Investigation on the Status and Determinants of Caregiver Burden on Caring for Patients with Chronic Wound

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Objective: To investigate the caring burden and its determinants of primary informal caregiver of patients with chronic wound.

Approach: A prospective cross-sectional study of 132 pairs of chronic wound care recipients and their informal caregivers was included. The characteristics of patients and their informal caregivers as well as caregiver burden assessment by the caregiver burden inventory (CBI) were measured. Single factor analysis and multiple regression analysis were carried out to explore the independent determinants of caregiver burden on caring for patients with chronic wound.

Results: Most of the caregivers were female with mean age of 54.57 ± 13.35 years, and 58.3% of the caregivers were adult children. The mean CBI score was 34.21 ± 9.69 at a medium level. The following variables increased the CBI scores of caregivers: long caring time per day for patients, powerlessness status of patients, insufficient self-efficacy, and social support of caregivers, the model was able to explain 67.5% of variance in caregiver burden ($F = 47.167$, $p = 0.000$, $R^2 = 0.675$, adjusted $R^2 = 0.660$).

Innovation: Caring burden of patients with chronic wound as a key consideration of patient-centered wound care has received relatively little attention. In this study we report the status of caring burden and reveal its determinants of primary informal caregiver of patients with chronic wound.

Conclusion: Wound professionals are suggested to pay attention to the caregiver burden of patients with chronic wound and develop family-centered intervention support service system according to the determinants of caregiver burden to alleviate the caregiver burden.

Keywords: caregiver burden, determinants, chronic wound, informal caregiver

INTRODUCTION

WITH SOCIAL DEVELOPMENT and the gradually aged population, chronic diseases have become a serious public health problem that affects human health.¹ The prevalence of chronic wound, especially pressure injury, di-

abetic foot ulcer, and venous leg ulcer, is increasing.^{2,3}

In view of the evolution process of chronic wound treatment, home care is a vital part of transitional care services.⁴ It is noted that home care for most patients with chronic wound

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Submitted for publication October 18, 2018.
Accepted in revised form January 2, 2019.

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is mainly supported by informal caregivers, like family members in Eastern culture. A considerable amount of care for people with chronic wound is provided at home by family members. They also play a key role in clinical decision-making of patient-centered treatment.⁵

However, caring for chronic wound probably gives rise to a major burden for the informal caregivers, as they always assist in dressing changes, hospital visits, dietary assistance, positioning management, hygienic care, surveillance, and so on.^{6,7} Caregivers face the physical, psychological, emotional, social, and financial challenges when caring for patients.⁸ These caregivers, under the influence of caregiver burden, may have destructive caregiving experience, such as feeling loss, burnout, and depression.^{9–11}

Some studies revealed that caregiver burden had a negative effect on health-related quality of life (HRQoL) of caregivers.^{12,13} Moreover, caregiver burden diminishes caregivers' power to provide better continuity of care for patients.¹⁴ Therefore, health professionals should pay attention not only to the patients with chronic wound but also to their informal caregivers.¹⁵

CLINICAL PROBLEM ADDRESSED

As caregivers play a significant role on caring for patients with chronic wound disease, it is critical for medical staff to understand the determinants that affect caregiver burden, which could help professionals to develop interventions for preventing caregivers' health problems. By far there is an increasing awareness of hazard of caregiver burden in the field of cancer, dementia, and inflammatory bowel disease,^{12,16,17} but research on the burden of informal caregivers of patients with chronic wound is still lacking, and little is known about the level of caregiver burden and associated factors. Hence, we sought to explore the condition and determinants of caregiver burden on caring for patients with chronic wound.

MATERIALS AND METHODS

Design

We conducted a prospective cross-sectional study.

Samples

The sample size was based on recommendation that the ratio of cases to potential variables was 10:1.¹⁸ The potential factors were between 10 and 30, so the expected sample size was 100–300. Finally the actual sample size met the study demand. Consecutive patients with chronic wound and their caregivers were investigated from one single

wound healing center of a teaching hospital in Shanghai, China, from July 2017 to December 2017. The setting was the earliest established wound healing center in Shanghai and is one of the most important and influential specialized centers in China. Patients were included if they (1) were outpatients with wounds >4 weeks irrespective of etiology, (2) were aged at least 18 years old, (3) were native Chinese, and (4) were conscious and had the ability to communicate with the investigator. Patients were excluded if they (1) had malignant disease or mental disorder, (2) were in the acute stage of complications, (3) had overwhelming changes in life within a month (*e.g.*, loss child or spouse), and (4) refused to participate in the study.

Patients were asked to identify their primary informal caregivers. Informal caregivers were those who provided support to a family member regarding his/her self-care, physical, psychological, or economic dependence.¹⁹ Caregivers were included if they (1) provided unpaid care, (2) had no professional nursing training, (3) maintained the most contact with the patients, and (4) were aged at least 18 years old. The exclusion criteria for the caregivers were the same as for the patients.

The study was approved by the hospital's ethics committees (No. 2015101). Study objectives and details were explained to all eligible samples. Participants who agreed to participate in the study were asked to sign informed consent. Patients and caregivers were investigated separately by trained surveyors to collect data with corresponding study instruments. Average survey completion time was 24 min. Information was received immediately after investigation and quality control procedure was operated by the independent personnel from the study team.

Measures

Caregiver burden should be weighed from various aspects to represent the multidimensional relationship between caregiver burden and the health status of both patients and their caregivers.²⁰ We chose the potential variables according to the literature review and stress/health process model that emphasized that the burden of caregivers should be explored from a multidimensional perspective, and included primary stressors and secondary stressors.²¹ In our study, the primary stressors included patients' sociodemographic information, wound-related information, self-care ability, psychological power, and HRQoL; the secondary stressors included caregivers' sociodemographic information, caregiving-related information, self-efficacy, and social support.

Patients were asked to provide (1) socio-demographic information including age, gender, education level, and marital status; (2) wound-related information including duration of wound, history of wound, etiology of wound, location of wound, and severity of wound (according to pressure ulcer scale for healing [PUSH] score); and (3) self-care ability. Patients were also asked to answer two scales to assess their psychological power (powerlessness assessment tool [PAT])²² and HRQoL (Cardiff wound impact schedule [CWIS]).²³ Both PAT and CWIS were validated in Chinese.

The Chinese PAT is a 12-item two-dimensional scale assessing the powerlessness for adult patients, especially for patients with chronic disease: self-perception of behavioral control and decision-making (nine items) and emotional responses to perceived control (three items). All items are scored on a 5-point Likert scale, from 1 (never) to 5 (always). The total scores of PAT range from 12 to 60, with higher scores indicating stronger feelings of powerlessness.

The Chinese CWIS is a 25-item tri-dimensional scale measuring the disease-specific HRQoL for patients with wound. All items are scored on a 5-point Likert scale, from 1 (always or very) to 5 (never or not at all). The final scores are computed using validated formula to calculate a total score ranging from 0 to 100.²³ A higher score indicates a better HRQoL.

Caregivers were asked to provide (1) socio-demographic information including age, gender, education level, marital status, and employment status and (2) caregiving-related information including relationship with the patient, whether living with the patient, number of contact hours per day with the patient, number of persons sharing care tasks, whether changing the dressing, and health status. Caregivers were also asked to complete three instruments to measure their caregiving burden (caregiver burden inventory [CBI]),²⁴ self efficacy (general self-efficacy scale [GSES]),²⁵ and social support (social support rating scale [SSRS]).²⁶ All of these instruments have been validated in Chinese^{26–28}

The Chinese CBI is a 24-item multidimensional questionnaire measuring burden within five subscales: time dependence, developmental, physical, social, and emotional burden. All items are scored on a 5-point Likert scale, from 0 (not at all) to 4 (very). The total scores of CBI range from 0 to 96, with higher scores indicating higher burden of caregivers.

The Chinese GSES is a 10-item unidimensional questionnaire measuring the belief in one's competence to cope with a broad range of stressful or

challenging affairs. All items are scored on a 4-point scale, from 1 (not at all) to 4 (very). The total scores of GSES range from 10 to 40, with higher scores indicating higher self-efficacy.

The SSRS is a 10-item multidimensional questionnaire measuring social support within three domains: objective support, subjective support, and social support availability. The total scores of SSRS range from 12 to 66, with higher scores indicating more social support.

Statistical analysis

We used SPSS17.0 statistics software for data analysis. The main outcome in this study was factors of caregiver burden. The Shapiro–Wilk Test was used to test normality of continuous variables. Continuous variables were calculated as means $\pm$ standard deviation (normal distribution) or median (non-normal distribution); categorical variables were calculated as frequencies and percentages. If the distribution was normal, *t*-test or analysis of variance was used for categorical independent variables analysis, if not, the nonparametric tests were adopted. Spearman correlation coefficients were calculated for continuous variables to explore the correlation between the characteristics of both patients and their caregivers, and the caregivers' burden. Variables considered as significant by univariate analyses were entered into multiple stepwise regression analysis to identify determinants associated with caregivers' burden. Significance was considered as $p < 0.05$.

RESULTS

Patient and caregiver characteristics

During the study period, 160 patients with chronic wound and their primary caregivers were recruited. Recruitment procedure of sample is shown in Fig. 1. Finally, a total of 132 patients and their respective caregivers met the inclusive criterion and completed the investigation. The characteristics of patients and caregivers are given in Tables 1 and 2, respectively. The male-to-female ratio of patients was 1.24 to 1 and the mean age was 69.29 (standard deviation [SD] = 17.26) years, whereas the median age was 71 years. In point of wound-related information, 33.3% of chronic wounds had a relapse. The result of wound etiology was as follows: pressure ulcer (24.2%), venous leg ulcer (18.2%), diabetic foot ulcer (15.2%), surgical wound (10.6%), injury (10.6%), and others (21.2%). In terms of severity of wound, the mean PUSH score was 11.86 ± 2.89 (median score = 13). Besides, the PAT score and CWIS score of patients were 35.96 ± 9.75 and 42.11 ± 8.41 , respectively.

Figure 1. Recruitment procedure.

Among the 132 caregivers, 59.1% was female and the mean age was 54.57 (SD=13.35) years, whereas the median age was 57 years. The relationship between caregiver and patient was as follows: 58.3% were adult children, 30.3% were spouse, 5.3% were parents, 3.8% were siblings, and 2.3% were recognized as “other.” With respect to the caregivers’ employment status, 59.1% were unemployed or retired. In the meantime, 68.9% of caregivers were living with the patients. The median number of contact hours of care provided daily by caregivers was 3.5 h, with a range of 1.5–18. Besides, 71.2% of caregivers had changed the wound dressing of patients at home. What is more, the GSES score and SSRS score of caregivers were 25.52 ± 3.68 and 37.95 ± 6.86 , respectively.

Current status of caregiver burden on caring for patients with chronic wound

The results of condition of caregiver burden are given in Table 3. The mean CBI score was 34.21 ± 9.69 at a medium level and the mean subscale score divided by item number was from 0.65 to 2.34. In addition, the heaviest load of caregivers was developmental burden (2.34 ± 0.53), followed by time-dependence burden (1.93 ± 0.72), physical burden (1.32 ± 0.73), social burden (0.92 ± 0.51), and emotional burden (0.65 ± 0.49).

Comparison of caregivers’ burden with different characteristics of patient/caregiver

Through single factor analysis, both etiology of patient with chronic wound ($F=3.529$, $p=0.006$) and location of wound ($F=3.866$, $p=0.006$) were associated with caregiver burden. Besides, as the wound severity ($R=0.275$, $p=0.007$) and powerlessness of patients ($R=0.714$, $p=0.000$) increased, caregiver burden presented an upward trend. In contrast, as the patients’ self-care ability ($F=12.802$, $p=0.000$) and quality of life ($R=-0.497$, $p=0.000$) increased, caregiver burden presented a downward trend.

With respect to the characteristics of the caregiver, as the number of caring time with patient increased, caregiver burden presented an upward trend. When caregivers were with poor health condition, caregiver burden was higher. If caregivers needed to change the wound dressing for patients at home, their caregiver burden became heavier. Self-efficacy and social support in patients were negatively associated with caregiver burden. The relationships of caregivers’ burden with statistically significant characteristics of patient/caregiver are given in Table 4.

In the influencing factors analysis, both significant patient and caregiver factors were included in the final multiple stepwise regression model

Table 1. Patient characteristics

Characteristic	Mean	SD	Median	Range	Number	%
Age	/	/	71	18–94	/	/
Gender						
Male	/	/	/	/	73	55.3
female	/	/	/	/	59	44.7
Education level						
Junior middle school or below	/	/	/	/	87	65.9
Senior high school	/	/	/	/	25	18.9
College/university or above	/	/	/	/	20	15.2
Marital status						
Single	/	/	/	/	49	37.1
Married	/	/	/	/	83	62.9
Duration of wound (month)	/	/	3.75	1–840	/	/
Previous history of wound						
No	/	/	/	/	88	66.7
Yes	/	/	/	/	44	33.3
Etiology of wound						
Pressure ulcer	/	/	/	/	32	24.2
Venous leg ulcer	/	/	/	/	24	18.2
Diabetic foot ulcer	/	/	/	/	20	15.2
Surgical wound	/	/	/	/	14	10.6
Injury	/	/	/	/	14	10.6
Other	/	/	/	/	28	21.2
Location of wound						
Head and neck	/	/	/	/	4	3.0
Trunk	/	/	/	/	7	5.3
Hip and perineal	/	/	/	/	29	22.0
Upper limb	/	/	/	/	2	1.5
Lower limb	/	/	/	/	90	68.2
PUSH score	/	/	13	4–16	/	/
Self-care ability						
Complete self-care	/	/	/	/	33	25.0
Partial self-care	/	/	/	/	89	67.4
Complete dependence	/	/	/	/	10	7.6
PAT score	35.96	9.75	/	/	/	/
CWIS score	42.11	8.41	/	/	/	/

/, Not available; CWIS, cardiff wound impact schedule; PAT, powerlessness assessment tool; PUSH, pressure ulcer scale for healing; SD, standard deviation.

(Table 5). Four factors were considered to be independently associated with caregiver burden, and the model was able to explain 67.5% of variance in caregiver burden ($F=47.167$, $p=0.000$, $R^2=0.675$). A high degree of powerlessness of patients (PAT score) was the only patient-related factor that was associated with higher caregiver burden. For the caregiver characteristics, a poorer self-efficacy condition, lower social support, and longer caring time per day with patient were associated with higher caregiver burden.

DISCUSSION

Transitional care services play a more and more important role in the treatment of patients with chronic disease. It is worthwhile to note that the shift from hospital to home care places increased demands and challenges on family caregivers.⁷ Caring for a family member with chronic wound

Table 2. Caregiver characteristics

Characteristic	Mean	SD	Median	Range	Number	%
Age	/	/	57	18–82	/	/
Gender						
Male	/	/	/	/	54	40.9
Female	/	/	/	/	78	59.1
Education level						
Junior middle school or below	/	/	/	/	54	40.9
Senior high school	/	/	/	/	44	33.3
College/university or above	/	/	/	/	34	25.7
Marital status						
Single	/	/	/	/	16	12.1
Married	/	/	/	/	116	87.9
Employment status						
Full-time job	/	/	/	/	39	29.5
Part-time job	/	/	/	/	15	11.4
Unemployed or retired	/	/	/	/	78	59.1
Relationship with the patient						
Son or daughter/in-law	/	/	/	/	77	58.3
Spouse	/	/	/	/	40	30.3
Parents	/	/	/	/	7	5.3
Siblings	/	/	/	/	5	3.8
Other	/	/	/	/	3	2.3
Living with the patient						
No	/	/	/	/	41	31.1
Yes	/	/	/	/	91	68.9
Number of contact hours per day with the patient	/	/	3.5	1.5–18	/	/
Number of persons sharing care tasks						
None	/	/	/	/	43	32.6
One person	/	/	/	/	56	42.4
Two persons	/	/	/	/	28	21.2
Three persons and above	/	/	/	/	5	3.8
Changing the dressing						
No	/	/	/	/	38	28.8
Yes	/	/	/	/	94	71.2
Health status						
Good	/	/	/	/	71	53.8
Fair	/	/	/	/	55	41.7
Poor	/	/	/	/	6	4.5
GSES score	25.52	3.68	/	/	/	/
SSRS score	37.95	6.86	/	/	/	/

GSES, general self-efficacy scale; SSRS, social support rating scale.

has been recognized as being a source of burden involving physical, psychological, emotional, social, and practical challenges. Caregivers usually assist wound patients to adapt the lifestyle changes and are instructed to change the dressing. So it is important to realize that chronic wound not only

Table 3. Caregiver burden inventory score of caregivers on caring for patients with chronic wound

Subscale	Item number	Range	Mean $\pm$ SD	mean $\pm$ SD (/Item number)
Time dependence	5	3–19	9.63 $\pm$ 3.59	1.93 $\pm$ 0.72
Developmental	5	5–18	11.71 $\pm$ 2.65	2.34 $\pm$ 0.53
Physical	4	0–13	5.27 $\pm$ 2.92	1.32 $\pm$ 0.73
Social	4	0–9	3.70 $\pm$ 2.03	0.92 $\pm$ 0.51
Emotional	6	0–15	3.91 $\pm$ 2.94	0.65 $\pm$ 0.49
Caregiver burden (total)	24	17–59	34.21 $\pm$ 9.69	/

Table 4. Comparison of caregiver burden inventory and various variables by single factor analysis

	Independent variable	CBI	t/F	Spearman correlation	p
Patient	Etiology of wound				
	Pressure ulcer	39.60 ± 9.14	3.529	/	0.006**
	Venous leg ulcer	30.54 ± 7.87			
	Diabetic foot ulcer	34.69 ± 8.55			
	Surgical wound	30.92 ± 9.96			
	Injury	29.86 ± 7.22			
	Other	31.33 ± 10.26			
	Location of wound				
	Head and neck	29.25 ± 12.18	3.866	/	0.006**
	Trunk	28.17 ± 8.75			
	Hip and perineal	39.41 ± 9.97			
	Upper limb	36.50 ± 10.61			
	Lower limb	32.59 ± 8.59			
	PUSH score	/	/	0.275	0.007**
	Self-care ability				
	Complete self-care	25.00 ± 6.54	12.802	/	0.000**
	Partial self-care	34.48 ± 8.63			
	Complete dependence	44.22 ± 11.26			
Caregiver	CWIS score	/	/	-0.497	0.000**
	PAT score	/	/	0.714	0.000**
	Number of contact hours per day	/	/	0.575	0.000**
	Changing the dressing				
	No	30.56 ± 9.89	-2.235	/	0.028*
	Yes	35.49 ± 9.35			
	Health status				
	Good	31.78 ± 8.92	3.00	/	0.050*
	Fair	36.48 ± 9.77			
	Poor	36.83 ± 11.92			
	GSES score	/	/	-0.433	0.000**
	SSRS score	/	/	-0.625	0.000**

In the single-factor analysis, variables were considered to be associated with caregiver burden at the level of $p \leq 0.05$.

* $p \leq 0.05$, ** $p \leq 0.01$.

CBI, caregiver burden inventory.

affects the patient but also the whole family and particularly the main informal caregiver.²⁹ Hence, deconstructing and alleviating caregiver burden are advantageous to the whole family. This study attempted to investigate the current condition of caregiver burden and to identify influencing factors.

The results showed that caregivers of patients with chronic wound experience a medium level burden. The CBI score (34.21 ± 9.69) is similar to the

value reported in a previous study by Zhou *et al.*³⁰ and even slightly higher than the score (CBI = 25.1 ± 18.2) of caregivers of patients with amyotrophic lateral sclerosis ($t = 9.210$, $p = 0.000$).³¹ Meanwhile the present research revealed the highest levels of caregiver burden in the developmental domain; reversely emotional burden was the domain wherein the lowest score was found. These findings were inconsistent with the previous report on caregiver burden in chronic disease.³² The differences in these results may be related to the age distribution pattern of the caregivers who were mainly adult children, they usually had to change their individual development plan, even quit job, to provide care and confronted with long-term adjustments. What is more, from the point of the cross-cultural analysis, the special "one child policy" and lack of long-term care insurance aggravated the load of middle-aged adults in caring for older patients in China.³³ Low level of emotional burden in this study may be affected by the traditional Eastern culture that caring for parents or family members was their responsibility and a kind of traditional virtue, so they may conceal their negative emotion. These findings had implication for clinical practice that professionals need to quickly and comprehensively assess caregiver burden to identify at-risk caregivers and those in need of intervention.^{5,34}

In this study, both patient and caregiver characteristics were entered into the stepwise regression analysis. Finally, four factors were identified to be associated with caregiver burden. Powerlessness status (PAT score) was the only patient-related characteristic that was positively associated with caregiver burden. To the best of our knowledge, the role of powerlessness status as a contributory factor had been rarely described.³⁵ One possible explanation for this relationship may be that increased powerlessness may reduce the treatment adherence and psychological and physical health of patients with chronic disease since it usually requires more persistent care and supervision.³⁶ Our results also showed several other caregiver-related factors associated with caregiver burden. Our research discovered that informal caregiver may experience heightened caregiver burden, further aggravated by the amount of caregiver time with the patient, which was in agreement with the results of previous studies.^{15,37} The longer the caring time, the higher the level of caregiver burden emerged. The reason may be that time spent on providing care generally increases along with disease progression.⁵ In addition to be full-time caregivers, they also had to engage in their own family affairs and take part in other social activities, which may be disturbed by the continuous

Table 5. Multiple regression analysis of influencing factors of caregiver burden

Model	B	t	p	F	p
(Constant)	40.131	6.304	0.000	47.167	0.000
PAT score	0.553	7.185	0.000		
SSRS score	-0.397	-3.708	0.000		
GSES score	-0.620	-3.362	0.001		
Number of contact hours per day	0.406	2.109	0.038		

In the stepwise multiple regression analysis, variables were considered to be associated with caregiver burden at the level of $p \leq 0.05$ ($F = 47.167$, $p = 0.000$, $R^2 = 0.675$, adjusted $R^2 = 0.660$).

home-care service.³² We also found that caregivers' self-efficacy and social support were important independent factors to perception of overload. Self-efficacy is the belief that someone has competence to complete a hard task or work. Previous published study had revealed that self-efficacy may improve the caring experience and quality of life of caregivers that result in perceiving of fewer burdens.³⁸ This investigation supported prior outcomes that the level of caregiver burden was negatively correlated with the level of social support they received.^{12,29} With better social support, caregivers can adapt to the role change more flexibly and obtain more resource to provide better home-care service, such as wound care, daily activities and hospital visits.³⁹

Wound caregiving has received relatively low attention and little is known about the impact of factors particular to chronic wound. Kuzuya *et al.* found that heavy caregiver burden was associated with mortality and hospitalization among community-dwelling dependent older adults.⁴⁰ Thus, the reduction of caregiver burden may not only improve the quality of life of caregiver but also prevent the deterioration of health outcomes of care recipients. Results of the study could help us to perceive caregivers who were at risk of high load care at the onset of patient treatment. What is more, we could get a glimpse of main determinants of the caring burden to develop targeted interventions for patients with chronic wound and their informal caregivers.

Some limitations must be identified. At first, due to data resource constraints, we carried out single-center research, not multicenter research. Second, we did not repeatedly measure the burden of caregivers at different time intervals. These limitations may impede the generalization of the results to the whole wound healing center.

In conclusion, caregivers of patients with chronic wound perceived a medium level burden. In particular, major predictors of feelings of being burdened were powerlessness status of patients, caring time per day for a patient, self-efficacy, and social support of caregivers. Wound professionals should pay attention to caring burden of wound caregivers and develop training plan and support service system according to the determinants of caregiver burden.

INNOVATION

Understanding the burden of chronic wound caregiving is important to develop a support pro-

KEY FINDINGS

- Caregivers of patients with chronic wound experienced a medium level burden.
- It was noteworthy that the level of caregiver burden in the developmental domain was the highest.
- The following variables were considered to be independently associated with caregiver burden: long caring time per day for patients, powerlessness status of patients, insufficient self-efficacy, and social support of caregivers.

gram. However, gaps in the literature remain. Caring burden of patients with chronic wound as a key consideration of patient-centered wound care has received relatively little attention. What is more, little is known about the determinants of caregiver burden especially to chronic wound. To the best of our knowledge, this study is the first to quantitatively measure the status of caring burden and determinants of informal caregiver of patients with chronic wound in detail. We should consider taking future actions to relieve the burden of caregivers of this population.

ACKNOWLEDGMENTS AND FUNDING SOURCES

The authors thank Dr. Y.F. Qian, a health statistician from Clinical Research Center, for reviewing all the data and all the patients and caregivers who participated in this study. The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This program was supported by grants from Shanghai Jiao Tong University School of Medicine—Nursing research project (Jyhz1806), the National Natural Science Foundation of China (Grant Nos. 81671917 and 81272111), Shanghai Ninth People's Hospital Research Project (Grant Nos. JYHL20182003 and JYHL20182110).

AUTHOR DISCLOSURE AND GHOSTWRITING

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article. No ghostwriters were involved in the preparation of this article.

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Abbreviations and Acronyms

CBI = caregiver burden inventory
 CWIS = cardiff wound impact schedule
 GSES = general self-efficacy scale
 HRQoL = health-related quality of life
 PAT = powerlessness assessment tool
 PUSH = pressure ulcer scale for healing
 SD = standard deviation
 SSRS = social support rating scale