

# Study on the Correlation between Caregiver Burden and Social Support of Low-Income Home-Based Patients with Advanced Cancer

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**Abstract:** Objective To explore the correlation between caregiver burden and social support of low-income home-based patients with advanced cancer. Methods A self-made questionnaire was used to investigate 110 caregivers of low-income home-based patients with advanced cancer. The questionnaire included general information of patients and caregivers, Zarit Caregiver Burden Scale (ZBI), and social support scale, etc. The survey data were sorted out by Excel software and entered into the database, and the statistical analysis was completed with R3.5.2 software. The data of patients and caregivers were analyzed by frequency, rate, and means  $\pm$  standard deviation ( $x \pm s$ ). The correlation index was used to analyze the relationship between caregiver burden and social support. Results According to the investigation and analysis, the home-based caregivers of low-income cancer patients have a heavy burden. The ZBI score is  $(33.76 \pm 13.67)$  points, with a median of 33.0 points, which belongs to moderate and severe burden; the caregivers of low-income cancer patients received less social support, and the utilization of social support was low, with an average of  $(32.70 \pm 7.17)$  points and a median of 32.5 points, lower than the norm of  $(34.56 \pm 3.73)$  points. There was a negative correlation between caregiver burden and social support and each dimension ( $P < 0.001$ ). Conclusion There is a close relationship between the burden of home-based caregivers and social support of low-income patients with advanced cancer. More attention should be paid to this group and more practical support and assistance should be provided to help reduce the pressure and burden of caregivers.

**Key words:** Patients with advanced cancer; Caregiver burden; Social support

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At present, the research on the treatment and nursing of patients with advanced cancer and patient caregivers is increasing day by day, and it is becoming more and more comprehensive and in-depth. The research on the burden of caregiver and social support of patients with advanced cancer is also often reported<sup>1</sup>. However, few attentions are paid to the low-income patients with advanced cancer who cannot afford hospitalization and can only stay at home nursing by family members, and moreover, few reports are about the burden of caregivers and social support for this group. Care is the focus and difficulty of the daily problems and challenges faced by family caregivers of patients

with advanced cancer, while the increasing of social support and the improvement of patients' symptoms can bring the hope for their lives. By taking caregivers of low-income home-based patients with advanced cancer as the study objects, this paper investigates and analyzes the burden of the caregivers and social support for low-income home-based patients with advanced cancer, explores the correlation between caregivers' burden and social support, puts forward some suggestions to improve social support, and calls for more social organizations to provide more social support to the caregivers of patients with advanced cancer so as to reduce caregivers' burden.

## DATA AND METHOD

### Objects

A convenient sampling method was used to select 110 primary caregivers for low-income home-based patients with advanced cancer who served in a hospice from June 2018 to October 2018. Inclusion criteria: (1) Aged 18 or above; (2) Nursed patients have poverty certificate; (3) Nurse patients more than 3 hours average daily, served as the main caregiver; (4) Voluntarily participate in this study. Exclusion criteria: (1) Indistinct consciousness; (2) Some special problems (such as mental abnormality and refusal of investigation).

### Data collection tools and their reliability and validity

In this paper, we collect information through questionnaire, which includes the basic data of patients and caregivers, caregivers' burden and social support.

(1) Basic information: basic information about the patient, including self-care ability, and payment of medical expenses, etc.; basic information about the caregiver, including the relationship between the caregiver and the patient, the time of care, and whether or not to live with the patient, etc.

(2) The caregiver burden calculation: Zarit's burden quantification table (ZBI) was used to measure the burden on the patient's family members. The ZBI scale is formed by foreign scholars<sup>2</sup> with the integration of theory and practice. Wang Lie *et al.* introduced it and translated it into Chinese. The Cronbachs $\alpha$  of scale at Chinese version is 0.87-0.9. The results of structural validity analysis accord with the evaluation requirements of the scale. It shows that the scale has good reliability and is suitable for Chinese people<sup>3,4</sup>. The scale contains two dimensions of individual burden and responsibility burden, including 22 items, among which there are two main items of assessment for individual burden, namely, mental state and physical profile of caregiver, which is composed of 12 items (1, 4, 5, 8, 9, 14, 16, 17, 18, 19, 20, 21). The responsibility burden is used to evaluate caregiver's social life and economic condition, and consists of 6 items (2, 3, 6, 11, 12, 13). The items 7, 10, 15 are regarded as independent measurement items. Item 22 represents the total burden borne by

the caregiver<sup>3</sup>. The 5-grade scoring method was used to set the level from "no" to "always", corresponding to 0 - 4 points, the final score is corresponding to the situation of burden, and the higher the total score is, the bigger the burden and pressure faced by the caregiver will be. When the total score is below 21 points, it means that the caregiver burden is mild or non-burdensome, and 21 - 39 points means that the caregiver burden is moderate, and 40 points or more means that the caregiver burden is heavy<sup>3</sup>.

(3) Social support measurement: Social support rating scale (SSRS)<sup>5</sup> was selected, which was based on three dimensions: objective support, subjective support, and utilization of support. When the score was between 12 and 72 points, the higher the score is, the more help will be given at the social level<sup>4</sup>. Subjective support means all the support that can be classified into emotional categories; objective support means that caregivers receive some practical material assistance, including financial assistance, etc.; the utilization of support is the utilization rate of social assistance received by the patient's family members. This scale is widely used in China. The Cronbachs $\alpha$  coefficient of each dimension and overall reliability is 0.825 - 0.896, and the reliability and validity are high<sup>6</sup>. Methods of scoring: For articles 1 - 4 and 8 - 10, one item for each, 1, 2, 3, 4 points for items 1, 2, 3, 4, respectively, article 5 points is divided into four items of A, B, C, D for total scoring, 1- 4 points for each item from "no" to "fully support", 0 points for articles 6 and 7 if answering "no any source", and if answering "the following sources", one point for one source and so on, and 0 point for those who answered "no source". Analysis method of social support rating scale: total score: total score of 10 articles, objective support score: sum of scoring of articles 2, 6, 7; subjective support score: sum of scoring of articles 1, 3, 4, 5; utilization of support score: sum of articles 8, 9, 10.

### Data collation and statistical analysis

(1) All data collected shall be entered in Excel.

(2) Revman 3.5.2 software was used to complete statistical analysis of the data. The basic information of patients and caregivers was analyzed by frequency, rate, mean  $\pm$  standard deviation ( $\bar{x} \pm s$ ). Pearson correlation analysis was used to

analyze the caregiver burden and social support.

## RESULTS

### Basic information on patients with advanced cancer

Among 110 patients, gender: more men than women; age: 29 - 89 years old; the average age:  $61.78 \pm 12.79$  years old. Course of disease: > 24 months accounted for the most. Place of residence: Most of them live in villages and towns. Payment channels: Most are NRCMI or URBMI, and a few are paid at their own expense or in other ways. Family payment of medical expenses: Because the study objects are low-income family, most of them are relatively difficult to pay, but there are also 7 study objects have the ability to pay completely, and objects may not want to express their financial situation truthfully due to self-esteem; perhaps, there are other ways of economic support and treatment support, or that patients' family can bear the palliative care cost since it is not high. Nature of disease: including cancers of digestive system, respiratory system, cardiovascular system, brain cancer, and reproductive system. See Table 1.

### Basic situation of caregivers of patients with advanced cancer and caregivers' burden level

#### Basic situation of caregivers

Gender: More female caregivers (61.81%) than male caregivers, aged 20 - 78 years old, with an average age of  $48.52 \pm 13.09$  years old, caregivers basically are over 30 years old, with the majority of over 50 years old. Relationship with cancer patients: The number of caregivers being children is similar to that of caregivers being couples. Education: 51.7% of the caregivers at junior middle school educational background and below. The total days of care: The days of care of more than 6 months accounts the largest proportion, being 45.45%. See Table 2.

#### Caregiver's burden level

Among 110 caregivers, the total score of ZBI was 9 - 79 points, the average score was ( $33.76 \pm 13.67$ ) points, the median score was 33.0 points, and the level of burden was mostly in the medium and heavy level. The specific classification of caregivers' burden is shown in Table 3.

### Status of social support for caregivers of low-income home-based patients with advanced cancer

The total score of social support of 110 caregivers was 15 - 50 points, with an average of  $32.70 \pm 7.17$  points and a median of 32.5 points, which was lower than the norm ( $34.56 \pm 3.73$ ) points<sup>7</sup>. The score of subjective support was 8 - 30 points, with an average of ( $17.56 \pm 4.78$ ) points and a median of 18.0 points; the score of objective support was 3 - 13 points, with an average of ( $7.87 \pm 2.0$ ) points and a median of 8.0 points; the score of utilization of support was 1 - 12 points, with an average of ( $7.17 \pm 2.11$ ) points and a median of 7.0 points. The score of subjective support was in the upper middle level, which showed that caregivers received higher subjective support.

### Influencing factors of burden of caregivers of low-income home-based patients with advanced cancer

The caregiver burden was analyzed by multivariate linear regression with the caregiver's total burden. The personal information of study objects and the related influencing factors were analyzed by statistical and regression analysis with classified variables. The independent variable assignment is shown in Table 4.

The effect of the caregiver's education level, total days of care and the burden of care was significant ( $P < 0.01$ ). The more educated caregivers had lower burden of care than the less educated caregivers. The longer the total days of care is, the heavier the burden of caregivers will be. Child care burden was lesser than that of couple ( $P < 0.1$ ); caregivers who had difficulty in paying medical expenses were more likely to have heavier care burden than caregivers who could afford it (no statistical difference). There was no significant correlation between caregiver's gender, religious belief, patient's self-care ability and caregiver burden ( $P > 0.05$ ). See Table 5. This statistical analysis model performs a collinearity test, which shows that there is no collinearity between independent variables, and  $R^2 = 0.95$ , which has higher test efficiency.

### **Correlation analysis between the caregiver burden and social support**

Pearson correlation analysis showed that the total burden of caregivers and the total score of social support and other different dimensions were negatively correlated ( $p < 0.001$ ), as shown in Table 4:

## **DISCUSSION**

### **The heavier burden of caregivers of low-income home-based patients with advanced cancer**

The study objects were low-income home-based patients with advanced cancer, and the caregivers were basically their families. The results suggest that this type of caregiver has a heavier burden. The study of cancer caregivers by Rha, Park, Song, Lee, Lee<sup>8</sup>, shows that caregivers feel a greater burden, which is consistent with the results of this study, indicating that there is psychological stress in caregivers of cancer patients. However, the literature of domestic Zhang Bing *et al.*<sup>1</sup> suggests that the main caregivers of enterostomy patients have no burden or only mild burden. The main reason for this difference is the differences of the study objects. On the one hand, the caregivers in this study were engaged in home-based care for a long time, most of them were over 1 month, or even more than 6 months, there was a correlation between the total number of days of care and the burden of care, the longer the time, the heavier the burden, and the caregivers may have social isolation and personal exhaustion, and the more important factor is that the patients in this study came from low-income families, with poor economic condition, caregivers undertook cumbersome accompanying tasks, lacking of financial resources, caregivers feel stressed when they fail to meet the needs of their role in caring for cancer patients<sup>9</sup>. Factors such as the breakdown of care and worries about the entire family's economy have left the caregivers of low-income families with a heavier burden than those of the average family<sup>13</sup>.

### **The social support for caregivers of low-income home-based patients with advanced cancer needs to be improved**

In the study of Zhang Bing *et al.*<sup>1</sup>, the social support level of the patients with enterostomy was higher than that of the norm, and all dimensions

were higher than that of this study. This may be because the patients not only had colorectal cancer, but also inflammatory bowel disease, trauma and so on, and they were all patients during hospitalization, and the time of care was relatively short. The study carried out by Bigatti, Wagner, Lydon-Lam, Steiner, Miller<sup>10</sup> showed that the social support level of the spouses of the patients with breast cancer was slightly lower than that of the norm, and the results were similar to that of this study. However, in the utilization of support, the score of this study was lower than that of the study of Wei Xiaoli, which showed that financial pressure could reduce the utilization of social support.

### **The correlation between caregiver burden and social support of low-income home-based patients with advanced cancer**

The results showed a negative correlation between total caregiver burden and social support and various dimensions in patients with advanced cancer with poor economic status ( $P < 0.001$ ). The study<sup>11</sup> on 195 caregivers of inpatients with cancer made by Li Wenjie, the study made by Wei Xiaoli *et al.*<sup>10</sup> on breast cancer patients and spouse caregivers and the study of Mosher<sup>12</sup> have shown the importance of social support for caregivers of cancer patients, both of which show low support for relatives of patients with advanced cancer, and positive correlation between social and family support for caregivers of cancer patients and caregiver burden. The results are consistent with the results of this study. Social support is an important component of stress relief and a key resource for individuals to take full advantage of and to relieve stress. Social support can effectively relieve stress and avoid physical and mental illness. The caregivers of low-income home-based cancer patients undertake the care tasks in the home environment for a long time, ignoring their own social role and reducing the time and ways to participate in social activities, so the opportunities for social support are limited. Some caregivers have to leave their jobs to take care of patients at home, resulting in lower family income, so in such a way, they not only need to pay high medical expenses, but also need to bear household daily expenses, aggravating the financial burden, thus increasing

the responsibility burden. Long-term home-based caregivers give priority to patients' needs, their own personal interests and hobbies are ignored, and they are gradually separated from the social group, since lacking of social support and care, their personal burden is also increased. The sources of social support include family members, relatives and friends, community organizations, volunteers, and medical staff, etc. Therefore, attention should be paid to this group, the society should try its best to give psychological guidance and instruction and improve caregivers' care-giving skills and teach treatment nursing-related knowledge, so that caregivers' self-confidence is increased. Caregivers should be encouraged to seek social support, so as to reduce their physical and economic burdens and improve their physical and mental health, thus to further improve the quality of life of patients.

## CONCLUSION

Society has always focused on helping and supporting cancer patients, while the physical and mental health of the caregivers of low-income patients with advanced cancer is less concerned. The results of this study show that the care burden of this group is heavy, with low social support level, and caregiver burden is closely related to social support. It is suggested that medical institutions or community service hospitals can give caregivers more guidance on disease health knowledge so as to improve the nursing level of caregivers. At the same time, it shall increase social support and give caregivers a variety of support to ease the stress and financial burden of caregivers. The main objects of this study are patients with advanced cancer and caregivers in a broad sense and the study scope is wide. It is hoped that future studies will clarify the correlation between caregiver burden of different types of cancer and social support.

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**Table 1**  
**General Situation of 110 Patients with Advanced Cancer**

Items	Number of cases	Percentage (%)
<b>Gender</b>		
Male	58	52.72
Female	52	47.27
<b>Age</b>		
<50 years old	16	14.54
50 - 70 years old	61	55.45
> 70 years old	33	30.00
<b>Course</b>		
< 6 months	27	24.54
6 - 12 months	19	17.27
12 - 24 months	18	16.36
> 24 months	46	41.81
<b>Self-care ability</b>		
Complete self-care	22	20.00
Partial self-care	61	55.45
Not self-care	27	24.54
<b>Place of residence</b>		
County level city	26	23.63
Township	48	43.63
Village	36	32.72
<b>Medical expenses payment form</b>		
Self-pay	28	25.45
NRCMI	45	40.90
Medical insurance	33	30.00
Other: Donations, etc.	4	3.63
<b>Household Medical Fee Payments</b>		
Fully payable	7	6.36
Barely payable	31	28.18
Difficulty in payment	72	65.45
<b>Nature of disease</b>		
Digestive system cancer	19	17.27
Respiratory system cancer	26	23.63
Cardiovascular system cancer	22	20.00
Cerebral nerve system cancer	29	26.36
Reproductive system cancer	12	10.90
Other	2	1.81

**Table 2**  
**General Information on 110 Home-based Caregivers of Patients with Advanced Cancer**

Items	Number of cases	Percentage (%)
<b>Gender</b>		
Male	42	38.18

Female	68	61.81
Age		
<30 years old	11	10.00
30 - 50 years old	49	44.55
> 50 years old	50	45.45
Relationship		
Couple	54	49.09
Child	56	50.90
Degree of education		
Junior middle school below	10	9.09
Junior middle school	47	42.72
High school or technical secondary school	27	24.54
Junior college or above	26	23.63
Religious belief		
Yes	4	3.63
No	106	96.36
Total days of care		
<30 days	14	12.72
30 - 90 days	37	33.63
> 90 days	9	8.18
> 180 days	50	45.45

Table 3  
Caregiver Burden Score (n = 110)

Caregiver's burden	Number of cases	Score ( $\bar{x} \pm s$ )	Proportion (%)
No or minor burden (0 - 20 points)	20	15.15±3.39	18.18
Moderate burden (21 - 39 points)	49	29.46±5.38	44.54
Heavy burden (44 - 88 points)	41	47.95±8.16	37.27
Total score	110	33.75±13.66	100.00

Table 4  
Independent Variable Assignment of Caregiver and Caregiver Burden Influencing Factors

classification of independent variables	Parameter coding
Self-care ability of patients	Complete self-care
	Partial self-regulation
	Not self-care
Caregiver's gender	Male
	Female
Relationship between caregivers and patients	Couple
	Child
Patient's disease course	< 6 months
	6 - 12 months
	12 - 24 months
	> 24 months
Caregiver's religious belief	Yes
	No
Medical expenses payment ability	Fully payable
	Barely payable
	Difficulty in payment
Total days of caregiver's care	<30 days
	30 - 90 days
	> 90 days
	> 180 days
Caregiver's education degree	Junior middle school below

Junior middle school	2
High school or technical secondary school	3
Junior college or above	

**Table 5**  
Multivariate Linear Regression Analysis of Total Burden of Caregivers (n = 110)

Independent variables	Regression coefficient	Standard error	Standard regression coefficient	t value	P value
Caregiver's gender	-0.269	0.745	-0.009	-0.362	0.718
Relationship between caregivers and patients	-1.945	1.156	-0.071	-1.683	0.095
Caregiver's religious belief	-0.023	1.786	0.000	-0.013	0.989
Patient's disease course	0.371	0.068	0.278	5.411	0.000**
Caregiver's education degree 1	-4.882	1.354	-0.338	-3.604	0.000**
Caregiver's education degree 2	-3.864	1.456	-0.189	-2.652	0.009**
Caregiver's education degree 3	-4.359	1.512	-0.662	-2.882	0.004**
Patient's self-care ability 2	-0.755	0.879	-0.033	-0.859	0.392
Patient's self-care ability 3	0.435	1.036	0.407	0.420	0.675
Total days of caregiver's care 1	4.341	0.318	4.159	13.65	0.000**
Medical expenses payment ability 2	2.425	1.472	0.086	1.647	0.102
Medical expenses payment ability 3	2.597	1.401	0.095	1.853	0.066
Patient's age	0.070	0.038	0.000	1.812	0.073
Caregiver's age	-0.077	0.044	-0.058	-1.737	0.085

Notes : \*\*\* : P<0.001, \*\* : P<0.01

**Table 6**  
Correlation Analysis of Social Support and Caregiver Burden (n = 110, r)

Social support	Care burden	Objective support	Subjective support	Utilization of support
Social support	1.000	-0.467a	0.741	0.906
Care burden	-0.467a	1.000	-0.404a	-0.434a
Objective support	0.741	-0.404a	1.000	0.572
Subjective support	0.9.6	-0.434a	0.572	1.000
Utilization of support	0.658	-0.331a	0.372	0.377

Note: a: p<0.001