients (n=216)	Caregivers (n=216)
Age (years)	71.59±8.49	70.46±9.13
Gender		
Female	115（53.3%）	90（41.7%）
Male	101（46.7%）	126（58.3%）
Education)		
≦Primary	145（67.1%）	152（70.4%）
≧Secondary	71（32.9%）	64（29.6%）
Place of residence		
Rural	N/A	131（60.6）
Urban	N/A	85（39.4）
Relationship		
Spouse	N/A	170 (78.7)
Others	N/A	46 (21.3)
Duration of caregiving		
<6 months	N/A	150 (69.4)
>6 months	N/A	66 (30.6)
Monthly income		
<200 US	N/A	36 (16.7)
200-500 US	N/A	125 (57.8)
>500 US	N/A	55 (25.5)
Tumor site		
Cervical	34 (15.8)	N/A
Thoracic	105 (48.6)	N/A
Lumbar	77 (35.6)	N/A
Paralysis		
Yes	75 (34.7)	N/A
No	141 (65.3)	N/A
Pain（VAS scales		
≦3	46 (21.3)	N/A
4-6	105 (48.6)	N/A
≧7	65 (30.1)	N/A

Values presented as mean and standard deviation or as count and proportion. Visual analogue scale（VAS）

Table 2. Univariate factor analysis of the caregiver burden with patient variables

Variable	Little/no	Moderate	Severe	Difference
Age (years)	71.88±9.02	70.87±8.69	71.34±8.76	P>0.05
Gender				
Female	18 (54.5)	69 (52.7)	28 (53.8)	P>0.05
Male	15 (45.5)	62 (47.3)	24 (46.2)	P>0.05
Education)				
≦Primary	22 (66.7)	88 (67.2)	35 (67.3)	P>0.05
≧Secondary	11 (33.3)	43 (32.8)	17 (32.7)	P>0.05
Tumor site				
Thoracic	16 (48.5)	64 (48.8)	25 (48.1)	P>0.05
Others	17 (51.5)	67(51.2)	27 (51.9)	P>0.05
Paralysis				
Yes	12 (36.4)	45 (34.4)	18 (34.6)	P<0.05
Pain（VAS scales				
<3	7 (21.2)	28 (21.4)	11 (21.2)	P<0.05
≧4	26 (78.8)	103 (78.6)	41 (78.8)	P<0.05

Table 3. Univariate factor analysis of the caregiver burden with caregiver variables

Variable	Little/no	Moderate	Severe	Difference
Age (years)	71.01±10.12	70.49±3.68	70.17±8.95	P>0.05
Gender				
Female	14 (42.4⬚)	54 (41.2⬚)	22 (42.3⬚)	P>0.05
Male	19 (57.6⬚)	77 (58.8⬚)	30 (57.7⬚)	P>0.05
Education)				
≦Primary	23 (69.7⬚)	92 (70.2⬚)	37 (71.2⬚)	P>0.05
≧Secondary	10 (30.3⬚)	39 (29.8⬚)	15 (28.8⬚)	P>0.05
Place of residence				
Rural	20 (60.6⬚)	79 (60.3⬚)	32 (61.5⬚)	P<0.05
Urban	13 (39.4⬚)	52 (39.7⬚)	20 (38.5⬚)	P<0.05
Relationship				
Spouse	26 (78.8⬚)	103 (78.6⬚)	41 (78.8⬚)	P>0.05
Others	7 (21.2⬚)	28 (21.4⬚)	11 (21.2⬚)	P>0.05
Duration of caregiving				
< 6 months	23 (69.7⬚)	91 (69.5⬚)	36 (69.2⬚)	P<0.05
>6 months	10 (30.3⬚)	40 (30.5⬚)	16 (30.8⬚)	P<0.05
Monthly income				
≦500 US	8 (24.2⬚)	33 (25.2⬚)	13 (25⬚)	P<0.05
>500 US	25 (75.8⬚)	98 (74.8⬚)	39 (75⬚)	P<0.05