



Factors influencing the burden on spousal caregivers of breast cancer survivors

Lin Tao^{1,2} · Xiaoxia Hu^{1,2} · Hongxiu Chen² · Shuwen Xiao³ · Xiaoxia Zhang^{1,2}

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Abstract

Purpose To examine the status of spouses' burdens of caring for breast cancer survivors and explore the relationships between social support, family resilience, breast cancer survivors' individual resilience, and caregiver burden.

Methods A cross-sectional study on 315 young and middle-aged breast cancer survivors and their spousal caregivers was conducted at eight comprehensive Southwest China hospitals. The caregivers completed the Chinese Version of the Family Resilience Assessment Scale, the Perceived Social Support Scale, and the Zarit Caregiver Burden Interview, while breast cancer survivors completed the shortened Chinese version of the Connor-Davidson Resilience Scale. Structural equation modeling was used to evaluate the relationships among social support, family resilience, survivors' individual resilience, and caregiver burden.

Results Caregiver burden (45.76 ± 14.66) was found to be severe. Social support, family resilience, and individual resilience were significantly negatively associated with caregiver burden ($\beta = -0.421, P < 0.001$; $\beta = -0.208, P < 0.001$; and $\beta = -0.444, P < 0.001$, respectively). Individual resilience not only partially mediated the relationship between family resilience and caregiver burden ($b = -0.052$; 95% confidence interval, $-0.110, -0.018$), but also partially mediated the relationship between support and caregiver burden ($b = -0.045$; 95% confidence interval, $-0.102, -0.011$).

Conclusions The findings suggest that higher social support, family resilience, and individual resilience tend to ease caregivers' burden. Healthcare workers should have an in-depth understanding of the care needs of survivors, actively contact social security departments and social organizations to provide financial, technical, and emotional support, and provide family-based care-skills training and psychological counseling to reduce spousal caregivers' burdens.

Keywords Breast cancer · Spousal caregiver · Resilience · Social support · Caregiver burden

Introduction

In 2020, the latest data from the International Agency for Research on Cancer of the World Health Organization report as many as 2.26 million new cases of breast cancer worldwide, surpassing 2.20 million cases of lung cancer

[1]. Breast cancer has replaced lung cancer as the world's leading cancer sub-type. Fortunately, the treatment effectiveness of breast cancer is better, and its five and ten years relative survival rates have been reported to be 90.0% and 80.0%, respectively [2]. This indicates that the quality of life of breast cancer survivors is an important aspect that needs to be focused on. Breast cancer is regarded as a "couple disease" and has been posited to trigger marital crises [3]. Bonding and intimacy in marriage, including physical closeness as well as emotional, spiritual, or intellectual intimacy, are major concerns among breast cancer survivors [4]. However, the huge burden of providing care for a loved one with breast cancer typically exhausts spousal caregivers and makes it difficult for them to achieve perfect physical and mental intimacy with their wives. In particular, the population of Chinese females diagnosed with middle- and late-stage breast cancer are in their youth and middle ages, which means their young lives and careers become hindered; this

Lin Tao and Xiaoxia Hu contributed equally to this work.

✉ Xiaoxia Zhang
zhangxiaoxia@scu.edu.cn

¹ Department of Breast Surgery, West China Hospital, Sichuan University, No. 37 Guoxue Street, Chengdu 610000, China

² West China School of Nursing, Sichuan University, Chengdu 610000, China

³ National Chengdu Center for Safety Evaluation of Drugs and National Clinical Research Center for Geriatrics, West China Hospital, Sichuan University, Chengdu 610000, China

subsequently causes their spouses to endure the high burden of caring for them, which undoubtedly is huge blow to couples [5].

Caregiver burden is defined as the physical, psychological, and financial distresses emanating from providing care to patients afflicted with illnesses [6]. In contrast to stroke and paralysis patients, breast cancer survivors can take care of themselves and usually do not need formal assistance from professional caregivers or special care workers. Family members often become their caregivers—referred to as informal caregivers—from the point of diagnosis and throughout their cancer survivorship journey. Yan [7] and Kilic [8] describe family caregivers as those who have a friendship or kinship with patients and provide uncompensated care to them at home. Such caregivers may be parents, spouses, children, siblings, friends, and even neighbors. For young and middle-aged breast cancer survivors, the male spouse is usually the main family caregiver. Nakaya et al. [9] reported that when women suffer from malignant tumors, their spousal caregivers face a higher risk of psychological distress and bear a greater caregiver burden.

The impact of cancer diagnosis and treatment process on cancer patients and their family caregivers is more in pairs [10], and cancer patients and spousal caregivers can influence each other [11]. Coping with cancer is not just a capability that individuals must develop on their own but also includes adaptation by the entire family system. Studies have shown that caregiver burden is linked to characteristics of survivors, including their demographic factors, stage of tumor, employment, and type of health coverage, among others [12, 13]. It is also related to the characteristics of caregivers, such as their demographic factors, employment, care duration per day, sleep time per day, having or not having co-caregivers, and having or not having minor children, among others [14–16]. The characteristics of family, such as size and monthly income, have also proved to be important factors influencing the burden of caregivers [17]. Families can provide cancer survivors with an internal support and are their main source of spiritual, financial, and emotional support. Caregivers will consider using available resources, including internal resources from in-home support (family resilience and individual resilience) [18, 19] and external resources from out-of-home support (social support) to alleviate their negative stress response, such as the caregiver burden [12].

Resilience refers to an individual's positive adaptation capabilities in the face of adversity, trauma, tragedy, threats, or major stressors. Put differently, it is the ability to recover from difficult experiences [20]. Patterson et al. [21] believed that a family, as a social system, can be considered “resilient” in ways that parallel the descriptions of individual resilience. When a family faces a major crisis, the power that helps them resist, successfully control, and recover from adversity is family resilience. Li et al. [18] reported that family resilience and breast cancer survivors'

individual resilience were negatively correlated with caregiver burden, and survivors' individual resilience mediated the relationship between family resilience and caregiver burden, indicating that there is a correlation between survivors' individual resilience, family resilience, and caregiver burden. Furthermore, according to Chen et al. [22], family resilience and social support were positively correlated with individual resilience. Cancer is a serious stress event for patients and their families, and social support serves as a buffer between stress events and individuals, and can buffer the impact of stress events on individual health [23]. Individuals getting good social support can alleviate the impact of stress events on the individual and reduce their physical and mental burden [24]. The more social support breast cancer survivors get and the more they can use the support, the more it helps improve their self-coping ability and promote individual adaptation [25]. When breast cancer survivors successfully cope or adapt, the emotional support and company time invested by caregivers will be relatively reduced, which will help reduce the burden on caregivers. Therefore, we speculate that survivors' individual resilience mediated the relationship between social support and caregiver burden. Although social support is also considered a protective factor against caregiver burden [24], little is known about the link between family resilience, social support, breast cancer survivors' resilience, and caregiver burden especially in young and middle-aged breast-cancer-affected couples.

In China, family size reductions, shortening of hospital stays, and limited community health resources have led to the extension of family care time, which has increased caregivers' responsibilities and burdens [26]. In families where the wife is a young and middle-aged breast cancer survivor, the male spouse's responsibilities and pressures are greater [17]. Therefore, we conducted this survey to identify and explore the factors influencing the burden of spouse caregivers. Firstly, we hypothesized that spousal caregivers in Southwest China bear a certain degree of caregiver burden. Second, we hypothesized that higher breast cancer survivors' individual resilience, family resilience and social support is related to lower caregiver burden. Thirdly, we hypothesized that the relationship between family resilience and caregiver burden is mediated by individual resilience. Finally, we hypothesized that the relationship between social support and caregiver burden is also mediated by individual resilience.

Methods and variables

Sample and setting

From August 2019 to August 2020, we screened 315 women who underwent modified radical mastectomies, with support from their spousal caregivers ($n = 315$) at

breast surgery departments in Grade III A (> 500 beds) comprehensive hospitals in Sichuan Province. The four sub-regions of Sichuan Province were selected and divided by economic status, namely the provincial capital, Panxi, southern area, and northeast area. Two hospitals in each region were selected; eight tertiary comprehensive hospitals were included. We recruited patients who had received radiotherapy and/or chemotherapy for more than one month after surgery. To be eligible, these female patients had to (1) be aged 18–59 years; (2) have stage I–III primary breast cancer without metastasis; (3) have received radical mastectomy; (4) have completed initial breast cancer treatment (surgery, radiotherapy, chemotherapy) for ≥ 1 year; (5) have exhibited no recurrence; (6) be able to complete the study questionnaire independently or under the guidance of the researcher; and (7) voluntarily participate in the survey. To be eligible, the male participants had to (1) be the husbands of female breast cancer survivors and living with their wives; (2) be recognized by the survivor as the main caregiver, that is, be the one spending the most time providing care within 24 h; (3) be participants in the patient's medical decision making; (4) have no history of mental disorders, be able to communicate normally, and (5) be aware of the patient's condition. We excluded couples where only one of the spouses agreed to or was able to participate in the research and excluded those who withdrew or refused to participate in the study. We provided a free physical examination and a panel of blood tests for every breast cancer survivor willing to participate in the survey. A total of 320 couples were the initial participants. Three survivors declined to participate because of physical discomfort and two spousal caregivers refused to participate due to lack of interest. The final sample included 315 couples (participation rate = 98.4%).

Design and data collection

This was a descriptive cross-sectional study. The survey was conducted when the breast cancer survivors returned to the hospital to participate in the free physicals and blood tests. All couples were separated and completed the questionnaire in quiet rooms. The survivor questionnaire included items focused on demographic characteristics, individual resilience, and social support. The spousal caregiver questionnaire included items focused on demographic characteristics, family resilience, and caregiver burden. The researchers hired data collectors in the tertiary hospitals and conducted online training for these data collectors. The training content included the purpose and requirements of the survey, data collection methods, explanations of the contents of the measurement scales, and precautions for data collection. The questionnaire was mailed

to the data collectors of the four sub-regions' hospitals. Before distributing the formal survey, each data collector used a unified instruction language to explain the purpose and significance of the research to the interviewees. After obtaining informed consent, the data collectors distributed the questionnaires face-to-face.

Variables

Independent variable: family resilience

The Shortened Chinese Version of the Family Resilience Assessment Scale (FRAS-C) measures family resilience, including three domains (32 items): (a) family communication and problem-solving (FCPS), (b) utilizing social resources (USR), and (c) maintaining a positive outlook (MPO) [27]. The FRAS-C is scored on a 4-point scale from 1 (strongly disagree) to 4 (strongly agree), with a score range of 32–128. Higher scores indicate greater family resilience. This scale has excellent reliability and validity.

Independent variable: individual resilience

The Chinese version of the Connor-Davidson Resilience Scale (CD-RISC10) measures individual resilience, including 10 items. The FRAS-C is scored on a 5-point scale from 0 (not true at all) to 4 (true nearly all the time). The CD-RISC10 scores range from 0 to 40. Higher scores indicate greater individual resilience. The CD-RISC10 has excellent psychometric properties [28].

Independent variable: social support

The Chinese version of Perceived Social Support Scale (PSSS-C) measures social support, which includes two domains (12 items): (a) in-home and (b) out-of-home support. Items are scored on a 7-point scale from 1 (strongly disagree) to 7 (strongly agree), with total scores ranging from 12 to 84 [23]. Higher scores indicate greater social support. Scores of 12–36 indicate a low support level, 37–60 indicate an intermediate support level, and 61–84 indicate a high support level. The Cronbach's alpha was 0.84.

Dependent variable: caregiver burden

The 22-item Chinese version of the Zarit Caregiver Burden Interview (ZBI-C) measures caregiver burden, including two domains: (a) personal strain and (b) role strain [26]. The ZBI-C is scored on a 5-point scale from 0 (not true at all) to 4 (true nearly all the time). The ZBI-C scores ranged from 0 to 88.

Higher scores indicate higher caregiver burden. A score of <20 indicates no burden, 21–40, mild-to-moderate burden, and ≥ 41 , high to severe burden [29]. The Cronbach's alpha was 0.85.

Control variables

The following control variables were considered: marital status (first marriage = 1, remarry = 2), having or not having minor children (Yes = 1, No = 2), survivors' employment (unemployed or retired = 1, part-time job = 2, full-time job = 3), spousal caregivers' employment (unemployed or retired = 1, part-time job = 2, full-time job = 3), care duration per day (< 4 h = 1, 4–6 h = 2, 7–8 h = 3, > 8 h = 4), having or not having co-caregivers (Yes = 1, No = 2).

Data analysis

Descriptive statistics were used to describe the participants' sociodemographic characteristics and the main study variables (family resilience, individual resilience, social support, and caregiver burden). Data were analyzed using IBM SPSS 22.0 statistical software (IBM Corp., Armonk, NY) and IBM SPSS Amos 21.0 (IBM Corp., Armonk, NY). One-way analyses of variance were used to test for the associations between sociodemographic characteristics and spouses' burdens. The associations among family resilience, individual resilience, social support, and caregiver burden were examined by calculating the Pearson correlation coefficient. Structural equation modeling analysis was used to identify the associated factors of caregiver burden. The significant factors in univariate and correlation analyses were entered in a structural equation model, with the caregiver burden as the dependent variable. We reported multiple indices of fit, including chi-square, root mean square error of approximation (RMSEA), goodness-of-fit index (GFI), adjusted goodness-of-fit index (AGFI), incremental fit index (IFI), comparative-fit index (CFI), and Tucker-Lewis Index (TLI). The model was fitted multiple times using maximum likelihood, and the mediating effect of individual resilience was estimated using the bootstrap method.

Results

Descriptive statistics

A total of 315 couples (315 men [range = 22–69 years] and 315 women [range = 21–59 years]) were included in the study. Demographic characteristics are shown in Table 1. More than half of the couples had senior school education or above, 62.2% had minor children, and 44.1% of breast cancer survivors were unemployed. The tumor stage of most breast cancer survivors was stage II. Due to taking care of their wives, 21.3% of spousal caregivers slept less than 6 h

a day. Of the spouses, 79 (25.1%) reported that they have co-caregivers, 24 (7.5%) had parents, 38 (12.2%) had adult children, and 17 (5.4%) had siblings. There were significant differences in caregiver burden according to care duration per day, survivors' and spousal caregivers' employment, marital status, having or not having minor children, and having or not having co-caregivers (Table 2).

Family resilience, individual resilience, social support, and caregiver burden

Analysis results for family resilience, individual resilience, social support, and caregiver burden are shown in Table 3. The overall PSSS score was 57.71 ± 13.46 ; FRAS-C score was 107.34 ± 17.35 ; CD-RISC10 score was 23.10 ± 9.32 ; and ZBI-C score was 45.76 ± 14.66 .

Correlations between family resilience, individual resilience, social support, and caregiver burden

Pearson's correlation analysis (Table 4) showed that social support, family resilience, and their subscales were positively correlated with individual resilience. Furthermore, social support, family resilience, and individual resilience were negatively associated with caregiver burden.

Model test

Structural equation modeling was used to test the correlations among the variables (Fig. 1). The results showed that the models fit the data well ($\chi^2/df = 2.520$, RMSEA = 0.043, GFI = 0.932, AGFI = 0.917, IFI = 0.962, CFI = 0.975, NFI = 0.978, and TLI = 0.953). The model accounted for 32% of the variance in caregiver burden. The standard factor loading of the observed variables was between 0.379 and 0.916 (Table 5). The standardized estimation of each path in the model is shown in Table 6. The coefficients indicated that social support, family resilience, and individual resilience had a direct negative effect on caregiver burden ($\beta = -0.421$, $P < 0.001$; $\beta = -0.208$, $P < 0.001$; and $\beta = -0.444$, $P < 0.001$, respectively). In addition, "care duration per day" and "having or not having co-caregivers" have a direct positive effect on caregiver burden ($\beta = 0.134$, $P < 0.01$; $\beta = 0.107$, $P < 0.05$, respectively). Individual resilience was a partial mediator of the relation between family resilience and caregiver burden ($b = -0.052$; standard error = 0.022; 95% confidence interval, $-0.110, -0.018$; $p < 0.05$) with a bootstrap (10,000 samples). Individual resilience was also a partial mediator of the relation between social support and caregiver burden ($b = -0.045$; standard error = 0.022; 95% confidence interval, $-0.102, -0.011$;

Table 1 Demographic and clinical characteristics ($N=315$)

Variable (survivors)	Number (%)	Variable (caregivers)	Number (%)
Age range (years)	V	Age range (years)	
≤ 39	58 (18.4)	≤ 39	35 (11.1)
40–49	126 (40.0)	40–49	98 (31.1)
50–59	131 (41.6)	50–59	118 (37.5)
Education		60–69	64 (30.3)
Primary school	21 (6.7)	Education	
Middle school	113 (35.9)	Primary school	36 (11.4)
Senior school	94 (29.8)	Middle school	100 (31.7)
College or above	87 (27.6)	Senior school	122 (38.7)
Stage of tumor		College or above	57 (18.1)
I	57 (18.1)	Marital status	
II	134 (42.5)	First marriage	249 (79.0)
III	124 (39.4)	Remarried	66 (21.0)
Employment		Employment	
Full-time job	80 (25.4)	Full-time job	194 (61.6)
Part-time job	96 (30.5)	Part-time job	60 (19.0)
Unemployed	139 (44.1)	Unemployed or retired	61 (19.4)
Type of health coverage		Care duration per day (hours)	
Self-pay	40 (12.7)	< 4	57 (18.1)
Public fee	27 (8.6)	4–6	159 (50.5)
Medical insurance	248 (78.7)	7–8	63 (20.0)
Having or not having minor children		> 8	36 (11.4)
Yes	196 (62.2)	Sleep time per day (hours)	
No	119 (37.8)	< 6	67 (21.3)
Family size (number)		6–8	205 (65.0)
2	57 (18.1)	> 8	43 (13.7)
3	126 (40.0)	Having or not having co-caregivers	
4	86 (27.3)	Yes	79 (25.1)
5	39 (12.4)	No	236 (74.9)
6	7 (2.2)	Monthly family income per capita (USD)	
		< 450	145 (46.0)
		450–750	91 (28.9)
		> 750	79 (25.1)

$p < 0.05$) with a bootstrap (10,000 samples). Since these two-confidence interval did not include zero, we concluded that individual resilience had a significant mediation effect.

Discussion

The purpose of this study was to explore the relationship between breast cancer survivors' individual resilience, family resilience, social support, and caregiver burden, and to identify the factors related to caregiver burden in South-west China. In our study, we found that spousal caregivers experienced a high degree of burden, higher than it was recorded in studies conducted in Eastern China [18, 30], possibly due to differences in regional economic status [31].

As hypothesized, we found that higher individual resilience, family resilience, and social support might reduce spousal caregivers' burdens. The relationship between family resilience and caregiver burden was partially mediated by breast cancer survivors' individual resilience. Furthermore, the relationship between social support and caregiver burden was also partially mediated by individual resilience.

The characteristics of survivors, caregivers, and families are regarded to be crucial in the caregiver burden. For example, Wu et al.'s [32] research shows that care duration is a predictor of caregiver burden, with greater care duration leading to heavy caregiver burden. Bekdemir and Ilhan [33] reported that caregiver employment status, home type, etc., were significant predictors of caregiver burden. Our study also showed that care duration per day was found to

Table 2 Differences in caregiver burden by sociodemographic characteristics of couple ($N=315$)

Characteristics	Caregiver burden		F	95% confidence interval (M)	
	M	SD		Lower	Upper
Marital status			5.106*		
First marriage	44.88	14.63		42.98	46.63
Remarry	49.36	14.29		45.85	52.88
Having or not having minor children			6.619*		
Yes	47.40	14.52		45.36	49.45
No	43.06	14.54		40.41	45.70
Employment(patients)			10.914**		
Full-time job	39.35	14.30		36.17	42.53
Part-time job	47.80	15.57		44.65	50.96
Unemployed or retired	48.04	13.15		45.84	50.25
Employment(spouse)			4.971*		
Full-time job	44.11	14.08		42.11	46.10
Part-time job	45.98	14.61		42.20	49.76
Unemployed or retired	50.80	15.55		46.82	54.79
Care duration per day (hours)					
< 4	38.77	11.95	11.710**	35.60	41.94
4–6	45.06	14.75		42.75	47.37
7–8	48.13	13.99481		44.6024	51.6515
> 8	55.81	13.16884		51.3499	60.2612
Having or not having co-caregivers			6.790		
Yes	42.08	13.49		39.05	45.10
No	46.70	14.85		45.09	48.90

Only significant results have been listed

* p -value < .05, ** p -value < .01, M , mean; SD , standard deviation

Table 3 Analysis results: family resilience, individual resilience, social support, and caregiver burden

Parameters	Mean	SD	Min	Max
Social support	57.71	13.46	16	84
In-home support	20.03	4.88	4	28
Out-of-home support	37.69	10.25	10	56
Family resilience	107.34	17.35	32	128
FCPS	77.13	13.57	23	92
USR	10.41	1.89	3	12
MPO	19.80	3.78	6	24
Individual resilience	23.10	9.32	6	40
Caregiver burden	45.76	14.66	21	76
Role strain	14.12	4.93	6	24
Personal strain	25.25	9.11	12	42

be significant factors of caregiver burden in a structural equation model. It is worth mentioning that although survivors' and spousal caregivers' employment did not enter the structural equation model in the end, one-way analyses of variance showed that survivors' and spousal caregivers' employment were associated with caregiver burden. Compared with unemployed breast cancer survivors and male

spouses (including unemployed or retired spouse), when either spouse has a job (including full-time and part-time), the burden of the caregiver is lower. On the one hand, the income of both spouses may help reduce the family's financial burden; on the other hand, breast cancer survivors can rehabilitate and return to work after treatment to help divert attention and integrate into society [34, 35]. This is an important step towards recovery as it helps reduce the mental and psychological stress of breast cancer survivors and their spouses. However, 44.1% of breast cancer survivors participating in this study are still unemployed after completing initial treatment. Therefore, it is particularly important for the government to provide employment opportunities for breast cancer survivors. Additionally, having or not having co-caregivers were found to be significant factors of caregiver burden in a structural equation model. Of the spousal caregivers in our study, 74.9% did not have assistance or co-caregivers and had to bear the pressure of caregiving alone. Chinese males are generally unwilling to reveal or share family pressures and are even more unwilling to mention to others that their wives suffer from breast cancer because of the stigma attached; this hinders achieving some relief from negative emotions and results in mental and physical health issues [36, 37].

Table 4 Correlations between PSSS, FRAS-C, CD-RISC10, and ZBI-C

	FCPS	USR	MPO	Family resilience	Individual resilience	Out-of-home support	In-home support	Social support	Personal strain	Role strain	Caregiver burden
FCPS	1	0.338**	0.750**	0.983**	0.238**	0.098	0.061	0.097	-0.219**	-0.205**	-0.235**
USR	0.338**	1	0.318**	0.443**	0.134*	0.028	0.058	0.042	-0.177**	-0.182**	-0.202**
MPO	0.750**	0.318**	1	0.839**	0.211**	0.129*	0.098	0.134*	-0.159**	-0.131*	-0.164**
Family resilience	0.983**	0.443**	0.839**	1	0.247**	0.108	0.076	0.109*	-0.225**	-0.209**	-0.242**
Individual resilience	0.238**	0.134*	0.211**	0.247**	1	0.199**	0.199**	0.223**	-0.206**	-0.277**	-0.251**
Out-of-home support	0.098	0.028	0.129*	0.108	0.199**	1	0.523**	0.951**	-0.078	-0.152**	-0.112*
In-home support	0.061	0.058	0.098	0.076	0.199**	0.523**	1	0.761**	-0.163**	-0.269**	-0.211**
Social support	0.097	0.042	0.134*	0.109	0.223**	0.951**	0.761**	1	-0.118*	-0.213**	-0.161**
Personal strain	-0.219**	-0.177**	-0.159**	-0.225**	-0.206**	-0.078	-0.163**	-0.118*	1	0.559**	0.955**
Role strain	-0.205**	-0.182**	-0.131*	-0.209**	-0.277**	-0.152**	-0.269**	-0.213**	0.559**	1	0.773**
Caregiver burden	-0.235**	-0.202**	-0.164**	-0.242**	-0.251**	-0.112*	-0.211**	-0.161**	0.955**	0.773**	1

* $p < 0.05$ ** $p < 0.01$

Fig. 1 Final model of caregiver burden. * p -value < 0.05, ** p -value < 0.01, *** p -value < 0.001. Values on paths are path coefficients (standardized β s). The oval boxes represent latent variables, while the rectangular boxes represent observed variables. Only significant results have been showed

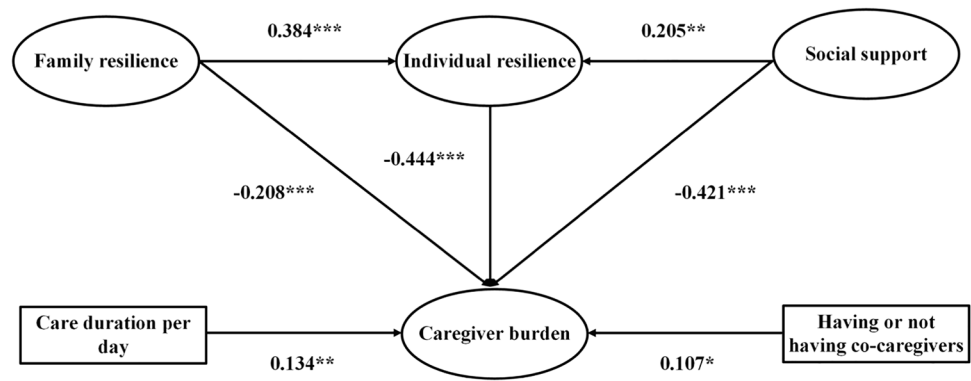


Table 5 Standardized factor loading of the observed variables on latent construct

Latent construct	Observed variable	Factor-loading
PSSS-C	In-home support	0.850
	Out-of-home support	0.616
FRAS-C	FCPS	0.916
	USR	0.379
	MPO	0.818
Caregiver burden	Personal strain	0.652
	Role strain	0.871

This study demonstrated that not only did family resilience have a direct effect on the burden of spousal caregivers, but it also had an indirect effect on the burden of spousal caregivers through individual resilience. When a wife is diagnosed with cancer, experiences surgical trauma, and faces a huge impact of breast loss, she must bear the physical discomfort of medical treatments along with psychological discomfort. Family members' unity, assistance, optimism, and positive attitude can help individuals survive these burdens [18]. The present study demonstrated that family resilience and individual resilience are positively correlated. When individuals face crises and challenges, encouragement and support from family can promote individuals' self-reliance and activeness in their work and life, which might lead to spousal caregivers experiencing lower caregiver burden.

Table 6 Standardized estimation of each path in the model

Path	Path coefficient	Estimates	S.E	C.R	P
Individual resilience <--- Family resilience	0.384	0.565	0.089	6.323	<0.001
Individual resilience <--- Social support	0.205	0.185	0.059	3.118	0.002
Caregiver burden <--- Family resilience	-0.208	-0.277	0.075	-3.669	<0.001
Caregiver burden <--- Social support	-0.421	-0.343	0.057	-5.962	<0.001
Caregiver burden <--- Individual resilience	-0.444	-0.401	0.057	-7.023	<0.001
Caregiver burden <--- Care duration per day	0.134	0.104	0.037	2.798	0.005
Caregiver burden <--- Having or not having co-caregivers	0.107	0.171	0.076	2.254	0.024

S.E., standard error; C.R., critical ratios

Medical staff should fully realize the role of family resilience in reducing the burden on spousal caregivers, implement family-centered nursing intervention, and help spousal caregivers adapt to their caregiving roles.

Individuals or family members should strive to have an open mind when facing crises and challenges, which can help the caregivers accept and tolerate problems and difficulties, and bring in openness to external social relationships, actively seeking support from relatives, friends, or members of society [38, 39]. This study showed that social support had both a direct effect on the burden of spousal caregivers as well as an indirect one, through individual resilience. This result is consistent with that of Jabłoński et al. [40] and Ustaalioglu et al. [41]. The social-support buffer-theory model supports the fact that, when an individual experiences a stressful event, social support can play a buffering role, reducing the stress of caregivers and the negative emotions caused by the stressful event, thereby maintaining the individual's health. Social support can meet caregivers' needs by providing emotional, material, and informational support; it is likely to raise reported levels of happiness and health. The more social support a caregiver receives and the higher the utilization of the support, the less burdened the caregiver feels. Therefore, it is necessary to strengthen the construction of a social support and security system to enrich the external resources available to spousal caregivers.

However, our results also show that social support for breast cancer patients and their spousal caregivers is at a

moderate level, lower than that of social support demonstrated by Tao et al. [42] in their survey of breast cancer patients during radiotherapy and chemotherapy in the same region of China in 2019. The differing results may be because breast cancer patients receive more attention during treatment. Once the treatment ends and a patient enters the recovery period, financial and emotional support from relatives, friends, or social groups may be reduced. Additionally, due to the ongoing COVID-19 pandemic, family, friend gatherings, and social group activities have been drastically reduced. This may have resulted in the cancer survivors feeling forgotten, ostracized, and/or rejected. In addition to potentially creating the perception of discrimination, long-term social restrictions are more likely to result in feelings of social alienation, which is not conducive to breast cancer survivors' reintegration into society or to the restoration of social roles [39, 43]. Irani et al. [44] reported that the caregiving tasks that are now offered more often than usual included providing emotional support to the patients. The medical staff should modify their caregiving approach by making full use of network resources to leverage new technology and caregiving routines during the ongoing COVID-19 pandemic. Furthermore, training on caregiving skills and psychological counseling should be offered through caregiver network education projects, caregiver network forums, and other means to provide communication and exchanges between spousal caregivers and to mitigate any negative emotions.

Limitations

As this is a cross-sectional study, it is impossible to infer the causal relationship between family resilience, individual resilience, social support, and caregiver burden. At the same time, from the time of diagnosis of the disease to the end of treatment, caregiver burdens change constantly. Hence, future studies should conduct longitudinal surveys of spousal caregivers at different points in time to understand more clearly the changing trends of spousal caregivers' burdens. In this study, breast cancer survivors report social support while spouse caregivers report family resilience. This may not fully reflect the support within and outside the family because it only captures the views of either wife or husband. Due to lack of objectivity, errors may be introduced. It is better to explore family resilience and social support from the perspective of the whole family, such as couples, parents, children, and siblings, among others. In addition, more detailed characteristics of survivors, spousal caregivers, and families should be considered in future studies. Caregivers' individual resilience has been found to be associated with caregiver burden [19]. Finally, other potential variables, such as self-efficacy, type of family, coping style, family functioning, and health status of caregivers, should also be considered in future research.

Conclusion

The spousal caregivers of breast cancer survivors in underdeveloped areas in China have experienced rigorous caregiver burdens, but good social support, family resilience, and individual resilience can reduce these burdens. Social support and family resilience could also enhance breast cancer survivors' individual resilience. Therefore, relevant government and medical departments should establish sound social support and security systems for spousal caregivers, actively provide any available social support, and conduct family-based care-skills training and psychological counseling to reduce the burden of spousal caregivers.

Author contribution Lin Tao, Xiaoxia Hu, and Xiaoxia Zhang contributed to the study conception and design. Material preparation, data collection, and analysis were performed by Lin Tao, Xiaoxia Hu, Hongxiu Chen, and Shuwen Xiao under the supervision of Xiaoxia Zhang. The first draft of the manuscript was written by Lin Tao and Xiaoxia Hu. All authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.

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Data availability Interested stakeholders may communicate with the corresponding co-author (Xiaoxia Zhang) to access de-identified data sets.

Code availability Interested stakeholders may communicate with the corresponding co-author (Xiaoxia Zhang) to access syntax files for analyses.

Declarations

Ethics approval The Clinical Trial and Biomedical Ethics Committee of West China Hospital, Sichuan University (No. 2019(512)) approved the data collection procedures that involve study participants to ensure their accordance with the ethical standards.

Consent to participate Informed consent was obtained from all individual participants included in the study.

Consent for publication Not applicable/no identifying information used for any individual participant.

Competing interests The authors declare no competing interests.

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