

## RESEARCH ARTICLE

# Quality of Life of Male Spouse Caregivers for Breast Cancer Patients in China

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### Abstract

**Background:** The aim of this study was to describe the characteristics of male spouse caregivers of breast cancer patients in China, assess their quality of life (QOL), and investigate the influencing factors. **Materials and Methods:** A total of 243 breast cancer patient-spouse caregiver dyads were recruited from four hospitals in Shanxi and Anhui province of China. A cross-sectional design was applied to collect data and the Chinese version of the Medical Outcomes Study 36-item Short Form (SF-36) was used to measure caregivers' QOL, and the Chinese version of M.D. Anderson Symptom Inventory (MDASI-C) was applied to measure patient symptom severity and interference. Pearson's correlation was used to examine the correlations between caregiver burden and QOL. The multiple regression analysis was used to determine the most predictive factors influencing QOL. **Results:** The scores of all SF-36 scales were above 50.0, which were much lower than that of general mainland Chinese males. Mental QOL was significantly worse than physical QOL. Spouses demographic characteristics, caregiving-related variables and patient symptoms were related to spouse QOL. Caregiver burden has a negative relationship with QOL. **Conclusions:** A decrease in life events and patient symptoms, as well as increase in spouse sleeping time and family income, ought to improve QOL.

**Keywords:** Quality of life - spouse caregivers - breast cancer patients - China

*Asian Pac J Cancer Prev*, 15 (10), 4181-4185

### Introduction

Breast cancer has been a major threat to women's health in China with the increasing of its incidence rate. According to the Department of Health, there are nearly 0.13 million newly diagnosed breast cancer patients every year in China (Ministry of Health of the People's Republic of China, 2012). Because of the debilitating nature of breast cancer and its treatment, patients have to be in hospital many times. For breast cancer patients in China, husbands are the primary caregiver due to the bound of traditional Chinese culture and the limited medical resources. They often accompany their wives for treatment, stay overnight at hospital, and take a variety of caregiving tasks, such as feeding, bathing, dressing, alertness for patient's need, appeasing patients, etc. With husbands supportive care, patients always did better physically and emotionally (McLean et al., 2007).

Though the vital role of caregivers in supporting cancer patients is well recognized, the healths of spouse caregivers have not received much attention from family members and medical staff in China. Caregivers always focus more on the patients, but neglect their own health. Caregiving responsibilities may create various burdens

on spouse caregivers, especially subjective burden, symptom burden and economic burden (Grunfeld et al., 2004; Zahlis et al., 2010; Palos et al., 2011; Lopez et al., 2012). The prevalence, severity and persistence of burden among cancer caregivers have a profound impact on both patients' and caregivers' quality of life (QOL) (Tang, 2006). The psychological distress of spouse caregiver may even higher than that of normal husbands, patients and other family caregivers (Hasson-Ohayon et al., 2010). Several studies have showed that Chinese caregivers of cancer patients were more vulnerable to emotional and psychological distress (Chan et al., 1999; Hu et al., 1999; Chen et al., 2004; Chiou et al., 2009). The psychological impairment and mood disturbance of spouse caregiver also increase the risk of spouse mortality within 1 year (Christakis et al., 2006).

To the best of our knowledge, many studies focused on either female spouses or samples of male and female spouses together, but we had little knowledge about the male spouse caregivers, especially Chinese sample. Few researchers have tried to explore both the patients' and spouses' factors that influenced the health of spouse caregiver. To provide better evidence and new ideas about long-term care for the government, and to give

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effective interventions to improve the care situation, we need a better understanding of QOL in male spouse caregivers and the influence factors affecting their health. The purposes of this study were to evaluate QOL in male spouse caregivers of breast cancer patients in China, and investigate the factors influencing the QOL of spouse caregivers.

## Materials and Methods

This study was conducted from August 2011 to May 2012 at the First and Second Affiliated Hospital of the Fourth Military Medical University, Shanxi Provincial Tumor Hospital and the Affiliated Hospital of Wannan Medical College. This study was approved by the research ethics committee of the Fourth Military Medical University, and the ethical committee of the data collection hospitals in Shanxi and Anhui province. All participants provided informed consent. Data were collected by face-to-face interview. For those caregivers and patients who were illiterate or had difficulty in reading or writing the questionnaires, the researcher read the questions to them and recorded their responses. Demographic and clinical information of patients were confirmed by researcher from medical records. The self-report survey consisted of two questionnaires which were completed by patients and spouse caregivers separately. Four parts of the survey were used for analysis and discussion: 1) patients and spouse demographic characteristics, 2) spouse caregiver burden, 3) spouse quality of life and 4) patients clinical characteristics, included symptom severity and interference. A cross-sectional design was applied to collect data from patients with breast cancer and from their male spouse caregivers.

### Sample characteristics

To ensure that our study would cover a wide range population, we recruited subjects from inpatient units of the Departments of Clinical Oncology or Breast Cancer Centers through four public hospitals in two provinces of China. We identified patients who 1) had a diagnosis of breast cancer, 2) were married with a man, 3) were able to complete the questionnaire by themselves or guided by researchers. Eligibility criteria of spouse caregivers included: A man who 1) were more than 18 years old, 2) were considered as the primary caregiver by patients, 3) had provided informal care to patients at least 72 hours prior to the time of the survey, 4) were able to complete the questionnaire by themselves or guided by researchers. Those who 1) had difficulty in communicating in Chinese or understanding the questionnaire, 2) had a history of psychiatric disorder or suffering from neurological disorder were excluded from the study. A total of 249 patients and their spouses were consented to participate in the survey. But 6 couples did not complete all the questionnaires. Ultimately, responses from 243 couples were included in the analysis.

### Measures

Quality of Life Caregivers' quality of life was measured by the Chinese version of the Medical Outcomes

Study 36-item Short Form (SF-36) (Li et al., 2003). It is composed of 36 items and divided into eight domains: physical functioning, role-physical, bodily pain, general health, vitality, social functioning, role-emotional and mental health. The item 1 measures health transition. Scores on each scale range from 0 to 100, with a score of 100 indicating the highest rating of health. The SF-36 can also be divided into two parts, Physical Component Summary scale (PCS) and Mental Component Summary scale (MCS). The internal consistency for the subscales of the Chinese version ranged from 0.74 to 0.94.

**Symptom severity and interference** The Chinese version of M.D. Anderson Symptom Inventory (MDASI-C) was applied to measure the severity of cancer-related and treatment-related symptoms (13 items) and their interference with daily activities (6 items) (Wang et al, 2004). Symptom severity was measured on a scale of 0 (not present) through 10 (as bad as can you can imagine). Symptom interference was measured using a scale of 0 (did not interfere) through 10 (interfered completely). The time period used for recall of the symptoms and their interference was 'within the past 24 hours'. The Cronbach alpha coefficients of the two parts on Chinese version were 0.86 and 0.84.

### Statistical analysis

Descriptive analysis was used for demographic variables, QOL and patients symptom. The correlations between caregiver burden and QOL were examined by Pearson's correlation. t-tests were performed to test whether there was a significant relationship of QOL between spouse caregiver and the normal male population. The multiple regression analysis was used to determine the most predictive factors of the outcomes. In stepwise variable selection methods, mean scores of PCS and MCS were treated as dependent variables, and independent variables contained spouses demographic characteristics, caregiving-related variables, patients demographic and clinical characteristics. P values were two-sided, and less than 0.05 were considered statistically significant. All data were analyzed by SPSS for Windows, Version 17.0.

## Results

### Sample characteristics

The demographic and caregiving-related characteristics of 243 spouse caregivers are summarized in Table 1. Overall, the mean age was 49.5 years (SD=9.4, range=26-80 years) and the mean duration of marriage was 24.5 years (SD=9.7, range=1-56 years). 38.7% of caregivers were reported having health problems. A large number of them were not employed (68.3%), had completed a secondary/technical education (51.4%), lived in urban (68.3%) with an average monthly family income of <2000 yuan (59.7%). They had someone to share caregiving (71.6%), and were responsible for the care of other family members (53.9%).

The demographic and clinical characteristics of 243 patients are presented in Table 2. The average age of patients was 47.4 years (SD=9.0, range=24-78 years), which was slightly younger than their husbands' age. The

distribution of educational level was similar to spouse caregivers. Most of them were not employed (66.3%), had undergone mastectomy (78.2%), receiving chemotherapy/radiotherapy (59.3%). The mean duration of disease was 10.6 months (SD=27.2, range=0.5-252 months). 22.8% of patients were diagnosed with stage II cancer, but 27.6% of patients could not be assured about their cancer stage because the information was missing or unclear.

### QOL of spouse caregiver

Table 3 summarizes the status of spouse caregivers' QOL. All SF-36 scales received scores above 50.00 which was much lower than the level of general mainland

**Table 1. Demographic and Caregiving-Related Characteristics of Spouse Caregivers (n=243)**

Variable	Number (%)	Mean (SD)
Age (years)		49.52 (9.39)
<45	80 (32.9)	
45-59	127 (52.3)	
≥60	36 (14.8)	
Education		
Elementary	48 (19.8)	
Secondary/technical	125 (51.4)	
College and above	70 (28.8)	
Employment		
Yes	77 (31.7)	
No	166 (68.3)	
Health problems		
Yes	94 (38.7)	
No	149 (61.3)	
Daily sleeping time (h)		7.28 (1.55)
<6	25 (10.3)	
6-8	179 (73.7)	
>8	39 (16.0)	
Life events		
Yes	50 (20.6)	
No	193 (79.4)	
Living district		
Urban	166 (68.3)	
Rural	77 (31.7)	
Monthly average family income (Yuan)		
<500	44 (18.1)	
500-999	32 (13.2)	
1000-1499	35 (14.4)	
1500-1999	34 (14)	
≥2000	98 (40.3)	
Duration of marriage (years)		24.51 (9.71)
≤10	19 (7.8)	
11-20	65 (26.7)	
21-30	104 (42.8)	
≥31	55 (22.6)	
Minor children		
Yes	72 (29.6)	
No	171 (70.4)	
Daily care (h)		17.77 (7.83)
1-5	20 (8.2)	
6-10	51 (21.0)	
11-15	22 (9.1)	
16-20	10 (4.1)	
21-24	140 (57.6)	
Caring duration (months)		9.83 (23.64)
≤3	143 (58.8)	
3.1-11.9	57 (23.5)	
≥12	43 (17.7)	
Someone to share caregiving		
Yes	174 (71.6)	
No	69 (28.4)	
Care of other family member		
Yes	131 (53.9)	
No	112 (46.1)	

Chinese males ( $t=-12.921\sim-1.438$ ,  $p<0.01$ ) (Pan et al., 2011). The score of mental component summary (MCS) was significantly lower than physical component summary (PCS) (64.99 V. 68.59,  $p=0.001$ ). Among the eight dimensions of SF-36, general health was rated lowest (M=50.20), while physical functioning was rated highest (M=87.51).

Our previous study have shown that the burden of the spouse caregivers was in the moderate level with a total

**Table 2. Demographic and Clinical Characteristics of Patients (n=243)**

Variable	Number (%)	Mean (SD)
Age (years)		47.38 (8.98)
<45	92 (37.9)	
45-59	126 (51.9)	
≥60	25 (10.3)	
Education		
None	20 (8.2)	
Elementary	41 (16.9)	
Secondary/technical	120 (49.4)	
College and above	62 (25.5)	
Employment		
Yes	82 (33.7)	
No	161 (66.3)	
Time since diagnosis (months)		10.60 (27.24)
≤3	153 (63.0)	
3.1-11.9	48 (19.7)	
≥12	12 (17.3)	
Cancer stage		
Stage I	55 (22.6)	
Stage II	68 (28.0)	
Stage III	17 (7.0)	
Stage IV	36 (14.8)	
Missing	67 (27.6)	
Treatment at present		
Surgery	78 (32.1)	
Chemotherapy/radiotherapy	144 (59.3)	
Symptom management / follow-up	21 (8.6)	
Surgery type		
None	37 (15.2)	
Conserving	16 (6.7)	
Mastectomy	190 (78.2)	
Symptom severity (MDASI-C)	243 (100.0)	109.00 (38.17)
Symptom interference (MDASI-C)	243 (100.0)	57.00 (19.95)

**Table 3. Quality of Life Scores of Spouse Caregiver**

	Mean	SD	Actual range of scores
SF-36			
Physical functioning	87.51	12.57	30-100
Role-physical	62.34	42.18	0-100
Bodily pain	74.28	17.68	0-90
General health	50.2	16.45	0-80
Vitality	67.53	20.6	0-100
Social functioning	73.71	21.6	0-100
Role-emotional	52.81	46.3	0-100
Mental health	65.89	20.08	0-100
Mental component summary (MCS)	64.99	22.14	13-93
Physical component summary (PCS)	68.59	17.58	0-99

**Table 4. Correlation between Caregiver Burden and QOL**

QOL	Caregiver burden					
	Sacrifice control	Loss of /anger	Embarrassment /criticism	Self-dependency	Total	
MCS	-0.43*	-0.40*	-0.45*	-0.02	-0.25*	-0.50*
PCS	-0.34*	-0.32*	-0.32*	-0.06	-0.19*	-0.39*

\*Correlation is significant at the 0.01 level (2-tailed)

**Table 5. Multiple Regression Model of QOL (Stepwise procedure)**

Predictor variable		Unstandardized coefficients (B)	Coefficients (Bet <sup>a</sup> )	t-statistic	p value	Corrected R <sup>2</sup>
PCS	Constant	66.133		9.632	0.000	0.399
	Health problems	-6.143	-0.350	-6.702	0.000	
	Monthly average family income	2.960	0.262	5.159	0.000	
	Life events	-5.909	-0.209	-4.018	0.000	
	Daily sleeping time	2.155	0.190	3.673	0.000	
	Age of spouse	-0.310	-0.166	-3.155	0.002	
	Care of other family member	-2.448	-0.165	-3.182	0.002	
MCS	Constant	47.515		6.852	0.000	0.378
	Life events	-8.119	-0.230	-4.343	0.000	
	Daily sleeping time	3.144	0.292	5.608	0.000	
	Patients' symptom severity	-0.314	-0.287	-5.445	0.000	
	Monthly average family income	3.875	0.274	4.382	0.000	
	Care of other family member	-4.082	-0.220	-4.109	0.000	
	Education of spouse	-5.236	-0.165	-2.563	0.011	
Someone to share caregiving	2.099	0.133	2.373	0.018		

score of 33.99 (SD=14.28, range=5-81). The proportion of each level was: mild (16.9%), moderate (49.8%) and severe (33.3%). 32.9% of them showed a high level of global burden. In this study, Pearson's correlation analysis found spouse self-criticism scores were not significantly correlated with any subscales or total scores of QOL. However, sacrifice, loss of control, embarrassment/anger, dependency and total ZBI scores showed significant negative correlations ( $r$  values ranged from 0.19 to 0.50,  $P < 0.01$ ) with PCS and MCS scores of spouse QOL. The highest correlation was considered between total caregiver burden and mental health ( $r = 0.50$ ,  $P < 0.01$ ) (Table 4).

#### Multiple linear regression analysis of QOL

Four categorical variables were examined for potential influence on the caregivers' QOL: spouse demographic and caregiving-related variables, patients' demographic and clinical characteristics. With ZBI, MCS, PCS scores as dependent variable separately, four types of variables were entered into stepwise regression as independent variables.

As depicted in Table 5, six variables have a significant relationship with spouse physical QOL. Those variables were all about spouse demographic and caregiving-related information. Health problems, life events, age of spouse, care of other family member were found having adverse effects on spouse physical health, while positive predictors were monthly average family income ( $\beta = 2.960$ ,  $p < 0.01$ ) and daily sleeping time ( $\beta = 2.155$ ,  $p < 0.01$ ).

Table 5 indicated seven significant predictors of spouse mental QOL. Among spouses demographic variables, life events ( $\beta = -8.119$ ,  $p < 0.01$ ), daily sleeping time, monthly average family income and education ( $\beta = -5.236$ ,  $p < 0.05$ ) were found to have effects on the spouse mental health. Among caregiving-related variables, predictors were care of other family member ( $\beta = -4.082$ ,  $p < 0.01$ ) and someone to share caregiving ( $\beta = 2.099$ ,  $p < 0.05$ ). Among patients variables, only symptom severity have a significant effect on spouse mental health ( $\beta = -0.314$ ,  $p < 0.01$ ).

## Discussion

Our study found the status of patient's symptom have

a significantly influences on spouse caregivers' QOL, as well as the mental well-being was worse than physical well-being. These results pointed that we should pay more attention on the stress experience of spouse caregiver, and assess patient's symptom when do research on spouse caregiver of breast cancer patients. The analysis of influence factors of QOL identified those who might be at higher risk or might need more professional care.

General health of male spouse caregiver of breast cancer patients was fairly worse than that of the control male. Their mental well-being was disrupted more seriously than physical well-being, and nearly one third of them kept doing a long time daily care even if they suffered from health problems and busy work. Our study found that the burden of spouse caregivers had an adverse effect on their quality of life, especially the mental health. Our result was consistent with the findings in Taiwan and Turkey, which reported significant associations between caregiver burden and QOL (Chan et al., 1999; Turkoglu et al., 2012). We developed their conclusions by classifying caregiver burden into five domains, and found sacrifice, loss of control, embarrassment/anger were the psychological burden, which have significant correlation with spouses mental QOL (Data not shown). This illustrated the importance of reducing psychological burden of spouse caregiver rather than physical burden.

The finding consisted with previous studies that QOL was affected by several factors. Spouse demographic and caregiving-related information were the strongest predictors. Patients' symptom rather than cancer stage, surgery type, treatment or demographic characteristics of patients had a significant impact on spouse caregivers' QOL. To identify factors that contribute to QOL among caregivers, physical QOL (PCS) and mental QOL (MCS) were used as independent variables separately. The results showed that family income and sleeping time have a significant beneficial effect on both physical and mental QOL. However, life events have a huge adverse impact not only on mental well-being but also on physical well-being. The possible suggestion to help improve spouse caregivers QOL includes coping strategies aimed at targeting life events and interventions to less the financial burden. In addition, spouses physical QOL was primary affected by

demographic variables of themselves than others. Older spouses with more health problems, less sleeping time and poor economy status have poor physical health naturally, and their physical burden increased with the addition of care of other family member.

It is an interesting finding that the higher level education of spouse, the lower mental health level they had. One possible explanation for this is that the high education populations are more likely to have a high expectation of healthy life and family, while the contradiction between cancer reality and their expectation may make them in emotional distress (Demirbag, 2012). Another finding was that patients' symptom has a significant adverse effect on caregivers mental QOL that was consistent with studies of symptom related to cancer in America and Norway (Palos et al., 2011; Valeberg et al., 2013). This finding indicated the importance of symptom management. We should deliver the knowledge and the effective coping way of symptoms to caregiver. At the same time, we found caring of other family member and having someone to share caregiving played a significant role in determining their mental well-being among caregiving-related variables. However, care duration had a significant effect on spouse QOL as reported in previous study (Hu, 1999; Chen et al., 2004) was not found which may be needed to clarify by further longitudinal studies in the same population.

In conclusion, the present study examined the QOL of spouse caregivers of breast cancer patients in China, and investigated the predictors influencing caregivers' QOL. The findings indicated that some attention should be paid to male spouse caregivers as a separate group. Nurses can understand the status of caregiver burden and QOL by assessing both patients and spouses. The mental health of spouse caregivers was disrupted more seriously than physical health. A decrease in life events and patients' symptom, as well as the increase in spouse sleeping time and family income ought to improve QOL.

## Acknowledgements

This study was supported by a grant to Dr. Ju-Fang Fu from Medical Department of Shannxi Province (Grant number: 2012SF2-08-4). The authors would like to thank all participants for sharing their experience in the study, and the staff of the participating hospitals for supporting the study.

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