

Relatives' quality of life and psychological disturbance: a new concern of SLE management

Furong Zeng¹ · Qianyun Xu¹ · Di Liu¹ · Hui Luo¹ · Ya-ou Zhou¹ · Wangbin Ning¹ · Jiangyan Chen¹ · Huali Zhang² · Haihong Liu³ · Yisha Li¹ · Xiaoxia Zuo¹

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Abstract It is known that the quality of life (QOL) and psychological status of patients with systemic lupus erythematosus (SLE) are severely impaired. However, a few reports have assessed the QOL and psychological status in relatives of these patients. This study aimed to assess the QOL and psychological status in relatives of patients with SLE and their impact on patients. A total of 104 patient–relative dyads were evaluated using a 36-Item Short-Form Survey (SF-36), Patient Health Questionnaire (PHQ-9), Generalized Anxiety Disorder Scale (GAD-7), and Social Support Rating Scale (SSRS). Relatives of patients with SLE exhibited an impaired QOL compared with the general population (69.59 ± 22.78 vs 78.18 ± 15.88 , $P < 0.001$) and suffered from depression (5.8 ± 5.4) and anxiety (5.8 ± 6.0). GAD-7 of relatives was positively correlated with GAD-7 of patients ($r = 0.210$, $P < 0.05$). Patients reported a lower global SF-36 score when their relatives had lower global SF-36 scores (50.13 ± 19.18 vs 58.44 ± 19.67 , $P < 0.05$) and significantly higher SSRS when their relatives had lower PHQ-9 (41.9 ± 8.7 vs 36.3 ± 6.2 , $P < 0.01$) or GAD-7 scores (42.8 ± 7.4 vs 36.7 ± 6.6 , $P < 0.01$). The QOL and psychological status in relatives of patients with SLE were adversely impaired. Associations exist

between the QOL and psychological status of relatives and patients with SLE. Therefore, both patients and their relatives should be taken into account when making management decisions.

Keywords Anxiety · Depression · Quality of life · Relative · Systemic lupus erythematosus

Introduction

Systemic lupus erythematosus (SLE) is a chronic autoimmune disease characterized by generation of autoantibodies, damage of multiple target organs, and relapsing and remitting course. After disease onset, the overall 5- and 10-year pooled survival rates of patients with SLE in China are 94 and 89%, respectively [1]. Patients with SLE have been reported to suffer from impaired quality of life (QOL) and compromised psychological health status [2]. Thus, besides controlling the immunopathological causes of the disease, factors such as anxiety and depression, which negatively influence the QOL of patients with SLE, should be also taken into consideration [3].

Patients with SLE having protean manifestations and poor psychological health pose a psychological and physical burden on their close relatives. Often, relatives have to accommodate their daily activities to adapt to the patient needs. Therefore, it is suspected that the QOL and psychological health of relatives of patients with SLE may be adversely affected. Anxiety and depression are the most common psychological problems experienced by family caregivers [4]. Moreover, the levels of anxiety and depression reported in cancer patients and their caregivers have been demonstrated to be positively correlated [5], indicating that the health status of relatives may have an impact on patients with SLE. Given the role that family members are expected to play in the

Furong Zeng and Qianyun Xu contributed equally to this work

✉ Yisha Li
liyisha@csu.edu.cn

¹ Department of Rheumatology and Immunology, Xiangya Hospital, Institute of Rheumatology and Immunology, Central South University, Changsha, Hunan 410008, China

² Department of Pathophysiology, Xiangya School of Medicine, Central South University, Changsha, Hunan 410078, China

³ Mental Health Center, Xiangya Hospital, Central South University, Changsha, Hunan 410008, China

supportive care of these patients, the poor QOL and impaired psychological status of their relatives may aggravate the mental status of patients. Thus, health care providers should emphasize that the unit of care includes both patients and their families.

Although it has been established that chronic diseases affect the QOL of not only patients but also family caregivers [6], the effect of such diseases on family members of patients is often unrecognized or underestimated. Previous studies have demonstrated that the physical and psychological statuses of caregivers of patients suffering from cancer or diabetes are severely impaired [7, 8]. Parents of children with juvenile chronic arthritis exhibit a high risk of psychological distress [9]. Surprisingly, considering the long disease duration of SLE, only a few studies have previously assessed the QOL and anxiety state in caregivers of patients with SLE [10, 11]. However, no studies have reported the detrimental impacts of poor QOL and psychological distress in relatives of patients with SLE. Therefore, this study assessed the QOL and psychological status in relatives of patients with SLE by evaluating their level of depression and anxiety and determining their impact on the health status of patients.

Materials and methods

Selection criteria for patients and relatives

The study was conducted between March and December 2016 in the Outpatient Clinic and the Inpatient Department of Xiangya Hospital, Central South University, China. A total of 120 patient–relative dyads were interviewed, and 104 completed the study. The relatives selected were those who co-resided with the patients and provided a minimum of 1 h of daily care [12]. SLE was diagnosed according to the criteria of the American College of Rheumatology. Patients with SLE or their relatives were excluded if (1) patients were unable to cooperate due to severe SLE activity; (2) patients suffered from neuropsychiatric symptoms, or a severe primary cardiovascular, liver, kidney, or hematological disease not related to SLE; (3) relatives suffered from a chronic disease or neuropsychiatric disorder; and (4) relatives did not fulfill the criteria of co-residing with the patient. Patients and relatives participated voluntarily in the study and signed written consent forms after being informed about the content of the survey by trained research coordinators.

Assessments

Demographic and clinical variables considered included age, gender, body mass index (BMI), marital status, level of education, employment status, disease duration, residence, and

relationship between patients and relatives. Disease activity was determined using the Systemic Lupus Erythematosus Disease Activity Index (SLEDAI). The SLEDAI score ranged between 0 and 15: 0–4, no activity; 5–9, mild activity; 10–14, moderate activity; and ≥ 15 , severe activity [13].

The QOL was evaluated using the 36-Item Short-Form Survey (SF-36), which consisted of 36 questions grouped into 8 domains measuring different aspects of QOL, including physical functioning (PF), role physical (RP), bodily pain (BP), general health (GH), vitality (VT), social functioning (SF), role emotional (RE), and mental health (MH). Physical summary scores (PCS, including PF, RP, BP, and GH), mental summary scores (MCS, including VT, SF, RE, and MH), and eight domains ranged from 0 to 100, where higher scores indicated better health [14].

Symptoms of depression were measured using the Patient Health Questionnaire (PHQ-9) that included nine items with a score from 0 = “not at all,” to 3 = “nearly every day.” The total score ranged from 0 to 27, with scores of 5, 10, 15, and 20 representing cutoff points for mild, moderate, moderately severe, and severe depression, respectively [15]. A score of ≥ 10 representing the optimum cutoff point for screening positive for depression disorders [16]. The Chinese version of PHQ-9 has been validated [17].

Symptoms of anxiety were measured using the Generalized Anxiety Disorder Scale (GAD-7), which comprised seven items with a score from 0 = “not at all,” to 3 = “nearly every day.” The total score ranged from 0 to 21, with scores of 5, 10, and 15 representing cutoff points for mild, moderate, and severe depression, respectively [18]. A score of ≥ 10 represented the optimum cutoff point for screening positive for anxiety disorders [19]. The Chinese version of GAD-7 has been validated [20].

Social support levels were measured using the Chinese version of the Social Support Rating Scale (SSRS). The SSRS consisted of 10 items and 3 dimensions, including objective support, subjective support, and support utilization. Each item was scored from 1 = “none,” to 4 = “great.” Higher scores indicated better social support [21].

Statistical analysis

The data were presented as mean \pm standard deviation (SD). Student *t* tests were used for variables with normal distribution, and variables with non-normal distribution were assessed by Mann–Whitney tests. Categorical variables were compared with the chi-square/Fisher’s exact test. Spearman correlation analyses were completed, identifying significantly associated predictor variables. The statistical analysis was performed using SPSS software for Windows version 19.0 (SPSS Inc., IL, USA). A *P* value less than 0.05 was considered statistically significant.

Results

Sociodemographic characteristics of patients with SLE and their relatives

The study population included 104 patients with SLE and 104 relatives. Table 1 summarizes the sociodemographic and clinical characteristics of the patients and their relatives. The mean age of patients with SLE and their relatives was 31.0 ± 11.7 years and 39.9 ± 11.3 years, respectively. Most patients were female (87.5%). The education level of 61.6% patients and 55.5% relatives was high school or higher. Of the 73.1% patients with active disease, 23.7, 31.2, and 18.3% suffered, respectively, from mild, moderate, and high disease activity according to SLEDAI criteria. Most relatives were spouses (44.7%) or parents (36.9%).

Table 1 Demographic characteristics of patients with SLE and their relatives

	Patients with SLE (<i>n</i> = 104)	Relatives (<i>n</i> = 104)
Gender (%)		
Male	12.5	48.5
Female	87.5	51.5
Age (year)		
Range	12–73	13–65
Mean \pm SD	31.0 ± 11.7	39.9 ± 11.3
Marriage (%)		
Married	59.2	88.0
Single ^a	40.8	12.0
Education (%)		
Middle school or lower	38.4	44.5
High school	30.8	32.3
College and above	30.8	22.2
BMI		
Range	14.98–36.00	14.52–32.81
Mean \pm SD	20.95 ± 3.44	22.68 ± 3.44
Disease duration (year)	4.6 ± 5.3 (0–25)	–
Employment (%)		
Employed	35.4	51.1
Unemployed	64.6	48.9
Residence (%)		
Village	62.5	66.0
City	37.5	34.0
Relationship (%)	–	
Spouse		44.7
Parents		36.9
Offspring		4.9
Others		13.6
SLEDAI	9.5 ± 5.6 (0–26)	–

^a Single includes those who are unmarried, divorced, or widowed

QOL of relatives

The scores of global SF-36, including PCS and MCS of relatives and patients, are shown in Fig. 1. Eight domains of SF-36 are shown in Table 2. The aggregated average global SF-36 score of relatives was 69.59 ± 22.78 , ranging from 20.75–97.00. Compared with the general population [22], all SF-36 domains and summary scores were significantly lower in patients with SLE ($P < 0.05$). Except for MH, all SF-36 domains and summary scores were lower in patients than in their relatives ($P < 0.05$). Although the scores of the relatives were higher than those of the patients with SLE, they were still significantly lower than those detected in the general population in terms of global SF-36, PCS, RP, MCS, RE, and MH ($P < 0.05$).

Psychological status of relatives

Overall, 46% of the relatives of the patients with SLE experienced symptoms of depression (PHQ-9 > 4) and 48% suffered from anxiety symptoms (GAD-7 > 4). Of these relatives, 27, 13, and 6% had mild, moderate, and severe depressive symptoms, respectively; and 25.5, 10.2, and 12.2% had mild, moderate, and severe anxiety, respectively. The PHQ-9 of relatives was significantly higher than that of the general population (5.8 ± 5.4 vs 3.64 ± 3.92 , $P < 0.001$), and so was the GAD-7 of the relatives (5.8 ± 6.0 vs 2.73 ± 3.56 , $P < 0.001$) [23]. No significant differences were found in the percentages of depression or anxiety between patients with SLE and their relatives (Table 3). The GAD-7 in women was higher than that in men (7.3 ± 6.7 vs 4.3 ± 4.3 , $P < 0.05$).

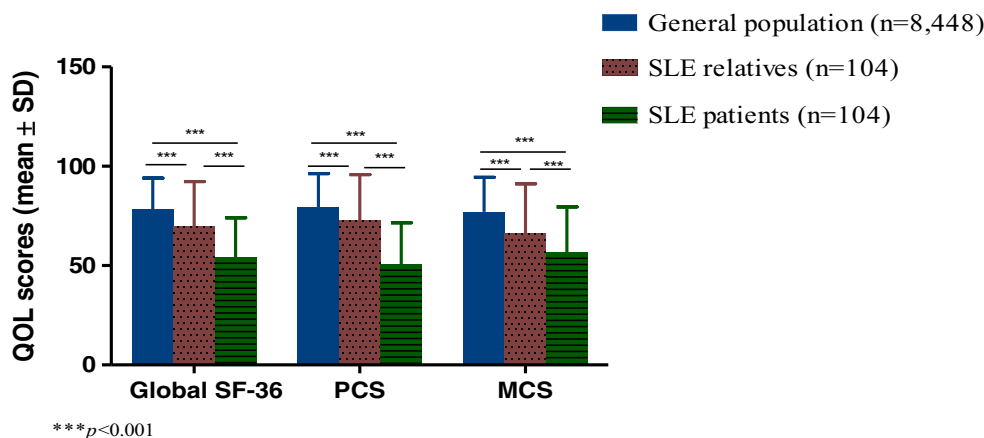
Relationship between QOL and psychological status in relatives of patients with SLE

The QOL differed based on the severity of depression and anxiety symptoms among relatives (Table 4). Those with lower PHQ-9 scores reported higher global SF-36, PCS, and MCS than those with higher PHQ-9 scores ($P < 0.001$). The same was true for symptoms of anxiety ($P < 0.001$). Global SF-36 among relatives was significantly negatively correlated with both depression ($r = -0.639$, $P < 0.001$) and anxiety ($r = -0.608$, $P < 0.001$).

Relationship of QOL and psychological status between patients with SLE and their relatives

The Spearman correlation analysis was used to test whether the QOL and psychological status of relatives of patients with SLE were correlated with the disease duration or activity in the patients with SLE. The QOL, PHQ-9, and GAD-7 of relatives were not related to SLEDAI or disease duration in patients with SLE ($P > 0.05$). Next, this study investigated

Fig. 1 Global SF-36, PCS, and MCS among SLE relatives, patients, and general population. *MCS* mental summary score, *PCS* physical summary score, *QOL*, quality of life



whether QOL and psychological status of the relatives correlated with those of the patients with SLE. GAD-7 of SLE relatives was positively correlated with GAD-7 of patients with SLE ($r = 0.210$, $P < 0.05$). No significant relationship was found between PHQ-9 of the relatives and patients. Cases were divided into two groups with a cutoff point of mean value of global SF-36 in relatives [24]. The patients reported a lower global SF-36 score when their relatives had a lower global SF-36 score (50.13 ± 19.18 vs 58.44 ± 19.67 , $P < 0.05$).

Relationship between depression, anxiety of relatives, and social support of patients with SLE

Patients with SLE were divided into two groups with a cutoff point of 10 according to PHQ-9 or GAD-7 of relatives. They reported significantly higher SSRS when their relatives had lower PHQ-9 (41.9 ± 8.7 vs 36.3 ± 6.2 , $P < 0.01$) or GAD-7 scores (42.8 ± 7.4 vs 36.7 ± 6.6 , $P < 0.01$) (Fig. 2). Moreover, SSRS of patients correlated negatively with the GAD-7 of the relatives ($r = -0.230$, $P < 0.05$).

Discussion

SLE is a chronic rheumatic autoimmune disease that requires lifelong treatments. Although it is known that patients with SLE experience severe depression and anxiety that result in the impaired QOL [24], only a few studies have assessed the QOL and anxiety of caregivers of patients with SLE [10, 11] and their influence on the patients. Relatively few studies have assessed the impact of the patient disease on the physical and mental status of caregivers of patients with chronic disorders such as cancer [7, 25]. In these cases, the relatives/caregivers exhibit an increased risk of psychological distress.

Only few different studies explored whether the QOL of caregivers was impaired and they arrived at different conclusions [10, 11]. In this study, the relatives of patients with SLE reported considerably more dissatisfaction with various aspects of life compared with the general population, even though they had a significantly lower functional impairment and better QOL compared with patients with SLE. The relatives of patients with SLE exhibited poor values for PCS and MCS, particularly with respect to RP, RE, and MH, compared

Table 2 Eight domains in SF-36 of relatives compared with the patients with SLE and the general population ($\bar{x} \pm s$)

	Relatives (n = 104)	Patients with SLE ^a (n = 104)	General population ^a (n = 8448)
PF	87.89 ± 14.45	70.58 ± 25.42***	89.01 ± 15.73
RP	70.54 ± 40.37	34.07 ± 37.36***	81.99 ± 31.65***
BP	77.47 ± 19.50	58.20 ± 27.41***	80.40 ± 19.79
GH	64.87 ± 21.19	44.03 ± 19.57***	66.03 ± 20.87
VT	67.37 ± 21.20	57.40 ± 21.42*	71.15 ± 18.09
SF	80.68 ± 22.43	65.44 ± 26.60***	84.60 ± 18.15
RE	59.78 ± 42.22	47.44 ± 40.69**	77.04 ± 35.45***
MH	64.94 ± 21.07	62.68 ± 18.96	75.23 ± 16.69***

BP bodily pain, *GH* general health, *MH* mental health, *PF* physical functioning, *RE* role emotional, *RP* role physical, *SF* social functioning, *VT* vitality

* $P < 0.05$, ** $P < 0.01$, *** $P < 0.001$

^a Compared with relatives

Table 3 Depression and anxiety between patients with SLE and their relatives

	Relatives (n = 104)	Patients (n = 104)	P
PHQ-9 (%)			0.136
<10	81.0	71.3	
≥10	19.0	28.7	
GAD-7 (%)			0.375
<10	77.6	83.0	
≥10	22.4	17.0	

with the Chinese population norms. Besides, their MH was impaired to the same extent as that of the patients with SLE. Moreover, patients with SLE reported a worse QOL when their relatives had a poor QOL, indicating that the impaired QOL of the relatives played a detrimental role on the QOL of the patients.

Higher levels of anxiety and depression were present in the relatives of patients with SLE compared with those present in the general population. The impaired psychological status among caregivers has also been previously reported by others in caregivers of cancer patients [26]. Family members who experienced more severe symptoms of depression or anxiety reported a worse QOL compared with those who had less depression or anxiety. SF-36 correlated negatively with both depression and anxiety in the relatives. This association between QOL and symptoms of depression and anxiety has also been observed in other diseases [26] and indicates that improvements in the QOL may be possible by alleviating emotional distress. Another finding of the present study was that female relatives reported more severe anxiety compared with the equivalent male group. It has been previously shown that anxiety disorders are more prevalent and disabling in women than in men [27], indicating that more attention should be paid to the psychological status of female relatives.

Next, the present study investigated whether a relationship existed between the QOL and psychological status in the

Table 4 Impact of depression and anxiety on the QOL in relatives of patients with SLE

	Global SF-36 (r)	PCS (r)	MCS (r)
PHQ-9 (r)			
<10	76.5 ± 17.3	78.6 ± 19.3	73.9 ± 19.2
≥10	48.2 ± 18.9	55.0 ± 18.3	41.4 ± 22.1
P	0.000	0.000	0.000
GAD-7 (r)			
<10	75.1 ± 18.7	76.9 ± 20.7	72.5 ± 20.3
≥10	56.9 ± 22.2	64.3 ± 20.8	49.5 ± 25.5
P	0.000	0.007	0.000

r relatives

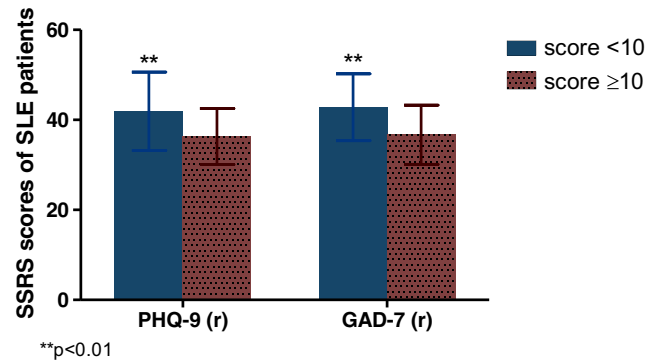


Fig. 2 SSRS scores of patients with SLE between relatives with different PHQ-9 or GAD-7 scores. r relatives

relatives of patients with SLE and the SLE duration or activity in the patients. It showed no significant relationship between them, indicating that the impaired QOL and psychological status present in the relatives of patients with SLE was a continuous process, not associated with the severity of the patient disease. Therefore, physicians cannot judge the QOL and psychological status of relatives simply according to the disease severity in the patients with SLE. Then, the study investigated whether the QOL and psychological status of the relatives correlated with those of the patients with SLE. It demonstrated that the levels of anxiety of the relatives correlated positively with the anxiety of the patients with SLE, indicating that there is association between QOL of relatives and patients with SLE.

Social support affects patients with SLE on QOL [28] and disease activity [29]. It was found that patients benefited from higher social support when their relatives reported less depression or anxiety. This indicated that the psychological status of the relatives exerted an impact on the patient social support. On the contrary, the social support of the patients with SLE correlated negatively with the anxiety of their relatives. When the relatives felt depressed or anxious, they were unable to offer sufficient affection and support to the patients.

Despite the findings that the relatives of patients with SLE were at risk for poor QOL and psychological health problems, little is known about the variables associated with their QOL and psychological status. The present study clarified the association between family members and the patients with SLE by emphasizing the importance of identifying those relatives who were at risk of experiencing psychological symptoms and by demonstrating that the QOL and psychological health status of the relatives affected the health of the patients with SLE. Moreover, the distress that the caregivers experienced influenced the collaboration between the clinicians and the family [30]. The recognition of impaired function and poor QOL in relatives of patients with SLE is relevant to physicians who care for patients with SLE.

The present study had some limitations such as single-center design, relatively small sample size, and exclusion of patients with SLE without relatives/caregivers. Further prospective studies are needed to validate whether the QOL of patients can be improved through intervention on the QOL and psychological status of the family members. Despite these limitations, it is possible to conclude that the relatives of patients with SLE who suffer from severe depression and anxiety report a significantly impaired QOL. The impaired QOL of relatives is associated with their depression and anxiety, and also with the QOL of patients with SLE. The psychological status of relatives is associated with the social support of the relatives. In summary, this study proposed a new approach to the management of patients with SLE by intervening on QOL and psychological status of family members who function as caregivers. Further prospective studies on the role of family members may provide novel approaches to improve treatment of patients with SLE through their caregivers.

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Compliance with ethical standards

Disclosures None.

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