Factors Related to Health-Related Quality of Life among Persons with Systemic Lupus Erythematosus in Wenzhou, China

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Abstract

Systemic lupus erythematosus (SLE) is a major global health issue affecting patients' health-related quality of life (HRQOL). This research aimed to examine HRQOL in persons with SLE and to examine the relationships between SLE symptoms, depression, social support, self-care, and HRQOL in this population. Ninety-two persons with SLE were recruited by simple random sampling from one hospital in Wenzhou, Zhejiang Province, China. Instruments included the Demographic Information Questionnaire, the SLE Symptom Checklist (SSC), the Chinese version of the Patient Health Questionnaire (PHQ-9), the Chinese version of the Perceived Social Support Scale (PSSS), the Exercise of Self-Care Agency (ESCA), and the Chinese version of the Lupus Quality of Life (LupusQoL). Data were analyzed by using descriptive statistics and the Pearson correlation coefficient.

The results revealed that the mean score of HRQOL among persons with SLE was 62.8 out of 100 (SD = 19.49). Self-care and social support were positively correlated with HRQOL ($r = .370$, $p < .01$; $r = .407$, $p < .01$, respectively). At the same time, depression and SLE symptoms showed negative correlations with HRQOL ($r = -.466$, $p < .01$; $r = -.436$, $p < .01$, respectively).

The findings underscore the necessity and relevance of targeted interventions focused on improving the HRQOL of individuals with SLE. To improve the quality of life in this population, nurses should develop an intervention that focuses on controlling SLE symptoms, preventing depression, and promoting SLE self-care and social support.

Key words: Health-related quality of life, SLE symptoms, Depression, Social support, Self-care

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Received 05/07/2024 Revised 27/01/2025 Accepted 10/03/2025

Significance of the Problem

Systemic lupus erythematosus (SLE) is a widespread autoimmune disease with the most prevalent chronic progressive illnesses. SLE involves multiple systems and organs, and its pathogenesis is currently unclear. Without timely treatment, persons with SLE will experience irreversible damage to their organs and ultimately succumb to the disease. (Askanase & Furie, 2022). According to a survey conducted in China, the average age at which an adult is diagnosed with SLE is approximately 30 years old, the male-to-female ratio is approximately 1:10-12, and females make up about 90% of SLE patients. The first symptoms and diagnosis of SLE often occur between the ages of 15 and 45 (Wu et al., 2017). The incidence rate of SLE varies around the world, Tian and collegues (2023) reported that the estimated incidence rate of SLE was 5.14 cases per 100,000 per year (ranging from 1.4 to 15.13), and about 400,000 people were diagnosed with SLE annually.

China, the largest country in the Asia-Pacific region, had a relatively higher prevalence rate of SLE at 30-70/100,000 compared to other ethnicities, generally ranging from 12-39/100,000. China also has one of the largest populations of newly diagnosed SLE cases globally, with an estimated annual incidence rate of 8.57 (ranging from 8.37-8.77) per 100,000 people, ranking the fourth highest globally. Although there have been advancements in treating SLE, the survival rate for patients with this disease has risen, reaching 90.3% over a 10-year year. Nevertheless, patients with SLE still have twice the risk of dying compared to the general population, making the causes of death particularly significant to consider (Wu et al., 2017) .

SLE affects individuals not only with physical health and mental health problems but also with socioeconomic burdens. The patients may suffer more from SLE complications such as pulmonary infection, lupus nephritis, skin irritation, hematologic problems, and fatigue (Jönsen et al., 2016). It was found that 60% of the patients have emotional difficulties, such as anger, pressure, depression, anxiety, and loss of confidence in treatment, which may lead to the aggravation of the disease, complications, and poor prognosis (Jönsen et al., 2016). Physical and psychological problems may cause loss of labor, social isolation, and economic burdens among persons with SLE. It was found that SLE patients have about 6 - 7 outpatient visits per year, and the sick leave time is 123 - 148 days per year, which seriously affects the everyday life of patients (Jönsen et al., 2016). SLE carries considerable medical costs in China, especially for patients with severe conditions. The outpatient expenses for SLE were $433 per visit and $2,072 per hospital stay. Significantly, a severe SLE flare was reported by 35.4% of patients, with the average cost per severe flare amounting to $1,616. The management of SLE activity and comorbidities creates a significant impact on health-related quality of life (HRQOL) (He et al., 2023).

At present, SLE cannot be cured, and treatment goals are to control the disease in the remission phase, reduce the recurrence of SLE complications, and improve the patient's HRQOL (Xu et al., 2019). Health-related quality of life refers to an individual's perceived physical and mental health over time, which focuses on the effects of health, illness, and treatment on quality of life (Ferrans et al., 2005) as well as the subjective satisfaction related to their economic, cultural

background and value orientation (Kaplan & Hays, 2022). It includes physical function, psychological function, social status, and health status (Kaplan & Hays, 2022). It was found that the HRQOL of persons with SLE was lower than that of other common chronic diseases (Mizukami et al., 2023). Previous findings indicated that individuals of Asian descent were at a higher risk of experiencing severe SLE (Rees et al., 2017). In addition, Chinese with SLE had lower HRQOL in all domains, primarily physical and emotional; furthermore, personality, life nervousness, and experiences of adverse life events may influence HRQOL and HRQOL improvements (Wang et al., 2024). Results from a previous study revealed that the average HRQOL score of Chinese SLE patients was 55.8 ± 19.4, while the average HRQOL score of other groups was 82.5 ± 9.5 (Carter et al., 2016). It is urgent to identify factors related to HRQOL among Chinese with SLE.

There were many factors related to HRQOL in SLE. Researchers pointed out that individual factors such as age, disease activity, damage, and severity are factors affecting HRQOL in SLE (Fernández-Llanio-Comella et al., 2016). *SLE symptoms* are a physical factor related to the HRQOL of persons with SLE. Fatigue and pain are the most common physical symptoms in SLE patients (Garcia et al., 2024). It was found that 67% - 90% of individuals with SLE report experiencing ongoing fatigue, which could affect critical components of their HRQOL and present obstacles to employment (Lou et al., 2021).

HRQOL among persons with SLE is not only related to physical health problems but also mental health problems. 60% of the patients have emotional difficulties, including depression, anxiety, and loss of confidence in treatment, which may lead to aggravation of the disease, complications, poor prognosis, and low HRQOL (Fernández-Llanio-Comella et al., 2016). It was found that 24% -30% of SLE patients suffer from *depression* (Figueiredo-Braga et al., 2018). SLE dramatically increases physical problems, economic pressure, and family burden, which may lead to depression (Figueiredo-Braga et al., 2018). A study in Mexican patients with SLE showed that depression was associated with HRQOL (Etchegaray-Morales et al., 2017). In addition, depression may have a significant impact on patients and directly reduce their HRQOL (Figueiredo-Braga et al., 2018); it is crucial to examine the relationships between depression and HRQOL among persons with SLE in China.

SLE is a chronic disease that needs long-term treatment. Persons with SLE must perform good *self-care* and follow the therapeutic regimen to maintain their health, control SLE conditions, and prevent SLE complications (Kusnanto et al., 2018). Researchers found that self-care activities could help to reduce the arthritis pain often experienced by people with SLE (Janke et al., 2015). In addition, a result from a previous study found that self-care could enhance the HRQOL in SLE patients by an average of 12.19% (Kusnanto et al., 2018).

Social support is one factor related to HRQOL. Social support refers to the perception of persons with SLE in receiving help and support from others, including family, friends, and significant others (Gottlieb & Bergen, 2010). A study showed that patients' social support was associated with HRQOL ($r = .48$, $p < .005$) (Jing et al., 2017), low social support caused a decrease in HRQOL, which

related to psychological change and physical health problems (Mizukami et al., 2023). In addition, social support was one factor related to HRQOL in the SLE population.

At present, conclusions about factors related to HRQOL in SLE are inconsistent and need to be further verified, especially in Wenzhou, China, which has limited information. Therefore, this study assessed HRQOL and its associated factors among persons with SLE in Wenzhou, China. Results from the study would benefit healthcare providers and help improve HRQOL among the SLE population in China.

Objectives of the Study

1. To describe HRQOL among persons with SLE in Wenzhou, China.
2. To examine associations between SLE symptoms, depression, social support, self-care, and HRQOL among persons with SLE in Wenzhou, China.

Conceptual Framework

The present study was conducted following Wilson and Cleary's modified model, which categorizes the variables used to assess HRQOL (Ferrans et al., 2005), and literature review. The model focuses on linear relationships among five health concepts moving along the causal pathway to overall HRQOL, beginning with the biological-physiological factors, symptoms, functional status, and general health perception of overall HRQOL. Moreover, the two domains - the individual and environmental characteristics - are directly affected by the five health concepts and the overall HRQOL (Ferrans et al., 2005).

This model was used to guide the study of how the four variables of SLE symptoms, depression, social support, and self-care affect overall HRQOL among SLE patients through a causal pathway. Regarding the Wilson and Cleary's modified model (Ferrans et al., 2005), SLE symptoms and depression belonged to the symptom domain. Social support represented the environment domain. Self-care represents the individual's functional status. All variables were associated with HRQOL among persons with SLE. The relationships among all variables are presented in Figure 1

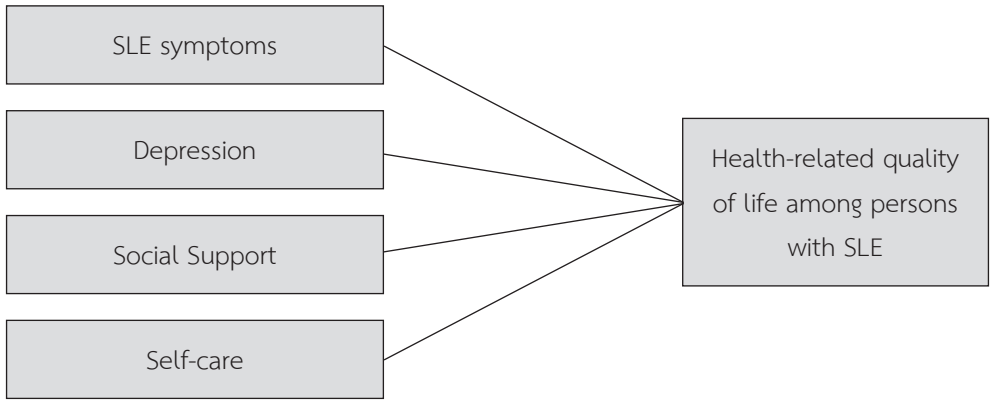

Figure 1 Study Framework

Methods

Research design

The descriptive correlational study was used to explore the association between SLE symptoms, depression, social support, self-care, and HRQOL among SLE patients in Wenzhou, China.

Population

The study participants were individuals diagnosed with SLE by a physician. They were followed up at the Rheumatology and Immunology Outpatient Department of the First Affiliated Hospital of Wenzhou Medical University between July 15 and October 12, 2023.

Sample and Sample size

The samples were persons diagnosed with SLE who came to follow-up at the outpatient Department of Rheumatology at the First Affiliated Hospital of Wenzhou Medical University, Zhejiang province, China. The inclusion criteria of the sample include: 1) age ≥18 years old; 2) have a particular ability to write and speak Chinese; 3) have a good sense of direction and time; 4) no previous record of mental illness; and 5) no cognitive impairment (screened from the medical record). The exclusion criteria of the sample include: 1) accompanied by other serious diseases, such as malignant tumors; 2) Lupus active mental illness.

The sample size was calculated using the G*Power 3.1.9.2 software for correlation designs. The effect size of .288 from previous research was utilized to calculate the sample size (Tamayo et al., 2010), with preset values of an alpha level of .05 and power of .80. The study's sample size was at least 92 subjects.

Sampling

Individuals who met the inclusion criteria were selected for participation through simple random sampling. Eight to ten participants were randomly selected each week (Monday to Saturday) until the specified sample size of 92 was reached.

Research Instruments

1. Demographic information questionnaire

The demographic information questionnaire included gender, age, height and weight, educational level, marital situation, employment situation, payment method, diagnosis time, and comorbidity.

2. The SLE Symptom Checklist (SSC)

The SSC scale, developed by Grootscholten et al. (2003), to measure SLE symptoms. The instrument was translated into Chinese; Cronbach's α was equal to .89, demonstrating strong reliability and validity (Yan et al., 2012).

The SSC included 38 items and evaluated the presence and burden of disease- and treatment-related symptoms in the past four weeks. Each item was scored from 0 (no), 1 (yes, but not burdensome), 2 (yes, a little burdensome), 3 (yes, quite burdensome), and 4 (yes, extremely burdensome). The total score ranged from 0 - 152. A higher score indicated that the symptoms of SLE patients were more severe. The Cronbach's alpha in this study was .89.

3. The Chinese version of the Patient Health Questionnaire (PHQ-9)

The Chinese version of the PHQ-9 scale (Wang et al., 2020) was used to measure the presence and intensity of depression among SLE patients. It was translated from the PHQ-9 scale developed by Spitzer et al. (1999). The Cronbach's alpha of the Chinese version was .86, which demonstrated good criterion and construct validity when tested on 1,045 participants from the Shanghai community (Wang et al., 2014).

The scale was a self-report questionnaire that assessed depressive symptoms and whether the symptoms had bothered the individuals during the past two weeks. The scale consisted of 9 items with scores ranging from 0 (not at all) to 3 (almost daily) with a total score range from 0-27. The severity of depression was diagnosed by the summed score, divided into four levels: mild depression (5-9), moderate depression (10-14), moderate to severe depression (15-19), and severe depression (≥ 20) (Wang et al., 2014). The Cronbach's alpha in this study was .86.

4. The Perceived Social Support Scale (PSSS)

The Chinese version of the PSSS was used to assess perceived social support among persons with SLE. This scale was translated by Huang et al. (1996) from the original version of PSS developed by Blumenthal et al. (1987). Cronbach's alpha for the Chinese version of PSSS was .88, which demonstrated good validity and reliability (Huang et al., 1996). The scale consisted of 12 items with three domains: family support, friends support, and significant other support. Each item was assessed using a rating scale ranging from 1(extremely disagree) to 7(extremely agree). The summed score of social support ranges from 12-84, divided into three levels: 12-36 representing "low support," 37-60 representing " moderate support", and 61-84 representing " high support" (Huang et al., 1996). Cronbach's alpha in this study was .88

5. The Exercise of Self-Care Agency (ESCA)

The ESCA scale was adopted to measure self-care of SLE patients, which was designed by Kearney and Fleischer (1979) and translated into Chinese by Wang and Laffrey (2000). The Cronbach's alpha of the Chinese version was 0.86, which indicates high reliability and validity. There are 43 items rated on a 5-point Likert scale from 0 (does not match me) to 4 (perfectly matches me). The total score range was 0-172, which categorizes self-care ability into three grades: low (< 56.76), medium (56.76-113.52), and high (> 113.52). The Cronbach's alpha in this study was .86.

6. The Lupus Quality of Life (LupusQoL)

The LupusQoL-China was used to measure the HRQOL among persons with SLE. This scale was originally developed by McElhone et al. (2007), and has been shown to be a validated instrument for measuring disease-specific HRQOL among SLE patients in the UK. The scale was translated into Chinese by Wang et al. (2013) as the first HRQOL-specific assessment tool for SLE in China, Cronbach's alpha for the LupusQoL-Chinese was .81.

The scale consisted of 34 items divided into eight domains: physical health (item1-8), pain (item 9-11), planning (item 12-14), intimate relationships (item 15-16), burden on others (item 17-19), emotional health (item 20-25), body image (item 26-30) and fatigue (item 31-34). The response was

given on a 5-point Likert scale, from 0 for "all the time" to 4 for "never," with a recall period of items of 4 weeks. The total raw score was summed from eight domains, from 0 to 136. For the standardized score, the mean raw domain score is transformed to scores ranging from 0 (worst HRQOL) to 100 (best HRQOL) by dividing by four and then multiplying by 100. The mean raw domain score is then calculated by totaling the item response score and dividing it by the number of items. The score was reported on a scale of 0 to 100, with higher values indicating a better HRQOL, 0 representing the worst HRQOL, and 100 the best HRQOL (McElhone et al., 2007). The Cronbach's alpha of this study was .81.

Ethical considerations

This research was approved by the Institutional Review Board of Burapha University under Protocol code G-HS024/2564 and by the Ethics Committee of the First Affiliated Hospital of Wenzhou Medical University under Protocol code KY 2021-091. Prior to data collection, all participants provided their informed consent. They were thoroughly briefed on the study's objectives and willingly took part in the process.

Data collections

Data were collected by simple random sampling at the Rheumatology and Immunology Outpatient Department. The eligible participants who indicated willingness to participate in the study were asked to sign a consent form and fill out the study questionnaire independently in a private setting. All information about the participants was kept confidential. The completeness of the questionnaire responses was verified by the researcher on site. Data collection was repeated until the prescribed sample size was achieved.

Data analysis

Data was analyzed using a statistical SPSS software package. The alpha (α) level of statistical significance was set at 0.05. Descriptive statistics were used to describe the participants' characteristics, including frequency, mean, and standard deviation. Pearson's product-moment correlation was used to examine the relationship between SLE symptoms, depression, social support, self-care, and SLE HRQOL.

Results

Part 1 Demographic characteristics of participants

Of the 92 participants, 94.6% were women. The participants ranged from 18 to 74 years (M = 38.83, SD = 12.02). 43.5 % of the participants completed secondary school. Most participants were married (75%), jobless (46.7%), and had social insurance (72.8%). 42.4 % of participants were diagnosed with SLE less than 60 months (M = 97.75, SD = 77.13). For health conditions, 45.7% of the participants had anemia, followed by 24% with arthritis, 22% with chronic kidney disease, and 20% with hypertension. In addition, 70.7% of participants had been hospitalized within the past three months.

Part 2 Description of HRQOL, SLE symptoms, depression, self-care, and social support among persons with SLE

Table 1 showed that the overall mean lupus quality of life score was 62.80 (SD = 19.49), indicating not to low but not to high QOL. Considering each dimension of HRQOL, the mean scores ranged from 56.98 (25.69) to 68.07 (23.17). The dimension that reported highest mean score was the intimate relationships (68.07 ± 23.17), followed by body image (66.58 ± 24.88), emotional health (65.26 ± 22.78), planning (64.22 ± 22.56), pain (63.77 ± 23.13), physical health (60.75 ± 21.96), fatigue (58.56 ± 21.33), and the lowest mean score was burden on others (56.98 ± 25.69).

Table 1 Description of HRQOL (n = 92)

Variable	Possible score	Actual score	*M*	*SD*
HRQOL	0-100	9.56-100	62.80	19.49
Physical health (8 items)	0-100	18.75-100	60.75	21.96
Pain (3 items)	0-100	0-100	63.77	23.13
Planning (3 items)	0-100	8.33-100	64.22	22.56
Intimate relationships (2 items)	0-100	12.50-100	68.07	23.17
Burden on others (3 items)	0-100	0-100	56.98	25.69
Emotional health (6 items)	0-100	0-100	65.26	22.78
Body image (5 items)	0-100	5-100	66.58	24.88
Fatigue (4 items)	0-100	0-100	58.56	21.33

Table 2 describes the mean total score of variables, including SLE symptoms, depression, self-care, and social support. The mean score of SLE symptoms was 28.84 (SD = 16.26). The mean score of depression was at a mild level (M = 7.51, SD = 6.30). The mean self-care and social support scores were at high levels (*M* = 118.96, *SD* = 24.72; *M* = 64.54, *SD* = 13.60, respectively).

Table 2 Description of variables (n = 92)

Variables	Range		*M*	*SD*	Level
	Possible score	Actual score			
SLE symptoms	0 - 152	0 - 69	28.84	16.26	-
Depression	0 - 27	0 - 24	7.51	6.30	Mild
Self-care	0 - 172	52 - 168	118.96	24.72	High
Social support	12 - 84	33 - 84	64.54	13.60	High

Part 3 Factors related to health-related quality of life among persons with SLE

Before examining the relationships between all variables and HRQOL, the assumptions of the Pearson correlation coefficient were examined, including normal distribution, linear relationship,

independent errors, and no outliers. All assumptions were met.

As presented in Table 3, results indicated that there were negative moderate significant relationships between SLE symptoms and depression with HRQOL ($r = -.436$, $p < .01$; $r = -.466$, $p < .01$, respectively). While there were positive and moderate significant associations between self-care and social support with HRQOL ($r = .370$, $p < .01$; $r = .407$, $p < .01$, respectively).

Table 3 Relationships between study variables and health-related quality of life among people with SLE (n = 92)

Variables	Correlation coefficient
SLE symptoms	-.436**
Depression	-.466**
Self-care	.370**
Social support	.407**

* $p < .05$, ** $p < .01$

Discussion

1. Health-related quality of life among persons with SLE

The result revealed that the overall mean score of lupus quality of life was 62.80 (*SD* = 19.49), and the mean scores of each dimension ranged from 56.98 (25.69) to 68.07 (23.17), which was not too low but not too high QOL, especially when compared to other common chronic diseases (Mizukami et al., 2023). However, the HRQOL score of patients with SLE in this study was higher than that of Carter and colleagues (2016), who conducted in Chinese with SLE in different settings. According to the revised version of Wilson and Cleary's HRQOL model (Ferrans et al., 2005), characteristics of the individual (such as age and economics) are directly related to overall quality of life. In this study, most participants were middle-aged; 58.7% were between 30 and 49 years old. They were diagnosed with SLE less than five years ago and had few SLE complications. Thus, they still had good physical functions and could perform any activities of daily living by themselves. Therefore, they perceived relatively high HRQOL. Moreover, most participants had jobs and social insurance; thus, they had less economic burden, which may have less psychological pressure. Therefore, they perceived that had better QOL (Li et al., 2022).

2. Factors related to health-related quality of life among persons with SLE

Study findings revealed that SLE symptoms and depression were negatively correlated with HRQOL ($r = -.436$, $p < .01$; $r = -.466$, $p < .01$, respectively). While there were positive relationships between self-care and social support with lupus HRQOL ($r = .370$, $p < .01$; $r = .407$, $p < .01$, respectively). The findings were consistent with the study hypotheses.

SLE Symptom

The result showed that SLE symptoms were negatively correlated with lupus quality of life

(r = -.436, p < .01), which means that the higher the SLE symptoms, the lower the quality of life perceived by patients with SLE. According to the revised Wilson and Cleary's HRQOL model (Ferrans et al., 2005), symptoms can affect an individual's QOL. In the current study, patients with SLE reported a low overall score of SLE symptoms (M = 28.84, SD=16.26). The most common symptoms occurrence included fatigue (66.2%), disturbed memory (64.9%), chubby face/cheeks (59.5%), and hair loss (56.8%). These symptoms were persistent problems, especially fatigue, which affects the patient's activities of daily living functions and work, which may cause them to perceive lower QOL (Jiang et al., 2018).

Depression

In this study, participants reported mild depression score (*M* = 7.51, *SD* = 6.30) and the results revealed that depression was negatively correlated with lupus quality of life (r = -.436, p < .01). It means that patients with SLE who reported higher depression perceived lower HRQOL. The finding is consistent with the revised Wilson and Cleary's HRQOL model (Ferrans et al., 2005), which proposed that psychological problems indirectly affect overall quality of life. The finding was consistent with the previous studies, which showed that female patients with SLE with lower levels of depression reported a higher quality of life (Figueiredo-Braga et al., 2018).

Self-Care

In this study, self-care was positively correlated with lupus quality of life (r = .370, p < .01). It means that patients with SLE who had better self-care reported higher HRQOL. The finding is consistent with the revised Wilson and Cleary's HRQOL model (Ferrans et al., 2005) which proposed that health status has an indirect effect on overall QOL. Self-care activities performed by SLE patients aim to maintain their health, control SLE conditions, and prevent SLE complications. The result from a previous study showed that improved self-care activities can reduce some part of SLE symptoms, such as pain and fatigue, which improves physical function (Kusnanto et al., 2018). It can help patients maintain emotional stability and increase adaptive coping, resulting in satisfaction with life and having better HRQOL (Cao et al., 2023).

Social support

In this study, social support was positively correlated with lupus quality of life (r = .407, p < .01). It means that patients with SLE who perceived higher social support would report having high HRQOL. According to the revised Wilson and Cleary model, the overall quality of life is directly related to the characteristics of the environment (Ferrans et al., 2005). Social support, one kind of the environment as mentioned in the model, was the perception of persons with SLE in receiving help and support from others, including family, friends, and significant others (Gottlieb & Bergen, 2010). It is one type of social environment which influences on health outcomes and overall QOL (Ferrans et al., 2005).

In this study, patients with SLE reported the mean total score of social support at a high level (M = 64.54, SD =13.60), which means participants with SLE perceived they had high support from their families, friends, and others, which may help them doing better self-care and being emotional

support; thus, they perceived better HRQOL. The result was similar to a previous study by Li and colleagues (2022), which found that the level of social support in SLE patients was closely related to health-related quality of life, and family was the primary source of social support. Social support has a buffering effect, which can enhance the patient's belief in fighting against the disease, eliminate their negative emotions, and improve patient compliance with the treatment, which helps to improve their quality of life (Mazzoni & Cicognani, 2016).

Implications for Nursing and Recommendations

These findings would enable nurses and caregivers to better understand QOL and its influencing factors among persons with SLE, particularly in Wenzhou, China. The study findings revealed that the HRQOL of individuals with SLE was impaired, especially regarding physical health. It deserves more attention from clinical nurses and caregivers.

The findings showed a noteworthy connection between SLE symptoms, depression, social support, self-care, and health-related quality of life. To improve HRQOL among persons with SLE, healthcare providers should develop an intervention focusing on clinical symptom management, teach them to perform good self-care and promote family support.

There are some limitations in the study. This is a cross-section study, and the result cannot represent HRQOL in the long term, especially in SLE, a chronic illness. Thus, healthcare providers should continuously evaluate their physical symptoms, depression, self-care abilities, and HRQOL among persons with SLE every time they have a hospital visit. The study was conducted only in one city; the results cannot be generalized to persons with SLE in other locations. Therefore, the study should be replicated in other regions.

Acknowledgments

The authors would like to acknowledge Burapha University, Thailand, Wenzhou Medical University, and the First Affiliated Hospital of Wenzhou Medical University for supporting this study. We also thank all the participants for their cooperation and willingness. This research was supported by the Wenzhou Basic Science Research Program (2021Y1482).

Conflict of Interests:

The authors have no conflict of interest to disclose.

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