FACTORS RELATED TO HEALTH-RELATED QUALITY OF LIFE AMONG PERSONS WITH SYSTEMIC LUPUS ERYTHEMATOSUS IN WENZHOU, CHINA

YANG ZHU

A THESIS SUBMITTED IN PARTIAL FULFILLMENT OF
THE REQUIREMENTS FOR MASTER DEGREE OF NURSING SCIENCE
(INTERNATIONAL PROGRAM)
IN ADULT NURSING PATHWAY
FACULTY OF NURSING
BURAPHA UNIVERSITY
2024

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Health-related quality of life (HRQOL) of persons with systemic lupus erythematosus (SLE) was compromised. Identifying factors related to their HRQOL is crucial for healthcare providers. This study aimed to describe HRQOL among persons with SLE and to investigate associations between SLE symptoms, depression, social support, and self-are with HRQOL among persons with SLE in Wenzhou, China. Ninety-two participants with SLE were recruited by a simple random sampling from the First Affiliated Hospital of Wenzhou Medical University 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 Chinese version of Lupus quality of life (LupusQol), and the Exercise of Self-Care Agency (ESCA). Data were analyzed by using descriptive statistics and Pearson correlation coefficient.

Results showed that the overall mean score of health-related quality of life among persons with SLE was 62.80 (SD=19.49). There were positive association between self-care and social support with health-related quality of life ($r = .370$, $p < .01$; $r = .407$, $p < .01$, respectively). Depression and SLE symptoms had negative correlation with health-related quality of life ($r = -.466$, $p < .01$; $r = -.436$, $p < .01$, respectively).

The findings revealed that depression, SLE symptoms, self-care, and social support was related to HRQOL among persons with SLE. Nurses should develop intervention that focuses on controlling SLE symptoms, preventing depression, promoting SLE self-care and social support to improve quality of life in this population.

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CHAPTER 1
INTRODUCTION

Background and Significance of the Study

Systemic lupus erythematosus (SLE) is one of the most common chronic progressive diseases. The incidence of SLE varies worldwide, which is related to gender, age, race and time. The global SLE incidence and newly diagnosed population were estimated to be 5.14 (1.4 to 15.13) per 100,000 person-years and 0.40 million people annually, respectively (Carter et al., 2016). China, as the largest country in Asia-Pacific area, reported with relatively higher prevalence rate as 30 - 70/100,000 when compared to other ethnicities (generally 12 - 39/100,000) (Rees et al., 2017). At present, the total number of SLE patients in China is more than one million, ranking first in the world, which brings more burden and crisis to our future (Carter et al., 2016). It was found that in every age and ethnic group, women are more affected than men. The proportion of male to female was 1:10 to 1:12 (Wu et al., 2017).

SLE is an autoimmune disease in which the pathogenesis is still unclear (Askanase & Furie, 2022). Many studies have shown that genetic, endocrine, infection, immune abnormalities and some environmental factors are related to the pathogenesis of SLE. SLE is involving multiple systems and organs. It can also involve organs, skin and mucosa, joints, blood system and kidney (Kaul et al., 2016). Among those, the most common is kidney injury, and lupus nephritis is one of the most common complications. The Clinical manifestations of SLE are complex and diverse, and the course of disease is prolonged and occurs repeatedly. The most common symptoms of SLE include fever, joint pain, fatigue, and leukopenia.

At present, SLE cannot be cured and the goals of treatment are to reduce the recurrence of SLE or control the disease in remission phase, reduce adverse drug re actions, control organ damage, reduce mortality, and improve quality of life (Li et al., 2020). Treatment regimens for SLE include non-steroidal anti-inflammatory drugs (NSAID), antimalarial drugs, glucocorticoids, and immunosuppressant. At present, SLE cannot be cured; only through treatment regimens can help individuals achieve long-term remission. With the continuous development of SLE diagnosis and

treatment technology, the survival rate of SLE patients is rising. At present, the 10 - year survival rate has reached 90.3%, although the survival of SLE has improved dramatically in last 50 years, the risk of death for SLE patients are still 2 times greater than those of general population (Li et al., 2020).

The impacts of SLE to patients are various. With the improvement of the survival rate means the extension of the course of disease, which causes patients experience more suffering from disease activities, drug side effects, disease damage, physical disability, and loses labor force because of the long course and recurrent characteristics of 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 normal life of patients (Jönsen et al., 2016). In addition, severe recurrence of the disease results in an additional medical cost of about US 18,511 per year, which greatly increases the economic pressure and family burden of SLE patients (Somers et al., 2014). Because the remission and relapse of the disease often occur alternately, patients spend less time with friends, and gradually get out of touch with society.

The impact of SLE is not only causing physical health problems but also mental health problems. It was found that 60% of the patients have emotional difficulties, such as anger, pressure, depression, anxiety, and lose confidence in treatment, which may lead to the aggravation of the disease, complications, and poor prognosis. In addition, SLE greatly increases the economic pressure and family burden. The above phenomenon shows that SLE has great impact on patients and directly reduces health-related quality of life (HRQOL) of SLE patients.

HRQOL refers to the individual's health status under the influence of illness, medical intervention, aging and social environment changes, as well as the subjective satisfaction related to their economic, cultural background and value orientation. It includes many dimensions, including physical function, psychological function, social status and health status (Kaplan & Hays, 2022). Since HRQOL can comprehensively assess the health status and subjective feelings of patients and reflect the impact of diseases or health-related defects, both Outcome Measures in Rheumatology Clinical Trials (OMERACT) and European League against Rheumatism (EULAR) suggests that HRQOL should be used in the assessment of SLE patients at the same time of disease activity and organ damage. According to the previous literature, SLE has a

significant impact on HRQOL and the HRQOL of SLE patients is lower than that of other common chronic diseases (Mizukami et al., 2023). They found that the average HRQOL score of Chinese SLE patients was 55.8 ± 19.4, while the average HRQOL score of health control group was 82.5 ± 9.5, and the conclusion was that impaired HRQOL was more common in SLE patients than in regular population ($p < .001$) (Carter et al., 2016). Therefore, this study aimed to examine the factors associated with HRQOL in SLE patients. Only when we find out the factors that relate to the HRQOL of SLE patients, we can develop more scientific and targeted interventions for patients to improve HRQOL of patients.

According to the existing literature, it is found that there are many factors affecting HRQOL in SLE including individual factors and environmental factors. Previous study pointed out that social support and mental health are influential factors; it showed that influencing factors were income, economic status, psychological status, and disease activity (Warchoł-Biedermann et al., 2022). They pointed out that age; disease activity, damage, and severity are factors affecting HRQOL in SLE (Fernández-Llanio-Comella et al., 2016).

At present, conclusions about the influencing factors of HRQOL in SLE are not consistent and need to be further verified. In this study, Revised Wilson and Cleary model for health-related quality of life was used (Ferrans et al., 2005). According to the model, factors including SLE symptoms, depression, social support and self-care are selected to investigate its relationship with health-related quality of life among patients with SLE.

SLE symptoms refers to the symptoms of SLE patients one month before the survey time, such as joint pain, fatigue, oral ulcer, hair loss, etc. A research found that fatigue, pain, or musculoskeletal distress dominated the reported symptoms in approximately half of the patients, and only patients reporting fatigue scored lower on both mental and physical aspects of HRQOL (Pettersson et al., 2012). Another research found that 38 items in symptom checklist of SLE have different degrees of influence on the quality of life of SLE patients (Yan et al., 2012). In the Revised version of Wilson and Cleary's model, characteristics of the individual is categorized as demographic, developmental, psychological, and biological factors that influence health outcomes (Ferrans et al., 2005). Researchers can obtain the information of

characteristics of the individual by investigating the demographic data of SLE patients (such as gender, age, height, weight, marital status) and general information of the disease (such as release date, diagnosis date, course of disease, symptoms). In this study, SLE symptoms belong to the concept of the characteristics of individual. Thus, SLE symptoms was selected as an independent variable in this study.

Depression refers to a kind of psychological disorder in patients with SLE, characterized by sadness, loss of interest or pleasure, feelings of guilt or low self-worth, and even suicidal attempts or behavior. A Study found that HRQOL is associated with depression in Mexican patients with SLE ($r = -.61$, $p < .05$) (Etchegaray-Morales et al., 2017). However, existing studies have shown that the quality of life of SLE patients in different regions and races is different to a certain extent. There is no research literature that has found that the HRQOL of SLE in Wenzhou area is related to depression. In the Revised version of Wilson and Cleary's model, symptoms are defined as patient's perception of an abnormal physical, emotional or cognitive state, which can be categorized as physical, psychological, or psychophysical. In this study, depression belongs to the concept of the symptoms. Research shows depression (in up to 50% of patients) is the most common psychiatric manifestations of SLE patients (Etchegaray-Morales et al., 2017). Thus, depression was selected as an independent variable in this study.

Social support is the physical and mental health resources that a person obtains from the social environment, it may depend on individual, environmental and cultural factors (Drageset, 2021). Study showed that patients' social support was associated with HRQOL, low social support leads to a decrease in HRQOL, which may be related to psychological changes (Mizukami et al., 2023). The role of social support in chronic diseases, such as cancer, has been widely researched. But its impact on SLE has not been well confirmed in Wenzhou, China. In the Revised version of Wilson and Cleary's model, characteristics of environment are the interpersonal or social influences on health outcomes, including the influence of family, friends, and healthcare providers (McLeroy et al., 1988). In this study, social support belongs to the concept of the characteristics of the environment. Thus, social support was selected as an independent variable in this study.

Self-care refers to the individual's spontaneous regulatory behavior and self-care activities to maintain life, ensure their structural integrity and normal function, and promote health and happiness. It was found that self-care activities could help to reduce the arthritis pain often experienced by people with rheumatology disorders, such as SLE (Janke et al., 2015). Moreover, self-care was able to improve the HRQOL of SLE patients in Indonesia ($p < 0.001$) (Kusnanto et al., 2018). In the Revised version of Wilson and Cleary's model, functional status is defined broadly, as the ability to perform tasks in multiple domains, such as physical function, social function, role function and psychological function (Wilson & Cleary, 1995). In this study, self-care belongs to the concept of functional status. Thus, self-care was selected as an independent variable in this study.

From the literature review, many studies have shown that the HRQOL of life of SLE patients in different regions is low, which is worthy of our attention and research. Studies have shown that Asians are more likely to suffer from severe SLE (Jakes et al., 2012). As the largest country in the Asia Pacific region, the prevalence of SLE in China is 30 - 70/100,000, which is relatively high compared with other ethnic groups (generally 12 - 39/100,000) (Rees et al., 2017). Therefore, it is necessary and important to pay attention to the health-related quality of life of Chinese SLE patients.

Existing studies have shown that the quality of life of SLE patients in different regions and races is different to a certain extent, and the influencing factors of HRQOL are also different. At present, the research on HRQOL of SLE in China is insufficient, especially in Wenzhou. Therefore, this study aimed to examine factors associated to HRQOL among persons with SLE in Wenzhou, China. Results of the study can be used to develop interventions to help improve the quality of life among persons with SLE.

Research objectives

1. To describe health-related quality of life among persons with SLE in Wenzhou, China.

2. To examine associations between SLE symptoms, depression, social support and self-care with health-related quality of life among persons with SLE in Wenzhou, China.

Research hypotheses

1. There was association between SLE symptoms and health-related quality of life among persons with SLE in Wenzhou, China.

2. There was association between depression and health-related quality of life among persons with SLE in Wenzhou, China.

3. There was association between social support and health-related quality of life among persons with SLE in Wenzhou, China.

4. There was association between self-care and health-related quality of life among persons with SLE in Wenzhou, China.

Scope of Study

The purpose of this study was to describe the health-related quality of life, and to examine relationships between the selected variables including SLE symptoms, depression, social support, self-care, and health-related quality of life in persons with SLE. Data were collected in outpatient department of rheumatology, the First Affiliated Hospital of Wenzhou Medical University, Wenzhou, China.

Study Framework

A revised version of Wilson and Cleary's model for health-related quality of life (Ferrans et al., 2005) and literature review was used to guide this study. In the revised conceptual model, health-related quality of life was identified as a patient's health outcome in a continuous multidimensional domain. The model focuses on linear relationships among five health concepts moving along the causal pathway to overall HRQOL; begin with the biological-physiological factors, symptoms, functional status, and general health perception to overall HRQOL. Moreover, the two domains the individual and environmental characteristics are directly affected to the five-health concepts and the overall HRQOL (Ferrans et al., 2005).

Characteristics of the individual are categorized as demographic, developmental, psychological, and biological factors that influence health outcomes. Characteristics of the environment are either social or physical. Social environmental characteristics include the influence of family, friends, and healthcare providers on

health outcomes. Physical environmental characteristics include the settings influence health outcomes, such as home, neighborhood, and workplace (Ferrans et al., 2005). In addition, characteristics of the individual and characteristics of the environment affect all of domains in this model. Alterations in biological function can affect all the components of health. Symptoms refer to an abnormal physical, emotional, and cognitive state. Functional status is the patient's ability to do physical function, social function, role function, and psychological function. General health perceptions refer to a synthesis of all the various aspects of health. All of these components affect overall quality of life, which be defined as the patient's sense of well-being that stems from satisfaction or dissatisfaction with the areas of life that are important to them (Ferrans et al., 2005).

In this study, SLE symptoms and depression belonged to the symptom domain. Social support represented the environment domain. Self-care represented the individual's functional status. Guided by the model, all variables including SLE symptoms, depression, social support, and self-care were related to HRQOL among persons with SLE as presented in Figure 1.

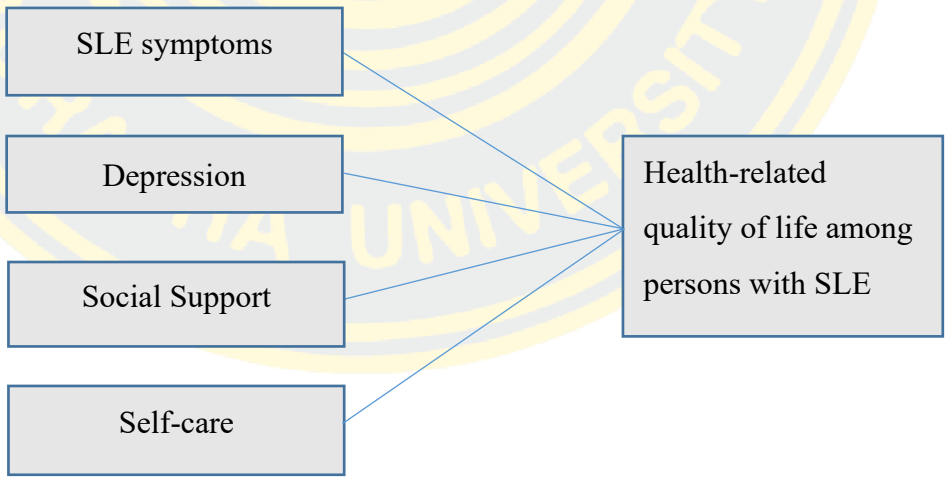

Figure 1 Research Framework

Definition of Terms

Persons with SLE refers to the persons who were diagnosed with SLE by physicians and came to regular follow up at the outpatient Department of

Rheumatology of the First Affiliated Hospital of Wenzhou Medical University, Wenzhou, China.

SLE symptoms refers to the symptoms that patients with SLE had experienced in the previous month, such as joint pain, fatigue, oral ulcer, hair loss, etc. SLE symptoms was measured by the Chinese version of SLE Symptom Checklist (SSC) developed by Yan et al. (2012).

Depression refers to the feeling of persons with SLE related to sadness and a lack of interest or pleasure in previously rewarding or enjoyable activities. In this study, depression was measured by the Chinese version of the Patient Health Questionnaire (PHQ-9) (Wang et al., 2014).

Social support refers to the perception of persons with SLE in receiving help and support from others including family, friends, and significant others. Social support of SLE patients was measured by Chinese version of the Multidimensional Scale of Perceived Social Support (MPSSS) (Huang et al., 1996).

Self-care refers to activities of persons with SLE that perform following the therapeutic regimen to maintain their health, control SLE conditions, and prevent SLE complications. It was measured by Chinese version of the Exercise of Self-Care Agency Scale (Wang & Laffrey, 2000).

Health-related quality of life (HRQOL) refers to perception of persons with SLE how diseases, treatments, and environment affect their senses of overall function and wellbeing. In this study, the health-related quality of life among SLE patients was measured by the Chinese version of the Lupus Quality of Life in SLE (Lupus QOL) (Wang et al., 2013).

CHAPTER 2
LITERATURE REVIEW

This chapter presents an overview of SLE, the revised Wilson and Cleary model for health-related quality of life, health-related quality of life among persons with SLE, and factors related to health-related quality of life in SLE patients.

Overview of SLE

SLE is one of the common diseases caused by rheumatism. The etiology and pathogenesis of SLE are still unclear. The survival rate of patients with SLE has increased due to the improvements in diagnosis and treatment. The 5-year survival rate of patients with SLE had increased from 50% to 60% in 1950s to more than 90% in 1990s and stabilized at 95% in high-income countries, at 92% in low-income and middle-income countries from 2008 to 2016 (Borchers et al., 2004; Merrell & Shulman, 1955; Tektonidou et al., 2017). SLE is no longer an acute and highly lethal disease, but a chronic and controllable disease (Tektonidou et al., 2017). However, it still has a significant impact on patients due to the disease, including physical, psychological, and social support. Previous study had shown that the HRQOL of SLE patients was lower than those other common chronic diseases (Mizukami et al., 2023).

Prevalence of SLE

According to previous epidemiological studies, SLE is developing into a global epidemic, showing an increasing trend year by year (Carter et al., 2016). Other studies have shown that incidence rate of SLE is related to race. For example, the prevalence rate of SLE patients in Asia is about 2 to 3 times that of white people (Lim et al., 2014). And some researchers have found that SLE develops more frequently, has a more severe disease course, causes more organ damage and has a higher mortality among Asian than in white individuals (Jakes et al., 2012). China, as the largest country in Asia-Pacific area, was reported with relatively higher prevalence rate as 30 - 70/100,000 when compared to other ethnicities (generally 12 - 39/100,000) (Rees et al., 2017; Zeng et al., 2008). China was the largest populations with newly diagnosed with SLE in the world, and the estimated annual incidence rate

of SLE in China at 8.57 (8.37-8.77) /100,000 people, which is the 4th highest in the world, it brings more burden and crisis to our future (Li et al., 2020). The diagnosis and treatment technology of SLE has made great progress in the past 50 years. The survival of SLE has improved dramatically in last 50 years, but, the risk of death for SLE patients are still 2 times greater than those of general population (Li et al., 2020).

Definition of SLE

Systemic lupus erythematosus (SLE) is a systemic autoimmune disease, which is characterized by systemic multiple-organ involvement, relapses with large amount of autoantibodies. If patients with SLE do not receive prompt treatment, they would get irreversible organ damage, which will ultimately lead to death. The causes of SLE are complicated, including genetics, sex hormones, exposure to various kinds of pathogens (e.g., viral and bacterial) (Li et al., 2020).

Pathology of SLE

SLE is an autoimmune disease with slow onset, diverse clinical manifestations, and involves many systems and organs. Due to the dysfunction of cellular and humoral immunity, a variety of autoantibodies are produced. SLE involves skin, joints, organs, and central nervous system, and is characterized by autoimmunity. There are many kinds of autoantibodies in patients, which affect not only humoral immunity, but also cellular immunity. Its pathogenesis is mainly due to the formation of immune complexes, the exact reason is not clear. The disease is an alternating process of repeated attack and remission. At present, the disease cannot be cured, but through regular treatment, most patients can better control the disease.

Diagnostic criteria for SLE

For classification as SLE, four criteria (at least one of them clinical and at least one immunological) have to be fulfilled or lupus nephritis has to be diagnosed histologically in the presence of ANA or anti-dsDNA antibodies (Petri et al., 2012).

Clinical criteria

1. Acute cutaneous lupus erythematosus (including “butterfly rash“)

2. Chronic cutaneous lupus erythematosus (e.g., localized or generalized discoid lupus erythematosus)

3. Oral ulcers (on palate and/or nose)

4. Non-scarring alopecia

5. Synovitis (≥ 2 joints) or tenderness on palpation (≥ 2 joints) and morning stiffness (≥ 30 min)

Serositis (pleurisy or pericardial pain for more than 1 day)

6. Renal involvement (single urine: protein/creatinine ratio or 24-hour urine protein, >0.5 g)

7. Neurological involvement (e.g., seizures, psychosis, myelitis)

8. Hemolytic anemia

9. Leukopenia (<4000/μL) or lymphopenia (<1000/μL)

10. Thrombocytopenia (<100 000/μL)

Immunological criteria

1. ANA level above laboratory reference range

2. Anti-dsDNA antibodies

3. Anti-Sm antibodies

4. Antiphospholipid antibodies (anticardiolipin and anti- β 2-glycoprotein I [IgA-, IgG- or IgM-] antibodies; false-positive VDRL [Venereal Disease Research Laboratory] test)

5. Low complement (C3, C4, or CH50)

6. Direct Coombs test (in the absence of hemolytic anemia)

Signs and symptoms of SLE

The clinical manifestations of SLE are various, constitutional symptoms are seen in more than 90% of patients with SLE and are often the initial presenting feature (Garcia et al., 2024). Fatigue, malaise, fever, anorexia, and weight loss are common, the first symptoms of SLE are different, and the early manifestations are mostly non-specific systemic symptoms, such as fever, general discomfort, fatigue, weight loss, joint pain and so on; early manifestations can also be symptoms of a certain system or organ, such as flare, Raynaud's phenomenon, oral ulcer, alopecia, lymphadenopathy, anemia, purpura, etc. Early manifestations may also be one or several laboratory indicators abnormal for early performance, such as proteinuria or hematuria, unexplained ESR increased, y globulin increased, abnormal liver function, abnormal ECG and so on (Kanderi et al., 2021).

Skin manifestations were found in more than 85% of SLE patients, characterized by butterfly shaped erythema on the bridge of nose and zygomatic

cheek, and vasculitis injury of fingers and toes. Patients can also appear photoallergy, alopecia, perinail erythema, reticular green spot, and Raynaud symptoms (Garcia et al., 2024). Anemia is present in more than 50 % of patients with SLE and most commonly is anemia of chronic disease. Lupus nephritis is a well-known and common complication of SLE and usually occurs early in the course of SLE (Ruacho et al., 2022). Approximately 80 to 90% of patients with SLE suffer from musculoskeletal involvement at some point during their disease course and may range from mild arthralgias to deforming arthritis (Mukkera et al., 2022). Any part of the gastrointestinal tract may be involved in SLE, Nausea, vomiting, abdominal discharge, abdominal pain or constipation may occur when SLE involves gastrointestinal system, and diarrhea is the most common (Garcia et al., 2024).

Complications of SLE

Complications in patients with SLE may occur either due to organ damage by the disease or due to the adverse effects of the medications. Disease process-related complications include but are not limited to accelerated atherosclerosis with a several-fold higher risk of coronary artery disease even in the younger population, end-stage renal disease, and neurological deficits, including blindness secondary to neuropsychiatric manifestations; patients with severe cutaneous lupus, especially discoid lupus, can suffer permanent skin damage and alopecia (Garcia et al., 2024). Anxiety and depression are more common in patients with SLE (Etchegaray-Morales et al., 2017). Several pregnancy-related complications are well known, including fetal loss, pre-eclampsia and eclampsia, congenital heart block, and neonatal lupus; medication-induced complications are common and require close monitoring; long-term corticosteroid use in SLE patients frequently leads to under-diagnosed and under-treated osteoporosis, leading to osteoporotic fractures; other complications of long-term use of corticosteroid therapy include avascular necrosis, glaucoma, cataract, weight gain, and poor control of Diabetes mellitus; high-dose corticosteroid use can also be associated with opportunistic infections and acute psychosis; long-term use of hydroxychloroquine may rarely result in maculopathy and retinopathy that is irreversible, and close ophthalmology examinations are recommended (Garcia et al., 2024). Cyclophosphamide use is associated with a significantly high risk of interstitial cystitis and bladder cancer even after drug discontinuation. SLE patients are

immunocompromised and at a significantly high risk of infections which is one of the significant causes of morbidity and mortality in SLE (Cavalli et al., 2022).

Treatment of SLE

According to 2020 Chinese guidelines for the diagnosis and treatment of systemic lupus erythematosus, the short-term treatment goals for patients with SLE are to control disease activity, reduce clinical symptoms, achieve clinical remission, or achieve the lowest possible disease activity (Li et al., 2020). The long-term goal is to prevent and reduce disease recurrence, reduce adverse drug reactions, prevent and control organ damage caused by disease, achieve disease stability, reduce mortality, and improve the quality of life of patients.

In drug therapy, NSAIDs can treat the skin, mucosa and joint symptoms of mild active SLE. For moderate active SLE, oral glucocorticoids can be sufficient, if necessary, combined with immunosuppressant. Severe active SLE, because of the presence of important organ involvement, its treatment can be divided into induction remission and maintenance treatment two stages: induction remission stage with sufficient glucocorticoid and immunosuppressive therapy, maintenance stage should gradually reduce the dosage of glucocorticoid according to the condition, and finally small dose maintenance. In addition to the above treatment methods, plasma exchange and specific immunoadsorption have short-term therapeutic effect on patients with SLE, which can significantly improve the clinical symptoms and immunological indexes. The side effects of hormone and immunosuppressant, such as infection, liver and kidney function damage, hypertension, osteoporosis, gastrointestinal reaction, mental symptoms and hair loss, should be prevented and paid attention to in the long-term medication.

In terms of non-pharmacological treatment, patients should avoid ultraviolet radiation, such as wearing wide-brimmed hats, parasols and long-sleeved clothes and trousers when going out; avoid taking drugs that are prone to cause drug-induced lupus, such as phenytoin sodium and hydrazinopyridazine; pay attention to warmth and prevent from getting cold; do not eat foods that are prone to triggering flare-ups, such as celery, shiitake mushrooms, beans, etc.; and women of childbearing age should pay attention to contraception, and should not take oestrogenic contraceptive pills. During the active period of the disease, patients should rest in bed; for patients

with joint pain, they should adopt appropriate postures so that the joints are in a functional position; during the remission period, patients should gradually resume exercise to enhance their physical fitness, and they should be encouraged to move from family to society and participate in recreational activities or easy work. Avoid the use of cosmetics or other chemical substances to reduce skin irritation.

Recurrence of SLE

The recurrence rate of SLE ranges from 0.19 to 1.76 episodes per person per year, and about 70% of patients follow a recurrent "relapse-remission" course. SLE recurrence is a common clinical feature of SLE patients (Fanouriakis et al., 2021).

Impacts of SLE

SLE significantly affected the patients. From the physical point of view, due to the long course and recurrent characteristics of SLE, patients suffer more disease activities, drug side effects, disease damage, even physical disability or lose labor force (Schmeding & Schneider, 2013). The clinical manifestations of SLE are varied, and more than 90% of SLE patients have constitutional symptoms, with malaise, depression, fever, anorexia and weight loss being common symptoms (Garcia et al., 2024), patients endure the effects of SLE.

SLE not only affects patients' physical health, but also their mental health. A Mexican study showed that about 50% of patients with SLE developed depression (Etchegaray-Morales et al., 2017). In addition, SLE changes body image, such as Butterfly-shaped erythema on the face, using hormone lead to obesity, which makes patients suffer from pressure, depression, anxiety, and lose confidence in treatment, then patients with poor treatment compliance may lead to the aggravation of the disease, complications, poor prognosis of patients, etc., and ultimately affecting the quality of life of patients (Rodrigues et al., 2021).

With the continuous development of SLE diagnosis and treatment technology, the survival rate of SLE patients has been improved. At present, 10 years of research 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 normal life of patients. In addition, severe recurrence of the disease results in an additional medical cost of about US $18511 per year (Jönsen et al., 2016), which greatly increases the economic pressure and family burden of SLE patients (Somers et al., 2014). A As

remission and relapse often occur alternately, patients spend less time with friends, and gradually out of touch with society.

Because SLE is a chronic disease, if individual can't perform good self-care, the disease may be relapse and cause complications. When they occur, it will affect the patient's physical and psychological health. Sometimes, even the patients perform good self-care, when the environmental changes, patients may still appear other complications. So the SLE patients have heavy burden and develop psychological problems, which affect their daily activities and social life.

Health-related quality of life

Definitions of health-related quality of life

The concept of quality of life was first put forward in the United States in the 1930s, and since then, the world has focused on quality of life. The WHO defined quality of life as a complete state of physical, mental and social well-being, not just the absence of disease or infirmity , the World Health Organization defines the quality of life as an individual's subjective feeling of life according to the value system of cultural background, which is influenced by the individual's goals, expectations, standards and concerns (Kuyken et al., 1995). Quality of life is critical in assessing the quality and outcome of health care, especially for chronic patients, because the disease is incurable (Moon et al., 2018). Quality of life covers a wide range of areas, one of which is health-related quality of life (HRQOL). It defined health-related quality of life as a person's perceived physical and mental health over time, which focus to the effects of health, illness and treatment on quality of life (Ferrans et al., 2005).

Health-related quality of life in SLE patients in China

SLE significantly affected the HRQOL of Chinese patients, therefore, HRQOL has a profound impact on people with SLE and it is therefore important to ascertain which factors deteriorate or improve the HRQOL of these individuals' ore important to ascertain which factors deteriorate or improve the HRQOL of these individuals. At present, there were no articles exploring the health-related quality of life and influencing factors among SLE patients in Wenzhou, China.

A previous study showed that Chinese SLE patients had lower HRQOL than controls in all domains ($P < 0.001$), especially in physical and emotional, furthermore, personality, life nervous and experiences of adverse life events may influence HRQOL and HRQOL improvements(Wang et al., 2024). A study of health-related quality of life in Han Chinese patients with systemic lupus erythematosus showed that poor educational background, old-age, and increased fatigue, disease activity, and might represent poor HRQOL (Jiang et al., 2018). A prospective study found that the impaired quality of life of SLE patients is more common than that of healthy controls, and this phenomenon is not affected by gender, age, education level and economic status; the quality of life of SLE patients with a history of organ injury is low, and the new organ injury will lead to a further decline in the quality of life of SLE patients (Mok et al., 2009). In China younger SLE patients had different clinical features and more inflammation (Wu et al., 2017). Different age groups, occupations, literacy levels, marital status, family financial status, and symptoms of SLE patients have an impact on quality of life (Liu et al., 2017). Study showed that the quality of life of SLE patients was affected by disease activity and mental disorder; socioeconomic status had no direct impact on the quality of life of SLE patients, while disease activity had a direct impact on the quality of life (Shen et al., 2013).

Revised Wilson and Cleary model for health-related quality of life

A revised version of Wilson and Cleary's model was used to guide this study (Ferrans et al., 2005). In the revised conceptual model, health-related quality of life was identified as a patient's health outcome in a continuous multidimensional domain. Health related quality of life (HRQOL) in the model included five aspects: biological function, symptom, functional status, general health perception, and overall quality of life. Based on this model, the current study examined the relationships among symptoms (depression and SLE symptom), functional status (self-care), characteristic of the environment (social support), and overall quality of life in persons with SLE.

The revised version of Wilson and Cleary model assumes that overall quality of life is directly affected by general health perceptions, characteristic of the individual and characteristic of the environment. Through general health perceptions, functional status indirectly affects the overall quality of life. Similarly, through

functional status and general health perceptions, symptom also indirectly effect the overall quality of life, and symptom is directly affected by biological function. According to this model, it described that overall quality of life, general health perceptions, functional status, symptom and biological function are five types that measure the prognosis of patients, and they are affected by characteristic of the individual and characteristic of the environment. Therefore, these characteristics have direct and indirect effects on the overall quality of life (Ferrans et al., 2005).

Characteristics of the individual

In the Revised version of Wilson and Cleary's model, Characteristics of the individual are categorized as demographic, developmental, psychological, and biological factors that influence health outcomes (Ferrans et al., 2005). Researchers can obtain the information of characteristics of the individual by investigating the demographic data of SLE patients (such as gender, age, height, weight, marital status, etc.) and general information of the disease (such as release date, diagnosis date, course of disease, symptoms, etc.).

Characteristics of the environment

Characteristics of the environment are significantly influenced by individual cultural heritage, which can affect patient in preventive care as well as treatment. Characteristics of the environment are either social or physical. Social environmental characteristics include the influence of family, friends, and healthcare providers on health outcomes. Physical environmental characteristics include the settings influence health outcomes, such as home, neighborhood, and workplace (Ferrans et al., 2005). In this study, social support belongs to the concept of the characteristics of the environment.

Biological function

In the Revised version of Wilson and Cleary's model, Biological function is viewed broadly and includes molecular, cellular and whole organ levels processes (Ferrans et al., 2005). It can directly or indirectly affect symptom, functional status, general health perceptions and overall quality of life.

Symptom

Wilson and Cleary (1995) defined symptoms as a patient's perception of an abnormal physical, emotional, or cognitive state, which can be categorized as

physical, psychological, or psychophysical (Ferrans et al., 2005). In this study, depression and SLE symptoms belong to characteristics of the symptom.

Functional status

Functional status is defined broadly, as the ability to perform tasks in multiple domains, such as physical function, social function, role function and psychological function (Wilson & Cleary, 1995). In this study, self-care belongs to the concept of functional status.

General health perceptions

In the Revised version of Wilson and Cleary's model, general health perceptions integrate all the components that come earlier in the model, and they are subjective in nature. This component is a synthesis of all the various aspects of health in an overall evaluation (Wilson & Cleary, 1995).

Overall quality of life

Overall quality of life is characterized as subjective well-being related to how happy or satisfied someone is with life as a whole (Wilson & Cleary, 1995).

Factors related to health-related quality of life in SLE patients

This section introduces factors related to the health-related quality of life among SLE patients. According to the revised version of Wilson and Cleary's model (Ferrans et al., 2005), the selected variables including SLE symptoms, self-care, depression, and social support had relationships with health-related quality of life.

Depression

Depression refers to a kind of psychological disorder in patients with SLE. SLE patients may be accompanied by rash, alopecia and kidney, joint, blood and mental nerve damage, most patients do not understand the disease, resulting in fear of the disease. Relapse, long-term treatment, decline in living and working ability, great economic losses, limited social and entertainment activities will inevitably bring mental pressure to SLE patients, resulting in depression. In addition, the economic pressure brought by SLE to patients and their families is also an important reason for patients' depression. Research showed depression (in up to 50% of patients) was the most common psychiatric manifestations of SLE patients (Etchegaray-Morales et al., 2017). The main clinical manifestations of SLE patients with depression are: sleep

disorders, loss of interest, emptiness, decreased sexual interest, anxiety, despair, and even suicidal behavior. A study found that HRQOL was associated with depression in Mexican patients with SLE ($r = -.61$, $p < .05$) (Etchegaray-Morales et al., 2017). However, existing studies had shown that the HRQOL of SLE patients in different regions and races was different to a certain extent.

SLE symptoms

SLE symptoms refers to the symptoms that patients with SLE had experienced in the previous month, such as joint pain, fatigue, headache, fatigue, ulcers in mouth or throat, hair loss, etc. As the survival rate increases, due to the long duration of SLE and the recurrent nature of the disease, the patient suffers more from the effects of the disease, such as fatigue, depression and anxiety, loss of labor and other afflictions (Gu et al., 2019). Fatigue and pain are two of the most common symptoms in SLE, persistent fatigue has a devastating effect on many aspects of a patient's life and is undoubtedly a factor in deteriorating quality of life, between 67% and 90% of SLE patients experience persistent fatigue and consider that fatigue may affect major aspects of health-related quality of life (Lou et al., 2021), thus ultimately adversely affecting their work, emotions, social relationships, independence, and daily functioning. A previous study showed the SLE symptoms was correlated with HRQOL of SLE patients, it found that 38 items in symptom checklist of SLE have different degrees of influence on the quality of life of SLE patients (Yan et al., 2012). Overall, it is important to prevent the symptoms of SLE to slow down the further progression of the disease and prevent complications from occurring.

Social support

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), it may depend on individual, environmental and cultural factors. A study showed that patients' social support was associated with HRQOL ($r = .48$, $p < .005$), low social support caused a decrease in HRQOL, which may be related to psychological changes (Jing et al., 2017). Previous study showed that social support levels for patients with SLE were closely related to the quality of life, and influenced by age, marital status, professional condition, and disease damage (Xu et al., 2019). Health education for patients and their families should be strengthened in chronic

disease management to enhance social support and finally, improve their quality of life.

Self-care

Self-care refers to the individual's spontaneous regulatory behavior and self-care activities to maintain life, ensure their structural integrity and normal function, and promote health and happiness. Self-care activities which performed by persons with SLE must following the therapeutic regimen, aims to maintain their health, control SLE conditions, and prevent SLE complications. Researchers found that self-care activities could help to reduce the arthritis pain often experienced by people with rheumatology disorders, such as SLE (Janke et al., 2015). A previous study found self-care could enhance the HRQOL in SLE patients by an average of 12.19% (Kusnanto et al., 2018) . It was also found that improve self-care activities can reduce some part of SLE symptoms, such as pain, fatigue, otherwise, it can help patients maintain emotional stability and increase adaptive coping. Higher body mass index, higher level of fatigue, and worse mental health were found in patients with lower self-care agency (Yang et al., 2018). Studies had indicated that health behavior can affect individuals' health status and later their quality of life, so the approach recommended was to modify health behavior through self-care activities to increase the quality of life for people with SLE (Kusnanto et al., 2018).

In summary, SLE symptoms, self-care, depression and social support were related with HRQOL among SLE patients, however, previous studies lack data support, and the effect between these factors and HRQOL have not been confirmed.

Summary

From the literature review, the HRQOL of SLE patients was low, which is worthy of our attention and research. Studies had shown that Asians were more likely to suffer from severe SLE (Jakes et al., 2012). As the largest country in the Asia Pacific region, the prevalence of SLE in China was relatively high (Rees et al., 2017).

SLE significantly affected the HRQOL of Chinese patients, and impaired HRQOL was more common in SLE patients than in regular population ($p < .001$) (Carter et al., 2016). The average HRQOL score of Chinese SLE patients was 55.8 ± 19.4, while the average HRQOL score of health control group was 82.5 ± 9.5 (Carter

et al., 2016). Therefore, HRQOL has a profound impact on people with SLE and it is therefore important to ascertain which factors deteriorate or improve the HRQOL of these individuals' ore important to ascertain which factors deteriorate or improve the HRQOL of these individuals.

Existing studies had shown that the HRQOL of persons with SLE in different regions and races was different to a certain extent, and the influencing factors of HRQOL were also different. At present, there are few articles exploring the health-related quality of life and influencing factors among persons with SLE in Wenzhou, China. Additionally, few studies have explored the association of all factors together in the revised Wilson and Cleary's model on HRQOL. Therefore, this study was based on the revised Wilson and Cleary's model and literature review to assess the HRQOL and to examine related factors of HRQOL among persons with SLE. The results of this study are expected to develop more scientific and targeted interventions for patients, so as to improve the quality of life of patients.

CHAPTER 3
RESEARCH METHODOLOGY

This chapter presents the research design, population and sample, research setting, research instruments, ethical consideration, data collection procedures, and data analysis procedures.

Research Design

The descriptive correlational design was used to investigate the relationships among SLE symptoms, depression, social support, and self-care with health-related quality of life among Chinese patients with SLE.

Population and Sample

Population

The population in this study was persons with SLE who were diagnosed by physicians and came to the outpatient Department of Rheumatology at the First Affiliated Hospital of Wenzhou Medical University for at least one month.

Sample

The samples were persons with SLE who were diagnosed by physicians and came to the outpatient Department of Rheumatology at the First Affiliated Hospital of Wenzhou Medical University, Wenzhou city, Zhejiang province, China.

The inclusion criteria of the sample include:

1. Age ≥ 18 years old
2. Have a certain ability to write and can speak Chinese
3. Have good orientation to place and time and has no history of mental illness, no cognitive impairment.

The exclusion criteria of the sample include:

1. Accompanied by other serious diseases, such as malignant tumors
2. Lupus active mental illness as presented in the medical record.

Sample size

The sample sizes of this study were calculated by using the G*Power 3.1.9.2 program for correlation design. The effect size of .288 was used, (Tamayo et al., 2010), alpha of .05, and power of .80 were used to compute the sample size. Therefore, the sample size should be at least 92 subjects.

Sample recruitment

A Simple random sampling was used to recruit samples in this study; each member of the population had an equal chance of being selected. The researcher used the Hospital Appointment System to review whether the patients attending the Rheumatology Outpatient Department met the inclusion criteria for the study with the help of a nurse at the clinic. The researcher noted down the queue number of the outpatients who met the criteria in the small piece paper. The paper folded and mixed in the bag prepared beforehand. The queue number was drawn randomly, the selected patients were asked by the researcher whether they would like to participate in the study, with the consent of the selected patient, the researcher guided the individuals to sign on the consent form and completed the questionnaires. About 8 to 10 individuals were recruited a day, which depend on the number of individuals who visited the rheumatology outpatient department (OPD) on that day. The samples recruited until reach the required sample size.

Research Setting

There are four hospitals with Rheumatic Immunology Department in Wenzhou, including the First Affiliated Hospital of Wenzhou Medical University, the Second Affiliated Hospital of Wenzhou Medical University, Wenzhou Central Hospital and Wenzhou People's hospital. Most SLE patients come to the Department of Rheumatology and Immunology of the First Affiliated Hospital of Wenzhou Medical University. It is estimated that 40 persons with SLE come to the outpatient Department of Rheumatology at this hospital per a day.

This study was conducted in the Rheumatology Clinic of the First Affiliated Hospital of Wenzhou Medical University with the reason of accessible population. The Rheumatology Clinic was open 6 days a week (Sunday to Friday). The staff included two nurses and five doctors. The doctors were mainly responsible for treatment and adjusting medications, while the nurses were mainly responsible for

measuring vital signs, provided direct care and health education related to SLE knowledge, treatment, and self-care.

Research instruments

Questionnaires were used to collect data, including the demographic questionnaire, the Chinese version of the Patient Health Questionnaire (PHQ-9), the Chinese version of Perceived Social Support Scale (PSSS), the Chinese version of Lupus Quality of Life (LupusQoL), the SLE Symptom Checklist (SSC) and the Exercise of Self-Care Agency (ESCA).

The demographic questionnaire

The demographic questionnaire was collected by the researcher, including gender, age, height and weight, education level, marital status, working status, payment method, diagnosis time, comorbidity.

The SLE Symptom Checklist (SSC)

The SLE Symptom Checklist (SSC) was adopted in this study to measure the symptoms of SLE patients, which was developed by Grootscholten et al. (2003) to investigation of symptom specificity in patients with SLE. The Chinese version was translated by Yan et al. (2012). The Cronbach's alpha coefficient of the scale is 0.89, indicating good reliability and validity (Yan et al., 2012).

The scale included 38 items, they were used to assess the presence and burden of disease- and treatment-related symptoms in the past 4 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), with a summed score ranging from 0 to 152. A higher score indicated that the symptoms of SLE patients were more severe.

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

The Chinese version of the Patient Health Questionnaire (PHQ-9) was used to measure the presence and severity of depressive symptoms of SLE patients in this study. The PHQ-9 scale was developed by Spitzer et al. (1999) and was derived from the PRIME-MD the Primary Care Evaluation of Mental Disorders (PRIME-MD).This scale has been used as a depression screening tool in primary care. PHQ-9 has been translated into more than 80 languages and is widely used around the world. It has

demonstrated sufficient reliability and validity and has been used in different populations, for example, in inpatients in general hospitals, in primary care populations, and in primary care for elderly patients.

The Chinese version was translated by Wang et al. (2014). Compared with other instruments, the Chinese version of PHQ-9 has the advantages of simplicity, self-examination, versatility, and ease of scoring. Cronbach' s alpha for the Chinese version of the Patient Health Questionnaire was .86 and good criterion and construct validity was demonstrated when testing on 1,045 participants from a Shanghai community (Wang et al., 2014).

The scale was a self-report questionnaire that consisted of nine items based on the DSM-IV criteria for assessing symptoms of depression. The questionnaire assessed whether the symptom had bothered the individual during the previous two weeks. There were 9 items and each item ranged from 0 (not at all), 1 (several days), 2 (more than half the days), and 3 (nearly every day), with a summed score ranging from 0 to 27. The severity of depression was diagnosed by the summed score, divided into 4 level: mild depression (5-9), moderate depression(10-14), moderate to severe depression(15-19), and severe depression (≥ 20) (Wang et al., 2014).

The Perceived Social Support Scale (PSSS)

The Chinese version of the Perceived Social Support Scale (PSSS) was used to measure the SLE patients' subjective experience of social support in this study. The Chinese version of PSSS was translated by Huang et al. (1996) from the Version proposed by Blumenthal et al. (1987). Cornbrash's α for the Chinese version of PSSS was .88 and good criterion and construct validity was demonstrated when testing on 206 samples (Huang et al., 1996). The PSSS was a kind of social support scale, which measures the degree of social support from family and other people perceived by individuals respectively and reflects the total degree of social support perceived by individuals with the total score.

The scale had 12 items and 3 dimensions, including family support (item3, 4, 8, 11), friends support (item 6, 7, 9, 12), significant other support (item 1, 2, 5, 10). Each item ranged from 1 to 7, 1 (extremely disagree), 2 (very disagree), 3 (slightly disagree), 4 (neutral), 5 (slightly agree), 6 (very agree), and 7 (extremely agree). The summed score of social support ranged from 12-84, divided into 3 levels: low support

(12-36), moderate support (37-60), and high support (61-84). For the subscale; family, friends and significant others subscale mean scores range from 4-28, divided into 3 levels: low support (4-12), moderate support (13-20), and high support (21-28) (Huang et al., 1996).

The Lupus Quality of Life (LupusQoL)

The LupusQoL-China was adopted in this study to measure the health-related quality of life. The scale was originally developed by McElhone et al. (2007), and has been demonstrated to be validated as a disease-specific health-related quality of life (HRQOL) instrument for adults with SLE 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. The Cronbach's α for the LupusQoL-Chinese was .811 and good criterion and construct validity was demonstrated when testing on 208 subjects with SLE.

The LupusQoL-China was used to evaluate the quality of life of SLE patients in the past 4 weeks. It included 34 items, which were divided into 8 dimensions: physical health (item1-8), pain (item9-11), planning (item12-14), intimate relationships (item15-16), burden on others (item17-19), emotional health (item20-25), body image (item26-30) and fatigue (item31-34). Each item ranged from 0 to 4, divided into 5 levels: 0 (all of the time), 1 (most of the time), 2 (a good bit of the time), 3 (occasionally), and 4 (never). Item scores were totaled for each domain and the mean raw domain score was obtained by dividing the total score by the number of items in that domain. The mean raw domain score was transformed to scores ranging from 0 (worst HRQOL) to 100 (best HRQOL) by dividing by 4 (the number of Likert responses) and then multiplying by (McElhone et al., 2007), as below:

$$\text{transformed score for domain} = \frac{\text{mean raw domain score}}{4} \times 100$$

The summed score of this scale ranged from 0-136. Higher scores indicate higher level of HRQOL.

The Exercise of Self-Care Agency (ESCA)

The Exercise of Self-Care Agency (ESCA) was adopted in this study to measure self-care of SLE patients, which was designed by Kearney and Fleischer

(1979) according to Orem's self-care theory. Wang and Laffrey (2000) translated the scale into Chinese, and Chinese researchers widely use the scale to measure the self-care agency of patients with chronic diseases. The Cronbach's alpha coefficient of the scale is 0.86, which has good reliability and validity (Wang & Laffrey, 2000).

The scale had 4 dimensions, including active versus passive response to situations, motivations, the knowledge base, and the sense of self-worth. The scale had 43 items on a 5-point Likert-type scale ranging from 0 (it does not describe me) to 4 (it completely describes me). Eleven items were reversed. The total score of the scale ranged from 0 to 172, which reflects the self-care agency of the subjects. According to the total score, the self-care ability was equally divided into three levels: low (< 56.76), moderate (56.76-113.52) and high (113.52). Higher scores indicated higher level of self-care agency.

Quality of instruments

The instruments used in this study were the Chinese version. They were tested and validated by the experts in some previous studies, which mean all instruments had good validity. The Cronbach’s alpha was found in previous studies to show that the reliability of all instruments applied in this study was ideal. The reliability of the instrument was used Cronbach’s alpha coefficients to determine the reliability of each questionnaire with additional 30 patients with SLE (not selected from the existing sample), who had the same characteristics as the sample of the study. The reliability of instruments the Patient Health Questionnaire (PHQ-9), the Perceived Social Support Scale (PSSS), the Lupus Quality of Life (LupusQol), the Exercise of Self-Care Agency (ESCA), the SLE Symptom Checklist (SSC) were test in the 30 persons with SLE, the Cronbach’s alpha for each subscale were .81, .94, .949, .925, .885, respectively.

Protection of the rights of human subjects

This research proposal was approved by the Institutional Review Board of Burapha University (Protocol code G-HS024/2564) and the Ethics Committee of the First Affiliated Hospital of Wenzhou Medical University (Protocol code KY2021-

091). During the data collection process, all participants were informed in detail of the purpose of the study and voluntarily participated in the process. The researchers promised to collect data for analysis purposes only, and the study did not disclose the personal information of the participants. Participants voluntarily participated in the study and had the right to refuse or withdrew from the study during the research process. Before collecting data, participants signed informed consent. All data were stored in a safe place, if participants wanted to know the result of this study, participants could contacted the researchers. If the participant reported seriously depressed, the researchers would help them to visit the physician.

Data collection procedures

The data collection process of this study was as follows:

1. After the researcher got approval from the IRB of BUU and the IRB of the First Affiliated Hospital of Wenzhou Medical University, China for ethical review. The researcher asked permission for data collection from the Faculty of Nursing in BUU and the First Affiliated Hospital of Wenzhou Medical University, China regarding the objectives and procedures of the study information.

2. After the researcher got permission from the First Affiliated Hospital of Wenzhou Medical University, China. The researcher went to the rheumatology OPD, explained the data collection procedure to the staff who work at the OPD.

3. Then the researcher went to the outpatient department before 8 A.M (Except for Saturday). Based on the information in the registration records, the researcher talked to the patients to find the participants who meet the inclusion criteria. Then the researcher used a random sampling technique to select the participants.

4. Participants were informed about the aim of the study, ethical issues, and human protection of the study. Participants volunteered participate in the study and signed a written consent form.

5. Then the researcher took the participant to a separate room to complete the questionnaire survey without interference.

6. The researcher used the Demographic Questionnaire, the Patient Health Questionnaire (PHQ-9), the Perceived Social Support Scale (PSSS), the Lupus

Quality of Life (LupusQoL) and Exercise of Self-Care Agency (ESCA) to conduct a questionnaire survey on each participant. Participants completed the questionnaire independently. If they had any questions, they could ask the researcher.

7. Each participant took about 20-30 minutes to complete questionnaires, and the data collection time was from 8 am to 5 pm.

8. In the process of data collection, if the participants reported having seriously depressed, the researchers would help them with psychological care and transfer them to the physician.

9. All procedures were repeated until the sample size was met.

Data analysis

The data was analyzed by using SPSS statistical software, the alpha (α) level of statistical significance was set at .05.

1. Descriptive statistics (frequency, percentage, mean and standard deviation) was used to describe patient demographic data and health-related quality of life.

2. The assumptions of Pearson correlation coefficient were examined, including normal distribution, linear relationship, independent errors, no outliers. All assumptions were met.

3. The relationship between SLE symptom, depression, social support, self-care and health-related quality of life were measured by using the Pearson's product-moment correlation.

CHAPTER 4
RESULTS

This chapter presents the results of the study about health-related quality of life and related factors (SLE symptoms, depression, self-care, and social support) among 92 persons with SLE in Wenzhou. The results are divided into three parts. The first part describes the demographic characteristics of participants including age, gender, disease duration, educational level, marital status, work status, payment method comorbidity, hospitalization (within the last three months). The second part describes information of study variables including SLE symptoms, depression, self-care, and social support among persons with SLE. Finally, the relationships among SLE symptoms, depression, self-care, and social support, with health-related quality of life among persons with SLE are presented.

Part 1 Description of demographic characteristics persons with SLE

Table 1 demonstrates the demographic characteristics of the persons with SLE including age, gender, disease duration, educational level, marital status, work status, payment method comorbidity, hospitalization (within the last three months). The participants were in middle age (M= 38.83, SD=12.02), 58.7% were between 30-49 years old. Most of the participants were female (94.6%). 43.5 % of the participants completed secondary school. Most of the participants were married (75 %). 46.7 % of participants were unemployed and some participants had jobs (44.6%). Most of the participants (72.8%) had social insurance. 42.4 % of participants were diagnosed with SLE less than 60 months (M=97.75, SD=77.13). Moreover, participants had complications including anemia (45.7 %) followed by arthritis (23.9 %), chronic kidney disease (21.7%), and hypertension (19.5%). In addition, 70.7% of participants had been hospitalized within the past three months.

Table 1 Description of demographic characteristics of participants (n=92)

Characteristics	Frequency(n)	Percentage (%)
Age group (Max=74, Min=18, M=38.83, SD=12.02)		
18-29	20	21.7
30-49	54	58.7
50-69	17	18.5
≥70	1	1.1
Gender		
Male	5	5.4
Female	87	94.6
Education level		
Less than primary	11	12.0
Primary school	16	17.4
Secondary school	40	43.5
Graduate and up	25	27.1
Marital Status		
Single	21	22.8
Married	69	75.0
Divorced	2	2.2
Work status		
In-service	41	44.6
Retired	8	8.7
Unemployed	43	46.7
Payment Method		
Social insurance	67	72.8
Other	25	27.2

Table 1 (Continued)

Characteristics	Frequency(n)	Percentage (%)
Duration of disease (Max=264, Min=3, M=97.75, SD=77.13)		
< 60 months	39	42.4
60-120 months	21	22.8
> 120 months	32	34.8
Comorbidity		
Diabetes	2	2.1
Hypertension	18	19.5
Anemia	42	45.6
Arthritis	22	23.9
Chronic Kidney Disease	20	21.7
Others	3	3.2
Hospitalization (Within the last three months)		
None	27	29.3
Yes	65	70.7

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

Table 2 shows that the overall mean score of depression was 7.51 (SD=6.30), which was mild depression. Considering the severity of depression, 35.9% of the participants had no depression as well as mild depression. Of the 92 participants, 6.5% were classified as severe depression.

Table 2 Description of depression (n=92)

Level of Depression	Frequency(n)	Percentage (%)
No depression (<5)	33	35.9
Mild depression (5-9)	33	35.9
Moderate depression (10-14)	13	14.1
Moderate to severe depression (>14-19)	7	7.6
Severe depression (≥20)	6	6.5

Table 3 presents description of the SLE symptoms, the overall mean score of SLE symptoms was 28.84 (SD=16.26). Among the 38 items, the top 5 symptoms that most severe were fatigue (1.71±0.96), hair loss (1.58 ±1.17), disturbed memory (1.52 ±1.14), nightmares (1.26 ±1.27), and vulnerable skin (1.16±1.15), which were the most burdensome symptoms to the SLE participants.

Table 3 Description of SLE symptoms (n=92)

Variable	Frequency(n)	Percentage (%)	M	SD
SLE symptoms			**28.84**	**16.26**
Painful joints	46	50.0	1.11	1.21
Painful muscles	43	46.7	0.92	1.10
Headache	39	42.4	0.84	1.06
Fatigue[1]	77	83.7	1.71	0.96
Ulcers in mouth or throat	20	21.7	0.35	0.73
Hair loss[2]	66	71.7	1.58	1.17
Skin rash	46	50.0	0.83	0.94
Red and painful eyes	30	32.6	0.49	0.76
Pain while breathing	24	26.1	0.40	0.74
Shortness of breath	35	38.0	0.63	0.89
“White” fingers in cold weather	24	26.1	0.38	0.69
Itch	25	27.2	0.49	0.88

Table 3 (Continued)

Variable	Frequency(n)	Percentage (%)	M	SD
Ankle oedema	31	33.7	0.57	0.87
Chubby cheeks/face	55	59.8	1.15	1.06
More appetite	38	41.3	0.68	0.94
Less appetite	28	30.4	0.51	0.87
Pimples	30	32.6	0.36	0.78
Facial hair growth	29	31.5	0.45	0.73
Blue/purple stretch marks on the skin	35	38.0	0.70	1.00
Spontaneous bruises	33	35.9	0.71	1.03
Poor wound healing	52	56.5	1.04	1.04
Muscle weakness	51	55.4	0.99	1.05
Blurred vision	45	48.9	0.91	1.00
Nightmares[4]	52	56.5	1.26	1.27
Mood changes	41	44.6	0.85	1.03
Nausea/vomiting	28	30.4	0.52	0.84
Stomach complaints	37	40.2	0.73	0.94
Sensitivity to sunlight	50	54.3	1.00	1.07
Sensitivity to artificial light	17	18.5	0.26	0.61
Fits	6	6.5	0.07	0.25
Fainting	11	12.0	0.17	0.53
Genital sores	6	6.5	0.08	0.31
Chest pain	27	29.3	0.05	0.85
Loss of concentration	47	51.1	1.09	1.16
Muscle cramps	40	43.5	0.88	1.11
Vulnerable skin[5]	53	57.6	1.16	1.15
Disturbed memory[3]	66	71.7	1.52	1.14
Weight gain	49	53.3	0.97	1.04

Table 4 presents description of self-care, with the overall mean score of 118.96 (SD =24.72). According to the ESCA scale, it showed that the participants had a high self-care agency.

Table 4 Description of self-care (n=92)

Variable	Possible score	Actual score	*M*	*SD*	Level
Self-care	0-172	52-168	118.96	24.72	High

Table 5 showed the mean total score of social support was high (M=64.54, SD=13.60), all of the participants had high scores on two dimensions, including family support (M=23.27, SD=4.61) and significant other support (M=22.05, SD=4.36).

Table 5 Description of social support (n=92)

Variable	Possible score	Actual score	*M*	*SD*	Level
Social support	12-84	33-84	64.54	13.60	High
Family	4-28	10-28	23.27	4.61	High
Friends	4-28	8-28	19.22	6.38	Moderate
Significant other	4-28	12-28	22.05	4.36	High

Table 6 showed that the mean summed score of lupus quality of life was 85.41(SD=26.50). The scale evaluated the quality of life of participants including 8 different domains. Higher score of each domains indicate higher level of HRQOL. Scores were ranked from highest to lowest: intimate relationships (68.07±23.17), body image (66.58±24.88), emotional health (65.26±22.78), planning (64.22±22.56),

and pain (63.77±23.13), physical health (58.56±21.33), and fatigue (58.56±21.33), burden on others (56.98±25.69).

Table 6 Description of HRQOL (n=92)

Domain	Total scores of items mean ± SD（range）	Standardized score mean ± SD
HRQOL	**85.41±26.50(13-136)**	
Physical health (8 items)	19.42±7.03(6-32)	60.75±21.96
Pain (3 items)	7.65±2.78(0-12)	63.77±23.13
Planning (3 items)	7.71±2.71(1-12)	64.22±22.56
Intimate relationships (2 items)	5.45±1.85(1-8)	68.07±23.17
Burden on others (3 items)	6.84±3.08(0-12)	56.98±25.69
Emotional health (6 items)	15.66±5.47(0-24)	65.26±22.78
Body image (5 items)	13.32±4.98(1-20)	66.58±24.88
Fatigue (4 items)	9.37±3.41(0-16)	58.56±21.33

Part 3 Relationships among SLE symptoms, depression, self-care, social support and health-related quality of life among persons with SLE

The assumptions testing of Pearson correlation coefficient was examined. Scatter plots were drawn to verify the linear relationship between independent variables and dependent variables; the histogram and the normal P-P Plot were drawn to examine normally distributed of data; there were no outliers. All assumptions were met.

The Pearson correlation test was used to examine the relationship between SLE symptoms, depression, self-care, and social support with health-related quality of life in SLE patients. Table 7 revealed that the SLE symptoms, depression, self-care and social support had significant correlations with health-related quality of life. Self-care and social support was positively correlated with lupus quality of life ($r = .333$, $r = .394$, $p < .01$, respectively), depression and SLE symptoms was negatively correlated with health-related quality of life ($r = .370$, $r = .407$, $p < .01$, respectively),

depression and SLE symptoms was negatively correlated with health-related quality of life (r = -.466, r = -.436, p < .01, respectively). In addition, the selected variables had moderate association with health-related quality of life.

Table 7 Relationships among the dependent variables and independent variables (n = 92)

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

*p＜.05, **p＜.01

CHAPTER 5
CONCLUSION AND DISSCUSSION

This chapter presents the summary of results and discussions of this study. Finally, the implications for practice and future research are discussed.

Summary of findings

The aims of this study were to describe health-related quality of life and its influencing factors among patients with SLE in Wenzhou, China, the study was guided by a revised version of Wilson and Cleary's model for health-related quality of life (Ferrans et al., 2005). Ninety-two participants were randomly recruited from the outpatient Department of Rheumatology at the First Affiliated Hospital of Wenzhou Medical University, Wenzhou city, Zhejiang province, China. Instruments consisted of six questionnaires, including the demographic questionnaire, the Patient Health Questionnaire (PHQ-9), the Perceived Social Support Scale (PSSS), the Lupus Quality of Life questionnaire, the Exercise of Self-Care Agency (ESCA), and the SLE Symptom Checklist (SSC). The reliability of instruments of the Patient Health Questionnaire (PHQ-9), the Perceived Social Support Scale (PSSS), the Lupus Quality of Life (LupusQol), the Exercise of Self-Care Agency (ESCA), the SLE Symptom Checklist (SSC) were test in the 30 patients with SLE, the Cronbach's alpha for each subscale were .81, .94, .949, .925, .885, respectively.

The results of this study indicated that most of the participants were female (94.6%). They were in middle age (M= 38.83, SD=12.02), 58.7% were between 30-49 years old. Most of the participants were married (75 %), 46.7% of the participants were unemployed, 43.5% of participants had secondary level of education. More than half of them (72.8%) had social insurance. About 41.3 % of the participants were diagnosed with SLE less than 5 years. In addition, nearly half of the participants had anemia (45.6 %). The majority of the participants had been hospitalized within past three months (70.7%).

According to the results, the overall mean score of depression of participants was mild (M=7.51, SD=6.30, score range 0-24). The mean score of SLE symptoms was 28.84 (SD=16.26, score range 0-69), and the most symptoms occurrence reported

by participants were fatigue, hair loss, disturbed memory, nightmares, and vulnerable skin. Participants reported their overall mean score of self-care was high (M=118.96, SD=24.72, score range 52-168). They reported the overall mean score of social support was high (M=64.54, SD=13.60, score range33-84), especially from family support (M=23.27, SD=4.61) and significant other support (M=22.05, SD=4.36). The mean score of quality of life was 85.41(SD=26.50, score range 13-136). Considering the eight subscales of HRQOL, the scores were ranked from the highest to the lowest as follows: the intimate relationships (68.07±23.17), body image (66.58±24.88), emotional health (65.26±22.78), planning (64.22±22.56), and pain (63.77±23.13), physical health (58.56±21.33), and fatigue (58.56±21.33), burden on others (56.98±25.69).

The results indicated that the SLE symptoms, depression, self-care and social support had a significant correlation with health-related quality of life. Self-care and social support was positively correlated with health-related quality of life ($r = .370$, $p < .01$; $r = .407$, $p < .01$, respectively), depression and SLE symptoms was negatively correlated with health-related quality of life ($r = -.466$, $p < .01$; $r = -.436$, $p < .01$, respectively).

Discussion

The purposes of this study were to describe health-related quality of life among persons with SLE in Wenzhou, China and to examine associations between SLE symptoms, depression, social support, and self-care with health-related quality of life. The discussion section focuses on objectives of the study as following.

Health-related quality of life among persons with SLE

In this study, the mean score of quality of life among patients with SLE was 85.41±26.50, which means that the quality of life for SLE patients was compromised, also the quality of life of SLE patients was consistently lower than that of healthy individuals (Gu et al., 2019). Results from this study were consistent to previous studies. Previous studies have also found that SLE has a significant impact on HRQOL and the HRQOL of SLE patients is lower than that of other common chronic diseases (Mizukami et al., 2023).

The HROQL score of this study was 85.41± 26.50 ($p < .001$) ,while previous study found that the average HRQOL score of Chinese SLE patients was 55.8 ± 19.4 ($p < .001$) (Carter et al., 2016), which indicated that the participants in our study had a higher HRQOL. According to the revised version of Wilson and Cleary's model (Ferrans et al., 2005), characteristics of the individual is directly related to overall quality of life. Age as the characteristic of the individual could affect HRQOL (Jolly et al., 2019). In this study, more than half of the participants were in middle age (M= 38.83), 58.7% were between 30-49 years old. The physical fitness and psychological state of patients at this age is relatively stable, they could perform any activities of daily living by themselves, therefore, they perceived relatively high HRQOL. Furthermore, most of the participants were female (94.6%), and 75% were married which may related to their perception of good HRQOL. Results from previous study showed that the quality of life of married female patients was higher than that of males (Jolly et al., 2019). Female patients are better at housework and better able to take care of themselves. Moreover, married patients receive more family support, and a higher level of family support is beneficial for improving their quality of life. SLE patients who are married or have a life partner not only receive care from their parents and relatives, but also have intimate companionship from their spouse, the companionship of family members facilitates better detection of the patient's psychological and emotional changes and physical and mental needs, helps alleviate psychological stress, and can also share the economic pressure during treatment.

Working status can influence HRQOL as well, research showed that people with less economic pressure tend to have a better quality of life (Li et al., 2022). In this study, 44.6% were employed, even though 46.7 % of the participants were unemployed, but 72.8% of participants used social insurance payments, indicating that most participants had a relatively light economic burden which may have less psychological pressure. According to the revised version of Wilson and Cleary's model, characteristics of the environment are directly related to overall quality of life. In this study, social insurance was one of characteristics of the environment, therefore, patients with social insurance may perceive higher quality of life than those who paid the fees by themselves. Also previous studies found that the

category of payment fees was one of the main factors affecting the quality of life of SLE patients (Sommers & Oellerich, 2013).

Education level may be another reason for a better score of HRQOL reported by participants in the current study. In this study, only 12% of the participants had an education level of less than primary school. Patients with high education level were good at using the social resources around them, they could obtain more information and had a better understanding of SLE-related knowledge. Therefore, they could take better care of themselves resulted in better control of SLE conditions or symptoms; thus, they perceived better quality of life level.

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

Findings from the current study showed that self-care and social support was positively correlated with lupus quality of life ($r = .370$, $p < .01$; $r = .407$, $p < .01$, respectively), depression and SLE symptoms was negatively correlated with lupus quality of life ($r = -.466$, $p < .01$; $r = -.436$, $p < .01$, respectively). The findings were consistent with the study hypotheses.

This study was guided by the revised Wilson and Cleary model (Ferrans et al., 2005). The model hypothesizes that the overall quality of life is directly related to general health perceptions and characteristics of the individual and environment. Functional status indirectly affects overall quality of life through general health perceptions. Similarly, symptom status also affects overall quality of life indirectly through both functional status and general health perceptions. Symptom status is influenced directly by biological and physiological factors. From here, those factors also affect overall quality of life. Finally, general health perceptions, functional status, symptom status and biological and physiological factors are affected by characteristics of the individual and environment. Therefore, these characteristics have both direct and indirect (through symptom status, functional status and general health perceptions) effects on overall quality of life (Wilson & Cleary, 1995). According to the current study, the hypotheses were to examine the relationships between HRQOL in patients with SLE and selected variables including symptoms (represented the symptom domain), self-care (represented the functional status domain), depression (belong to the symptom domain), social support (represented the characteristics of environment). The results can be discussed as follows.

SLE Symptom

In this study, SLE symptoms was negatively correlated with lupus quality of life ($r = -.436$, $p < .01$), it showed that the higher score of SLE symptoms in SLE patients, the lower their quality of life. According to the revised Wilson and Cleary model (Ferrans et al., 2005), the model hypothesizes that the overall quality of life is directly related to characteristics of the individual, in this study, SLE symptoms belongs to concept of characteristic of individual and it can affect patients' quality of life, it showed the overall mean score of SLE symptoms was 28.84 (SD=16.26), it means that the lower the score on the SLE symptom, the higher the HRQOL score reported by participants. In a survey of SLE patients, this study's result was consistent with a previous study conducted by Yan et al. (2012), it was found that the more symptoms a patient had the higher the symptom score, the greater the impact on the patient's life and the worse their quality of life. Some of the common symptoms include fatigue (66. 2%), disturbed memory (64. 9%), chubby face/cheeks (59. 5%), and hair loss (56. 8%). According to the previous report, fatigue is a common symptom, 90% of female SLE patients reported fatigue (Fonseca et al., 2014). Fatigue is a major factor influencing HRQOL in SLE patients, patients with higher levels of fatigue who had a lower HRQOL (Jiang et al., 2018). The patient's susceptibility to fatigue is one of the common symptoms in SLE, fatigue usually occurs before other symptoms of lupus, and it is a persistent problem that often affects the patient's activities of daily living functions and work. In addition to fatigue, patients may experience clinical manifestations such as facial erythema, hyperpigmentation, photosensitive alopecia, skin ulcers and fibromyalgia. Patients may experience weight gain and acne when using corticosteroids, as well as diarrhea, hair loss, fatigue, and changes in appearance when using immunosuppressant (Jolly et al., 2012).

Depression

In this study, depression was negatively correlated with lupus quality of life ($r = -.436$, $p < .01$), it indicated that participants' level of depression and quality of life are correlated, it means that the lower the score on the depression scale, the higher the patient's quality of life. Based on theory, it defined symptoms as a patient's perception of an abnormal physical, emotional, or cognitive state, which can be categorized as physical, psychological, or psychophysical, and symptom status also affects overall

quality of life indirectly (Wilson & Cleary, 1995). In this study, depression belongs to concept of symptoms, so depression can affect overall quality of life indirectly. Study showed the mean total score of depression of participants was mild (M=7.51, SD=6.30). The finding in this study was consistent with previous research. Findings from other study had showed that female SLE patients with lower level of depression, they had higher quality of life (Palagini et al., 2013). Study showed the occurrence of negative emotions are all risk factors for female patients with SLE with low quality of life, at the same time, negative emotions are intermediary factors of low quality of life (Figueiredo-Braga et al., 2018), it showed that the prevalence of negative emotions was higher in women than in men, and that negative emotions, such as depression and anxiety, have an undeniable and invisible impact on the quality of life of SLE patients (Lane et al., 1998)..

Self-Care

In this study, self-care was positively correlated with lupus quality of life ($r = .370$, $p < .01$). According to the revised Wilson and Cleary model (Ferrans et al., 2005), it defined functional status broadly, as the ability to perform tasks in multiple domains such as physical function, social function, role function, and psychological function. In this study, self-care belongs to concept of functional status; it affects quality of life through concept of general health perceptions. The result of this study, the mean total score of self-care was high (M=118.96, SD=24.72). Previous study showed the self-care of SLE patients was at moderate level (103.65 ± 15.64). The participants in this study hade a certain cultural level, only 12% of the participants had a level of education less than primary; the widespread dissemination of information has increased and enriched the avenues for patients to learn about SLE, making it easier to improve their health knowledge and self-care. Previous studies showed that improved the level of self-care in SLE patients could significantly enhance their quality of life (Cao et al., 2023).

Social support

In this study, social support was positively correlated with lupus quality of life ($r = .407$, $p < .01$), it showed that the higher the level of social support in SLE patients, the higher their quality of life, the result was similar to previous study (Li et al., 2022). According to the revised Wilson and Cleary model (Ferrans et al., 2005),

characteristics of the environment have significantly influenced by an individual's cultural heritage, which can affect participation in preventive care as well as treatment. Social environmental characteristics are the interpersonal or social influences on health outcomes, including the influence of family, friends, and healthcare providers. The overall quality of life is directly related to characteristics of the environment (Ferrans et al., 2005). In this study, social support belongs to the concept of characteristics of the environment. This study showed the mean total score of social support was high (M=64.54, SD=13.60),the result was similar to previous study (65.44±12.22) (Min, 2022). In a previous study, it was found that the social support level of SLE patients was closely related to health-related quality of life, and related factors such as age, marital status, and occupational status, SLE patients under 18 years old, without spouse, and without occupation had lower social support levels and lower quality of life scores (Xu et al., 2019). In this study, 75% of the participants were married, while nearly half (44.6%) of the participants were employed. Family is the main source of social support, and spouse taking care of the patient's daily life and accompanying them for medical treatment is the most effective way for patients to obtain psychological and emotional support. Good 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 and treatment effectiveness with high levels of social support. Therefore, social support for SLE patients is an important link in improving their quality of life (Mazzoni & Cicognani, 2016).

Implications

These findings would enable nurses and caregivers to have better understand the disease and related factors among persons with SLE, particularly in Wenzhou, China. The results of this study showed that the health-related quality of life among SLE persons in Wenzhou, China was not too high. Participants reported lower scores of Lupus quality of life on the dimension of physical health, fatigue, and burden on others. Clinical nurses and caregivers should pay more attention to these aspects by helping them control symptoms and SLE condition to improve their physical function.

This study indicated that the SLE symptoms, depression, self-care, and social support had a significant correlation with health-related quality of life, and

previous studies indicated that psychological intervention can effectively improve the health-related quality of life. Therefore, clinical symptom management should be accompanied by psychological interventions for SLE patients.

In addition, it is crucial for clinical nurses to communicate and educate their patients cultivating a healthy lifestyle through self-care is essential for women to help them Improve of HRQOL.

Future Research

This study selected four factors, including depression, self-care, social support, and SLE symptoms, to investigate their correlation with HRQOL. However, literature has found that there are still many factors that may be related to SLE HRQOL, which need to be further studied. The participants in this study were limited to one location, future study could design more sites to generalize the results.

There are many choices of assessment scales for measuring SLE HROQL, and future research should choose different scales based on different populations and characteristics. The result of LupusQoL scale in this study indicated that fatigue and burden on others were the worst domains of HRQOL, therefore, future research can focus on these dimensions and explore how nursing interventions can improve the HRQOL of SLE patients in these domains.

In addition, the article finds that the incidence rate of SLE patients was younger, the number of young people with SLE is gradually increasing, so it is very necessary to conduct research in the youth or children with SLE population in the future.

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APPENDICES

APPENDIX A

Questionnaires in English and Chinese

Part 1: The Demographic Questionnaire

Direction: Please read questions in part 1 carefully and give an honest answer. Answers to question part 2 will be collected from the medical record by the researcher. Please write "√" in the box of your answer or write your information in the space provided.

General information (To be completed by the participant)

1. Age:
2. Height: _____cm Weight: _____kg
3. Gender

   ☐ Male ☐ Female
4. Highest level of education

   ☐ Less than primary ☐ Primary school ☐ Secondary school

   ☐ Graduate and up
5. Marital Status

   ☐ Single ☐ Married ☐ Divorced ☐ Widowed
6. Work status

   ☐ In-service ☐ Retired ☐ Jobless
7. Payment Method:

   ☐ Social insurance ☐ other, ____please specify
8. When were you first diagnosed with SLE: ____month
9. Comorbidity:

   ☐ DM (Diabetes) ☐ HT (Hypertension)

   ☐ DLP (disease of lupus anemia) ☐ Arthritis

   ☐ Chronic Kidney Disease ☐ Others……..
10. In the last three months have you admitted into the hospital

    ☐ No ☐ Yes Diagnosis……

Part 2: The Patient Health Questionnaire (PHQ-9)

Note: This questionnaire is an important part of providing you with the best health care possible. Your answers will help in understanding problems that you may have. Over the last 2 weeks, how often have you been bothered by any of the following problems? When answering each question, please choose the answer that best describes your idea. Please tick "√" in the corresponding space.

(0 = not at all; 1 = Several days; 2 = More than half the day; 3 = Nearly every day)

	Not at all(0)	Several days(1)	More than half the days(2)	Nearly everyday (3)
1. Little interest or pleasure in doing things.				
2.Feeling down, depressed, or hopeless				
3……..				
4……..				
5……..				
9. Thoughts that you would be better off dead or of hurting yourself in some way.				

Part 3: The Perceived Social Support Scale (PSSS)

Direction: Please read each statement carefully and indicate how you feel about each statement.

Circle the

1 if you Very Strongly Disagree

2 if you Strongly Disagree

3 if you Mildly Disagree

4 if you are Neutral

5 if you Mildly Agree

6 if you Strongly Agree

7 if you Very Strongly Agree

	Very strongly disagree	Strongly disagree	Mildly disagree	Neutral	Mildly agree	Strongly agree	Very strongly agree
1. There is a special person who is around when I am in need.	1	2	3	4	5	6	7
2. There is a special person with whom I can share joys and sorrows	1	2	3	4	5	6	7
3. My family really tries to help me.	1	2	3	4	5	6	7
4…….	1	2	3	4	5	6	7
5……	1	2	3	4	5	6	7
6……	1	2	3	4	5	6	7
12. I can talk about my problems with my friends.	1	2	3	4	5	6	7

Part 4: The Lupus Quality of Life

Direction: Please read each statement, then check the one closest to your feelings and answer all questions truthfully.

(0 = "All of the time ", 1 = "Most of the time", 2 = "A good bit of the time ", 3 = "Occasionally" and 4 = "Never")

Frequency of the following events in the past 4 weeks	
1.Because of my lupus, I need help doing heavy physical work, such as digging soil in the courtyard, painting or decorating, and moving furniture	□0 All of the time □1 Most of the time □2 A good bit of the time □3 Occasionally □4 Never
2.Because of my lupus, I need help doing moderate physical work, such as vacuuming, ironing, shopping, cleaning the bathroom	□0 All of the time □1 Most of the time □2 A good bit of the time □3 Occasionally □4 Never
3……..	□0 All of the time □1 Most of the time □2 A good bit of the time □3 Occasionally □4 Never
4……..	□0 All of the time □1 Most of the time □2 A good bit of the time □3 Occasionally □4 Never
34. Because of my lupus, I often feel tired in the morning	□0 All of the time □1 Most of the time □2 A good bit of the time □3 Occasionally □4 Never
Please check that you have answered each question. Thank you for completing this questionnaire!	

Part 5: The Exercise of Self-Care Agency (ESCA)

Direction: Please read each statement, then check the one closest to your feelings and answer all questions truthfully.

Contents	Very Like Me	Generally Like Me	Moderately Like Me	Slightly Like Me	Not At All Like Me
1. I would gladly give up some of my usual ways of doing things if it meant improving my health.					
2. I like myself.					
3. I often feel that I lack the energy to care for my health needs the way I would like to.					
……..					
…….					
…….					
…….					
……..					
…….					
…….					
…….					
……..					
…….					
42. I remember when I had my last health check and return on time for my next one.					
43. I understand myself and my needs pretty well.					

Part 6: The SLE Symptom Checklist (SSC)

Direction: Please read each statement carefully, check the symptoms **one month ago**, check "no" if there are no symptoms, and tick "how burdensome " if there are symptoms. 0 = "no", 1 = "yes, but not burdensome", 2 = "yes, a little burdensome", 3 = "yes, quite burdensome" and 4 = "yes, very burdensome". Then check the item closest to your feelings and answer all the questions truthfully. Please tick "√" in the corresponding space.

	NO(0)	YES(1)	If yes, how burdensome			
			Not (1)	A little (2)	Quite (3)	Extremely (4)
Did you, in the past month, have …						
Painful joints						
Painful muscles						
Headache						
Fatigue						
Ulcers in mouth or throat						
Hair loss						
Skin rash						
……						
……						
……						
……						
……						
Loss of concentration						
Muscle cramps						
Vulnerable skin						
Disturbed memory						
Weight gain						

第一部分：人口调查问卷

说明：请仔细阅读第一部分的问题并给出诚实的答案。请在答案框中打“√”，或在提供的空白处填写您的信息.

一般信息（由参与者填写）

1. 年龄:

2. 身高: ____cm　　体重: ____kg

3. 性别

☐ 女性　　☐ 男性

4. 最高教育水平

☐小学以下 ☐ 小学 ☐ 中学 ☐ 大学及以上

5. 婚姻状况

☐ 单身 ☐ 已婚 ☐离婚 ☐丧偶的

6. 工作状况

☐就业 ☐退休 ☐无业

7. 支付方式:

☐社会保险 ☐其他，____需要说明

8. 你第一次被诊断为系统性红斑狼疮是什么时候:

9. 并发症:

☐ 糖尿病

☐ 高血压

☐ 贫血

☐ 关节炎

☐ 慢性肾病

☐ 其他……..

10. 最近三个月内你是否有住过院？

☐ 无　　☐ 有　诊断……

第二部分：患者健康调查表

注：本问卷是为您提供最佳医疗保健的重要组成部分.你的回答将有助于理解你可能遇到的问题.在过去的两周里，你多久会被以下问题困扰一次？在回答每个问题时，请选择最能描述您想法的答案.请在相应空格内打“√”.

（0=完全没有；1=几天；2=半天以上；3=几乎每天）

	完全不会	好几天	超过一周	几乎每天
1. 做事时提不起劲或没有兴趣		1		
2. 感到心情低落、沮丧或绝望		1		
3……..		1		
4……..		1		
5……..		1		
9：有不如死掉或用某种方式伤害自己的念头		1		

第三部分：中文版领悟社会支持量表

说明：请仔细阅读每一句话，并说明你对每一句话的感受.

选择

“1”表明你极不同意

“2”表明很不同意

“3”表明稍不同意

“4”表明中立

“5”表明稍同意

“6”表明很同意

“7”表明极同意

	极不同意	很不同意	稍不同意	中立	稍同意	很同意	极同意
1.在我遇到问题时有些人会出现在我身旁	1	2	3	4	5	6	7
2.我能够与有些人共享快乐与忧伤	1	2	3	4	5	6	7
3.我的家庭能够切实具体地给我帮助	1	2	3	4	5	6	7
4……	1	2	3	4	5	6	7
5……	1	2	3	4	5	6	7
6……	1	2	3	4	5	6	7
12.我能与朋友们讨论自己的难题	1	2	3	4	5	6	7

第四部分：狼疮生活质量

下列问题的设计目的是了解系统性红斑狼疮对您的生活有什么影响。请阅读每项陈述，然后勾选最接近您感受的选项。请尽可能如实回答所有问题。（0=“总是”，1=“大部分时间”，2=“很多时间”，3=“偶尔”，4=“从不”）

下列情况在过去4周发生的频率	
1.由于我的狼疮，我做体力活需要帮助，例如在庭院挖泥土、油漆和/或装饰、移动家具	☐0所有时间 ☐1大多数时间 ☐2很多时间 ☐3偶尔 ☐4从来没有
2.由于我的狼疮病，我做中等体力活需要帮忙，比如吸尘、烫衣服、购物、清理浴室和厨房	☐0所有时间 ☐1大多数时间 ☐2很多时间 ☐3偶尔 ☐4从来没有
3……	☐0所有时间 ☐1大多数时间 ☐2很多时间 ☐3偶尔 ☐4从来没有
4……	☐0所有时间 ☐1大多数时间 ☐2很多时间 ☐3偶尔 ☐4从来没有
34.由于我的狼疮，我经常在早上觉得疲惫不堪	☐0所有时间 ☐1大多数时间 ☐2很多时间 ☐3偶尔 ☐4从来没有
请检查确定您回答了每个问题，谢谢您完成本调查问卷	

第五部分：自我护理能力测定量表

说明：请仔细阅读每一句话，然后选择最接近你感受的一项，如实回答所有问题.

内容	非常像我	一些像我	没有意见	一些不像我	非常不像我
1.假如能改善我的健康，我愿意放弃一些固有的生活习惯					
2.我喜欢我自己					
3.我时常感到无法按照自己想要的方式来照顾自己					
……					
……					
……					
……					
……					
……					
……					
……					
……					
……					
42.我记得我最近一次健康检查的时间，下一次也会去做检查.					
43.我了解我自己和自己的需要.					

第六部分：系统性红斑狼疮症状特异性量表

指导：请仔细阅读每一个选项，检查一个月以来的症状，无症状勾选“否”，如有症状，请勾选影响程度。表中的0=“没有症状”,1=“有症状，基本无影响”，2=“有症状，有一点影响”，3=“有症状，严重影响”和4=“有症状，非常严重影响”。然后检查最接近你的感受的项目，并如实回答所有问题。请在相应空格内打“√”。

	没有(0)	有(1)	如果有，累赘的程度			
			基本无(1)	有一点(2)	严重(3)	非常严重(4)
在这之前的1个月，你出现的有						
关节痛						
肌肉痛						
头痛						
疲劳						
口咽溃疡						
脱发						
……						
……						
……						
……						
……						
注意力不集中						
肌肉痉挛						
皮肤容易受伤						
记忆力减退						
体重增加						

APPENDIX B

Invitation letters

MHESI 8137/ 518

Graduate School, Burapha University
169 Longhaad Bansaen Rd.
Saensuk, Muang, Chonburi
Thailand, 20131

April 1st, 2021

Dear Wenzheng Wang

On behalf of the Graduate School, Burapha University, I would like to request permission for Ms. YANG ZHU to use a research instrument for conducting research.

Ms. YANG ZHU ID 62910081, a graduate student of the master of Nursing Science Program (International Program), Major in Adult Nursing Pathway, Faculty of Nursing, Thailand, was approved her thesis proposal entitled: "Factors Related to Health-related Quality of Life Among Adults with Systemic Lupus Erythematosus in Wenzhou, China" under supervision of Assoc. Prof. Dr. Pornpat Hengudomsub as the principle advisor. She proposes to use a research instrument that is "Patient Health Questionnaire" from an article with entitled: "Reliability and Validity of the Chinese Version of the Patient Health Questionnaire (PHQ-9) in the General Population" by Wang, W., et al., published in *General Hospital Psychiatry*, 36(5), 539-544, 2014.

In this regard, you can contact Ms. YANG ZHU via mobile phone +86-1825-7765-201 or E-mail: 527228184@qq.com

Please do not hesitate to contact me if you need further relevant queries.

Sincerely yours,

(Assoc. Prof. Dr. Nujjaree Chaimongkol)
Dean of Graduate School, Burapha University

Graduate School Office
Tel: +66 3810 2700 ext. 701, 705, 707
E-mail: grd.buu@go.buu.ac.th
http://grd.buu.ac.th

APPENDIX C

Participant information sheet and consent form

PARTICIPANT'S IMFORMATION SHEET

Dear_____

I am Mrs Yang Zhu, a postgraduate student at Faculty of Nursing, Burapha University Thailand. My study is "Factors Related to Health-Related Quality of Life among persons with Systemic Lupus Erythematosus in Wenzhou, China". The objectives are to describe health-related quality of life among patients with systemic lupus erythematosus in Wenzhou and to investigate association between symptoms, depression, social support and self-care with health-related quality of life among patients with systemic lupus erythematosus in Wenzhou, China.

This study will be a survey study. Participating in this study is voluntary. If you agree to participate in this study, you will answer the following questionnaires, which will take approximately 30-40 minutes. During the data collection, period, the researcher will clarify any question posed by the participants for clarity regarding the language or content. You will not get any direct benefits by participating in this study. One of the questionnaires in this study is depression, if you report

Having seriously depressed, the researcher would help you to visit the physician. However, the information collected from this study can further identify factors that are related to health-related quality of life of SLE patients, and help nurses and other primary care providers develop more scientific and targeted interventions for systemic lupus erythematosus patients, so as to improve the quality of life of patients. The information will also help health care providers, especially nurses, to further study this population and conduct future intervention studies with this population. There will be no identified physical and psychological risk to the person participating in the study and no risk to the society.

You have the right to end your participation in this study at any time, and no necessary to inform the researcher, and it will not affect the quality of services you receive from the rheumatology outpatient department. Any information collected from this study, including your identity, will be kept confidential. A coding number will be assigned to you and your name will not be used. Findings from the study will be presented as a group of participants and no specific information from any individual participant will be disclosed. All data will be accessible only to the researcher which

will be destroyed one year after publishing the findings. You will receive a further explanation of the nature of the study upon its completion, if you wish.

The research will be conducted by Mrs Yang Zhu under supervision of my major-advisor, Assoc. Prof. Dr. Pornpat Hengudomsub. If you have any questions, please contact me at mobile number: + 8618257765201 or by email 527228184 @qq.com, and/or my advisor's e-mail address pornpath@buu.ac.th. Or you may contact Burapha University Institutional Review Board (BUU-IRB) telephone number 038 102 561-62. Your cooperation is greatly appreciated. You will be given a copy of this consent form to keep.

Yang Zhu

เอกสารแสดงความยินยอม

ของผู้เข้าร่วมโครงการวิจัย (Consent Form)

รหัสโครงการวิจัย : .....

(สำนักงานคณะกรรมการพิจารณาจริยธรรมในมนุษย์ มหาวิทยาลัยบูรพา เป็นผู้ออกรหัสโครงการวิจัย) โครงการวิจัยเรื่อง .....Factors Related to Health-Related Quality of Life Among Adults with Systemic Lupus Erythematosus in Wenzhou, China..... ให้คำยินยอม วันที่ ..... เดือน ..... พ.ศ. .....

Before giving my signature below, I have been informed by researcher about purposes, method, procedures, benefits and possible risk associated with participation in this study thoroughly, and I understood all of the explanation. I consent voluntarily to participate in this study. I understand that I have the right to leave the study any time I want, without fearing that it might affect the quality of health care services that I will receive from the hospital and rheumatology OPD hereafter.

The researcher has explained to me that all data and information of the participants will be kept confidential and only be used for the purpose of this study. I have read and understood the information related to participation in this study clearly and I am signing this consent form.

Signature .....

(.....)

Participant

APPENDIX D

Ethical approval letter and data collection letter

温州医科大学附属第一医院临床研究伦理委员会审查批件

（Review of Ethics Committee in Clinical Research (ECCR) of the First Affiliated Hospital of Wenzhou Medical University）

临床研究伦审 Issuing Number（2021）第（091）号

项目名称 Project	中国温州地区系统性红斑狼疮患者健康相关生活质量水平及影响因素分析 FACTORS RELATED TO HEALTH-RELATED QUALITY OF LIFE AMONG ADULTS WITH SYSTEMIC LUPUS ERYTHEMATOSUS IN WENZHOU, CHINA		
申办者 Applicant	温州医科大学附属第一医院	试验目的 Objective	临床科研 Clinical research
试验科室 Department	风湿免疫科		
试验项目负责人 Principal Investigator	朱鸾		
审查方式和时间 Form and Date	□ 会议审查 Review Conference，时间：_____ ☑ 快速审查 Fast track，时间：2021 年 05 月 24 日		
审查地点 Review Site	新院 1-4A18 会议室		
审查材料 Documents for Review	1、医学临床科研项目及伦理审查申请表，v1.0 版； 2、临床研究方案，v1.0 版，2021.04.30； 3、受试者知情同意书，v1.0 版，2021.04.30； 4、研究者团队成员目录（职责）； 5、主要研究者、团队成员简历及 GCP 证书，v1.0 版； 6、研究者责任声明； 7、CRF/临床观察表样板，v1.0 版。		
审查意见 Comments	根据国家卫健委《涉及人的生物医学研究伦理审查办法》(2016)，WMA《赫尔辛基宣言》和 CIOMS《人体生物医学研究国际道德指南》的伦理原则，经本伦理委员会审查，同意该项目开展。 According to the Regulations and Rules of "Ethical Reviews for Biomedical Research Involving Human Subjects" (2016) the National Health Commission of PRC , "Declaration of Helsinki" of WMA, and "International Ethical Guidelines for Human Biomedical Research" of CIOMS , the project was **approved** by **ECCR** .		
主任委员/副主任委员签字 Signature of the **ECCR** Chair		签发日期 Date	2021 年 05 月 25 日
温州医科大学附属第一医院临床研究伦理委员会（盖章） Ethics Committee in Clinical Research of the First Affiliated Hospital of Wenzhou Medical University (Seal)			

所注（Note）：

1. 临床研究应在批准之日起1年内实施，逾期未实施，本批件自行废止。临床研究过程中将接受伦理委员会的跟踪审查，审查频度为自批准之日起每12个月一次。（伦理委员会有权根据临床试验实际实施情况变更跟踪审查频度）
   The clinical study shall be implemented within 1 year from the date of approval. If overdue, the approval for this project shall be revoked. During the implementation of clinical research, tracking review will be conducted by **ECCR** every 12 months from the effective date of the initial approval (the ethics committee has the right to change the frequency of tracking review according to the actual implementation of clinical trials)
2. 请严格遵从已批准的研究方案，如果方案修改需以书面形式报告伦理委员会，经伦理委员会批准后方可执行。
   Please strictly follow the approved research protocol. Any revisions of the protocol must be reported to **ECCR** in written form. It can be conducted only after the modification was approved by **ECCR**.
3. 发生严重不良事件以及影响研究风险受益比的非预期不良事件，须在24小时内报告本伦理委员会。
   Serious adverse events and unanticipated adverse events that affect the risk-to-benefit ratio of the project must be reported to **ECCR** within 24 hours.
4. 暂停、方案违背或提前终止临床研究，请及时上报本伦理委员会。
   Any suspension, project violation or early termination of the clinical research, should be reported to **ECCR** promptly.
5. 完成临床研究，须提交研究完成报告给本伦理委员会。
   Please submit a completion research report to **ECCR** after completion of the project.

สำเนา

ที่ IRB3-068/2564

เอกสารรับรองผลการพิจารณาจริยธรรมการวิจัยในมนุษย์

มหาวิทยาลัยบูรพา

คณะกรรมการพิจารณาจริยธรรมการวิจัยในมนุษย์ มหาวิทยาลัยบูรพา ได้พิจารณาโครงการวิจัย

รหัสโครงการวิจัย : G-HS024/2564

โครงการวิจัยเรื่อง : Factors Related to Health-Related Quality of Life Among Adults with Systemic Lupus Erythematosus in Wenzhou, China

หัวหน้าโครงการวิจัย : MRS.YANG ZHU

หน่วยงานที่สังกัด : คณะพยาบาลศาสตร์

BUU Ethics Committee for Human Research has considered the following research protocol according to the ethical principles of human research in which the researchers respect human's right and honor, do not violate right and safety, and do no harms to the research participants.

Therefore, the research protocol is approved (See attached)

1. Form of Human Research Protocol Submission Version 2 : 4 June 2021
2. Research Protocol Version 2 : 4 June 2021
3. Participant Information Sheet Version 2 : 4 June 2021
4. Informed Consent Form Version 2 : 4 June 2021
5. Research Instruments Version 1 : 24 May 2021
6. Others (if any) Version - : -

วันที่รับรอง : วันที่ ๑๒ เดือน มิถุนายน พ.ศ. ๒๕๖๔

วันที่หมดอายุ : วันที่ ๑๒ เดือน มิถุนายน พ.ศ. ๒๕๖๕

ลงนาม นางสาววรมร แย้มประทุม

(นางสาววรมร แย้มประทุม)

ประธานคณะกรรมการพิจารณาจริยธรรมการวิจัยในมนุษย์ มหาวิทยาลัยบูรพา

ชุดที่ ๓ (กลุ่มคลินิก/ วิทยาศาสตร์สุขภาพ/ วิทยาศาสตร์และเทคโนโลยี)

MHESI 8137/ 1930

Graduate School, Burapha University
169 Longhaad Bangsaen Rd.
Saensuk, Muang, Chonburi
Thailand, 20131

July 30th, 2021

Dear President of The First Affiliated Hospital of Wenzhou Medical University

Enclosure: 1. Certificate ethics document of Burapha University
2. Research Instruments (Try Out)

On behalf of the Graduate School, Burapha University, I would like to request permission for Mrs. YANG ZHU to collect data for testing the reliability of the instruments.

Mrs. YANG ZHU ID 62910081, a graduate student of the Master of Nursing Science Program (International Program), Major in Adults Nursing Pathway, Faculty of Nursing, Thailand, was approved her thesis proposal entitled: "Factors Related to Health-Related Quality of Life Among Adults with Systemic Lupus Erythematosus in Wenzhou, China" under supervision of Assoc. Prof. Dr. Pornpat Hengudomsub as the principle advisor. She proposes to collect data from 30 adult patients with systemic lupus erythematosus in Outpatient Department of Rheumatology and Immunology, The First Affiliated Hospital of Wenzhou Medical University.

The data collection will be carried out from July 26th, 2021 - August 10th, 2021. In this regard, you can contact Mrs. YANG ZHU via mobile phone +86-1825-7765-201 or E-mail: 527228184@qq.com

Please do not hesitate to contact me if you need further relevant queries.

Sincerely yours,

Sorut Wong

(Assist. Prof. Dr. Sorut Wongsuttitham)
Associate Dean of Graduate School, Burapha University
Acting of Dean of Graduate School, Burapha University

Graduate School Office
Tel: +66 3810 2700 ext. 701, 705, 707
E-mail: grd.buu@go.buu.ac.th
http://grd.buu.ac.th

MHESI 8137/1362

Graduate School, Burapha University
169 Longhaad Bangsaen Rd.
Saensuk, Muang, Chonburi
Thailand, 20131

July 13th, 2023

To The director of the First Affiliated Hospital of Wenzhou Medical University,

Enclosure: 1. Certificate ethics document of Burapha University
2. Research Instruments

On behalf of the Graduate School, Burapha University, I would like to request permission for Mrs. Yang Zhu to collect data for conducting research.

Mrs. Yang Zhu, ID 62910081, a graduate student of the Master of Nursing Science Program (International Program) in Adult Nursing Pathway, Faculty of Nursing, Burapha University, Thailand, was approved her thesis proposal entitled: "Factors Related to Health-related Quality of Life Among Adults with Systemic Lupus Erythematosus in Wenzhou, China" under supervision of Assist. Prof. Dr. Khemaradee Masingboon as the principle advisor. She proposes to collect data from 92 adult patients with systemic lupus erythematosus in Outpatient Department of Rheumatology and Immunology of the First Affiliated Hospital of Wenzhou Medical University. The data collection will be carried out from July 15 - December 30, 2023. In this regard, you can contact Mrs. Yang Zhu via mobile phone +86-1825-7765-201 or E-mail: 527228184@qq.com

Please do not hesitate to contact me if you need further relevant queries.

Sincerely yours,

มัณฑนา รังสิโยภาส

(Assistant Professor Dr. Montana Rungsiyopas)
Vice-Dean for Academic Affairs
Acting of Dean of Graduate School, Burapha University

Graduate School Office
Tel: +66 3810 2700 ext. 701, 705, 707
E-mail: grd.buu@go.buu.ac.th
http://grd.buu.ac.th

BIOGRAPHY

NAME	Yang Zhu
DATE OF BIRTH	13 April 1992
PLACE OF BIRTH	Wenzhou
PRESENT ADDRESS	11-901, North District, Guobinyihao Community, Ouhai District, Wenzhou, Zhejiang, China
POSITION HELD	Registered Nurse
EDUCATION	2014-2016 Bachelor of Nursing (B.S.N), Wenzhou Medical University, Wenzhou, China. 2019-2021 Master of Nursing Science (International Program)(M.N.S), Faculty of Nursing, Burapha University, Chonburi, Thailand.