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紅斑性狼瘡患者的生活品質預測模式 – 運用路徑分析

The Predictive Model of Quality of Life for Systemic Lupus Erythematosus – A Path Analysis

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本論文係吳昭儀（R01429004）於國立臺灣大學職能治療學系所完成之碩士學位論文，於民國 104 年 1 月 27 日經下列考試委員審查通過及口試及格，特此證明。

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中文摘要

研究背景與目的: 紅斑性狼瘡為病因不明之慢性免疫系統疾病，過去 40 年來，隨著醫藥之進步，死亡率逐漸下降。然而，紅斑性狼瘡患者受到疾病影響，除了生理健康的不適外，也造成心理健康的改變。生活品質為一個人對生活滿意度的詮釋。疾病症狀如疲勞、疼痛、憂鬱，以及焦慮，最常被提及為影響紅斑性狼瘡患者生活品質之預測因子。許多學者嘗試建構症狀與生活品質相關之機制，然而先前研究結果並沒有清楚的架構出生活品質模式，因此本篇研究的目的為利用路徑分析驗證生理健康、心理健康、社會關係，以及環境生活品質模式。**研究方法:** 本研究 94 位個案來自台大醫院內科門診。個案符合以下收案標準: (1) 符合 1982 年美國風濕醫學會診斷標準；(2) 年齡 20 歲以上；(3) 教育程度小學五年級以上；(4) 簡短版認知功能分數高於等於 24 分；(5)正參與風濕免疫科門診追蹤治療。個案由醫師評估疾病活性量表(SLEDAI-2000)，再評估七個量表，分別為疲乏量表、疼痛量表、貝氏憂鬱量表(第二版)、貝氏焦慮量表、職能自我評估量表、自我掌控感量表，以及台灣簡明版世界衛生組織生活品質量表。此研究使用 SPSS 第 19 版以及 LISREL 第 8.51 版本軟體分析。**結果:** 本篇研究發現自我勝任感在四個生活品質層面皆為重要之預測因子，且疲勞、疼痛、憂鬱、焦慮藉由自我勝任感間接影響生活品質。在 4 個層面生活品質中可發現，疲勞、憂鬱、自我勝任感，以及環境衝擊分別為影響生理健康、心理健康、社會關係，以及環境生活品質重要因子。**結論:** 藉由此研究發現，臨床可對於影響生活品質最鉅之預測因子評估並針對症狀進行介入，改善患者生活品質並增進患者生活參與。

關鍵字: 職能治療、紅斑性狼瘡、生活品質、路徑分析

ABSTRACT

Background/Purpose: Systemic lupus erythematosus (SLE) is an autoimmune disease with unknown etiology. Within these 40 years, along with the progress of diagnosis, the mortality rate declined. However, the uncertainty of disease causes physical discomfort and mental health distress. Quality of life (QOL) describes how a person interprets its life satisfaction. Fatigue, pain, and depression symptoms are mentioned to be predictors of QOL in patients with SLE. Although many researchers want to find out the mechanism how symptoms lead to QOL. However, result is still unclear. Thus, the purpose of our study is to apply path analysis to verity our predictive QOL models. **Methods:** There were 94 participants in our study. Participants were recruited from an outpatient clinic of National Taiwan University Hospital and met the following criteria: (1) confirmed SLE diagnosis based on ACR; (2) aged above 20; (3) reached education level above 5th grade of elementary school; (4) reached a minimum score of 24 on MMSE; (5) stably followed up in clinics. Participant evaluated disease activity (SLEDAI-2000) by clinician. Patients evaluated fatigue (FACIT-F), pain (Pain-NRS), depression (BDI-II), anxiety (BAI), sense of competence (OSA-myself), environmental impact (OSA-environment), sense of mastery (Mastery scale), and QOL (WHOQOL-BREF-TW). We applied SPSS 19 and LISREL 8.51 to conduct data analysis. **Results:** The finding of study found sense of competence a critical predictor of QOL, and fatigue, pain, depression, and anxiety all indirectly influence QOL via sense of competence. Fatigue, depression, sense of competence, and environmental impact are the most influential predictors in physical health, psychological health, social relationships, and environmental domains of QOL. **Conclusion:** We hope by the confirmation of the predictive model of the study would provide directions for clinicians to derive strategies aiming at improvingQOL for patients with SLE.

Keywords: Occupational Therapy; SLE; quality of life; path analysis

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INTRODUCTION

The aim of the study is to propose a model to predictive the mechanism leading to lower QOL for patient with systemic lupus erythematosus (SLE). Systemic lupus erythematosus is an autoimmune disease with multifactorial etiology. Owing to the disturbances of the immune response, SLE may damage a variety of organs and systems, such as heart, joints, skin, lungs, blood vessels, liver, kidneys, and nervous system (Cervera et al., 2003). The course of disease is unpredictable and fluctuating. Currently, the most efficient way to control disease activity is through medication treatment, such as corticosteroids and immune-suppressants. However, there is no way to heal and recovery completely so far. From 1950 to early 2006, it had been found that the incidence rate of SLE has gradually increased within these decades (Danchenko, Satia, & Anthony, 2006). With the trend towards higher incidence and prevalence of SLE, how to cure and care them becomes a critical issue.

The definition of quality of life is a state of objective and subjective feelings, a broad range of life domains, and individual values (Felce & Perry, 1995). From the perspective of occupational therapy, engaging in valued and desired occupations helps to facilitate the well-being and health on people (Liddle & McKenna, 2000). Despite of the advanced medication and more understanding of this illness, a variety of symptoms still pose a threat on quality of life in patients with SLE. The relapsing disease activity makes it necessary to take medication everyday throughout their lives. Disease-related symptoms also interfere with patients' daily living. For example, they tend to feel tired and fatigue, to get pain symptoms from arthralgia and myalgia, and to have the depressed or anxiety mood. Low sense of competence and mastery finally makes them view their daily living as miserable lives (Sutanto et al., 2013). It is important for them to find out and learn strategies to get a

consistent source of support and information every day during their daily lives (Mazzoni & Cicognani, 2011).

Nowadays, many researchers look for solutions to deal with these disease-related symptoms. They find out the correlations between symptom-related variables in order to get more understanding of the complicated nature of SLE. Current researches didn't focus on the exact and explicit mechanism that leads to the result of lower quality of life or worse function. Such mechanisms are still unclear. Some studies only discussed the relationships among variables instead of how these variables influencing on QOL, and others didn't use quantitative methods to verify their models. For comprehensively and quantitatively investigating the mechanisms on how these factors lead to lower QOL, the study applies path analysis to verity a predictive model of QOL for SLE.

LITERATURE REVIEW

1. Systemic Lupus Erythematosus

1.1 Signs and symptoms

Systemic lupus erythematosus is a chronic autoimmune disease with a relapsing-remitting nature. The cause of disease is elusive. The common manifestations of the illness in the clinical are arthralgia, myalgia, photosensitivity, malar rush, and hematological abnormalities (Kulczycka, Sysa-Jedrzejowska, & Robak, 2010). Researches had shown most commonly seen comorbidity on them, such as depression, cardiovascular disease, renal diseases and so on (Robinson et al., 2010). People with SLE face different kinds of difficulties such as unpredictable illness, comorbidity, and emotional disturbance.

1.2 Etiology

Systemic lupus erythematosus (SLE) is an autoimmune disease of unknown etiology. Factors like genetic, hormonal milieu, environmental, and drug reactions are all considered to trigger the onset of SLE. Multifactorial interaction among various genetic and environmental factors is probably involved. Researchers have found out some specific antibodies on SLE patients, such as antinuclear antibodies were present in 78 percent of patients, and anti–double-stranded DNA antibodies in 55 percent of patients (Arbuckle et al., 2003). Environmental triggered may also be relevant, such as chemical or physical factors, dietary factors, infectious agents, hormones, and environmental oestrogens (Mok, 2003).

1.3 Diagnosis

Nowadays, the criteria of systemic lupus erythematosus is according to the American College of Rheumatology (ACR) revised criteria for the classification of SLE and patients should meet at least 4 of the 11 criterion to be diagnosed (Hochberg, 1997). The 11 criterion

are as follow: malar rash, discoid rash, photosensitivity, oral ulcers, non-erosive arthritis, pleuritis or pericarditis, renal disorder, neurologic disorder, hematologic disorder, immunologic disorder, and positive antinuclear antibody**.**

Nowadays, based on Peter H Schur et al., the reported prevalence rate of SLE is 0.02 to 0.15. The prevalence in Taiwan is 97.5 per 100,000 persons in a retrospective study (Lee et al., 2013). In women, prevalence rates vary from 0.164 (white) to 0.406 (African American) (Chakravarty, Bush, Manzi, Clarke, & Ward, 2007).

1.4 Global epidemiology

Due to the accuracy of diagnosis of the disease improved, 3 times of the incidence happened in the last 40 years of the 20th century. The incidence rates are 0.01 to 0.025 around the world (Danchenko et al., 2006; Pons-Estel, Alarcon, Scofield, Reinlib, & Cooper, 2010) and 4.87 per 100,000 person-years in Taiwan (Lee et al., 2013).

Through the advances in medical technology, the mortality rate has gradually declined (Urowitz, Gladman, Tom, Ibañez, & Farewell, 2008). In Taiwan, the survival rates of the occurrence within 5 years and 10 to 20 years were 93.4% and 89.6% (Lee et al., 2013). The average mortality rate was 1.2 per 100,000 population in Taiwan (Yeh, Yu, Chan, Horng, & Huang, 2013).

The disease is commonly seen on female than male, and the morbidity ratio on female and male is 9:1 in global (Gallop et al., 2012). In Taiwan, the sex ratio of SLE is little lower in 2013, 7.15:1, and the peak age is 40 to 49 years old (Lee et al., 2013).

1.5 The cost on SLE

Every patient with SLE receives nearly 12 times outpatient service and 0.4 inpatient treatment per year. Among inpatients, they spent about 9.6 days in the acute ward on

average in Taiwan (Chiu & Lai, 2010). The healthcare cost is high on patients with SLE. The national health insurance spends nearly US$ 14,156,301 and US$ 25,674,444 on medical costs for outpatient service and inpatient service and average cost was US$71.5 and US$1922.3 separately in Taiwan in 2007 (Chiu & Lai, 2010).

In a Swedish nationwide study, it stressed the relationship between total cost (direct and indirect cost) and quality of life on SLE. Direct cost represents the money spending on inpatient and outpatient services, and indirect cost was estimated by the loss of productivity such as the reduced working hours or the early retirement. It is reported that the reductions in disease activity were associated with substantial drops of healthcare resource utilization and costs (Kan et al., 2013). Surprisingly, not only disease activity but fatigue and corticosteroid doses had impacted on costs. Furthermore, fatigue was a statistically significant predictor for total costs, indirect costs, and direct costs. The existence of fatigue symptom increases the total cost on each patient comparing with non-fatigue group, €28,100 vs €12,637 ($p<0.0001$) (Bexelius, Wachtmeister, Skare, Jonsson, & Vollenhoven, 2013). A systematic review from 1990 to 2011 sorted out 14 cost-relevant literatures and concluded that the mean annual direct costs per patient was from US$2,214 to US$16,875, and mean annual indirect cost was from US$2,239 to US$35,540. Some studies also give us a notion that the poor mental and physical health are both predictors of increased costs (Meacock, Dale, & Harrison, 2013; Panopalis et al., 2008). Thus, monitoring and emphasizing on the mental and physical quality of life is the priority for multi-professions to manage and prevent on the expansion of cost on SLE.

2. Quality of Life

With the progress of the times, the most challenging thing is not the duration of life but promoting their quality of life (Fortin et al., 1998; Mok, 2011). It brings to a blend new

perspective toward this population's need and desire, not mainly focusing on their survival rate but their limitation on daily living and participation.

The definition of quality of life varies a lot and still has not reached a consensus. It can be attributed to the multi-conceptualized nature and the way authors approach quality of life differs from different perspectives (Leplege & Hunt, 1997). According to the World Health Organization, the definition of quality of life is "as individuals' perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns." Taxonomy is commonly used to define the complicating concept of quality of life. For instance, generic and disease specific quality of life is defined by whether the concept is targeted on a certain illness/disease or not. Objective and subjective quality of life are different because the former describes objective life conditions that apply to a population generally, and the latter, however, indicates one's subjective feelings and experiences. Health-related quality of life is defined as the sense of wellbeing toward physical, mental, and social condition while one person facing its disease and treatment (McElhone, Abbott, & Teh, 2006). Overall Assessment of wellbeing is so called health-related quality of life such as physical, emotional, functional and social wellbeing (Cella, 1994).

Occupational therapy is a profession focus on people's well-being and quality of life. From the perspective of occupational therapy, relationships have existed between occupation performance (function), health, and quality of life. Engaging in daily occupations is influential on one's well-being for occupation is the creator of an experience of mastery and control (Partridge et al., 1997). Having the capacity to participate in activities provides a sense of well-being. People can also gain and experience a sense of good quality of life if they can sense their life meaningful while engaging daily occupations (Pi, kur, Kinebanian, &

Josephsson, 2002). In fact, occupational therapists focus on the long-term health needs of people and help them develop healthy behaviors not only to improve their health, but also to minimize the health care costs associated with dysfunction.

In order to find out the predictors of QOL on SLE patients and establish the mechanism reduces QOL, a systematic review was thus conducted between November 2013 and February 2014 (Appendix A). Medline, CINAHL, and PsycInfo were the databases we used to identify articles and the Medical Search Headings (MeSH) we used were lupus erythematosus, systemic, quality of life, mental health, fatigue, pain, depression, and sleep. We based the search on the following strategy: (quality of life OR mental health OR fatigue OR depression OR pain OR sleep OR anxiety) AND systemic lupus erythematosus. The inclusion criteria were as follow: 1) involved human adult participants over 20 years with a diagnosis of SLE according to the 1982 American College of Rheumatology criteria; 2) articles within the last 5 years; 3) symptoms and QOL correlational research; 4) at least one QOL-related measurement are applied in the research. However, studies were excluded if: 1) establishment of questionnaires or tools; 2) psychometric properties of questionnaires or tools; 3) interventions; 4) book resources; 5) website information; 6) not available in English or; 7) not available in full text. Finally, 16 studies were included (Appendix B). Fatigue, pain severity, depression, anxiety, and disease activity were proved to be potential predictors of QOL on SLE patients. Large quantities of research have found that people with systemic lupus erythematosis have lower quality of life than normal population. For instance, a study done in Hong Kong compared patients with age and gender-matched control, after adjusting the deviation of education level and income, there is a significant difference between two groups' quality of life (Mok, Ho, Cheung, Yu, & To, 2009). The same result was shown by Almehed et al. (Almehed, Carlsten, & Forsblad-d'Elia, 2010). Linear regression was used by researchers to adjust for the matching factors in 3 studies, results all showed scores of

quality of life were lower than general population (Campbell, Cooper, & Gilkeson, 2008; Mak, Tang, & Ho, 2013; Zheng et al., 2009). Among these studies, four of them didn't adjust variables but showed the same results (Kulczycka, Sysa-Jedrzejowska, Zalewska-Janowska, Miniszewska, & Robak, 2008; Kuriya, Gladman, Ibanez, & Urowitz, 2008; Sliem, Tawfik, Khalil, & Ibrahim, 2010; Tam et al., 2008). However, inconsistent outcome was presented by Barnado et al. that MSC scores had no significant differences comparing with the control group. They explained this consequence is made by outliers in some cases in the control group (Barnado, Wheless, Meyer, Gilkeson, & Kamen, 2012).

Despite more advanced medication and longer survival rate, patients of systemic lupus erythematosus still have the relative lower about 30%-40% health related quality of life than healthy controls (Ramsey-Goldman & Rothrock, 2010). It has been a long time that researchers seek to find out the predictors attributing to the lower HRQOL. What they found was that the whole mechanism is complicated and that some variables have indirect effects to lower HRQOL. As we suggest disease activity and disease damage are the greatest contributors influencing HRQOL, however, many symptoms such as fatigue, pain, and depression mood, are largely deteriorating daily life on SLE.

Researchers tend to discover a few factors correlating to lower quality of life, such as demographic variables (age, education level, or employment status), disease activity, fatigue, pain symptom, depression mood, anxiety, and sense of competence. Fatigue, pain, and depression are also three of the most complaint symptoms on patients of SLE (Middleton, McFarlin, & Lipsky, 1994). More research on the nature of these symptoms must be investigated.

2.1 Demographic variables

Literature had examined socio-demographic characteristics (i.e., age, sex, race, education level, disease duration, socioeconomic status, work status, living status, and work satisfaction) with QOL. Age is largely discussed in research. In 2 studies, older age was estimated to be predictor of QOL, especially on physical health domain (Abu-Shakra et al., 2006; Alarcon et al., 2004) . Comparing younger SLE patients with older ones, study found the more impaired physical health and social relationships domains of QOL on age younger SLE patients (Goulia, Voulgari, Tsifetaki, Drosos, & Hyphantis, 2010). A progressive decline of QOL was said to start from age 25-34 to 55-64, and this decline may explain by the continuously coping with illness and managing disease such as taking medication daily and seeing doctors regularly (Rinaldi et al., 2004). However, Khanna et al. found controversial result (Khanna, Pal, Pandey, & Handa, 2004).

Education level was a predictor significantly associated with work disability. Patient with SLE with self-reported work disability had poor QOL, accompanied by decreased control further decreased QOL (Hyphantis, T., Palieraki, Voulgari, Tsifetaki, & Drosos, 2011; Panopalis et al., 2007). In a study done in Brazil, when levels of education was put into examination, they found a significant different between groups in physical, psychological, and environmental domain of QOL. The result showed education level indeed effects on QOL in many ways (dos Reis & da Costa, 2010).

The relationship between disease duration and QOL showed insignificant correlation among research. Commonly, disease duration could be separated into two groups, with longer than 5 years and less than 5 year, which represents the early onset or the relative chronic disease duration. In 2 studies, disease duration was not significant correlated with QOL (Khanna et al., 2004; Zhu, T. Y., Tam, Lee, Lee, & Li, 2010).

The association between work status, work disability and QOL hold a consensus proposition among research that they were significantly predictively correlated with each other. Research had contributed work disability and work disability to poor physical and environmental QOL (Almehed et al., 2010). Patients reported work disability status were found to have lower QOL (Hyphantis, T. et al., 2011).

2.2 Fatigue

Fatigue is one of the most complained co-morbid symptoms on SLE and presents a high prevalence among reference, ranged from 67% to 90% (Cleanthous, Tyagi, Isenberg, & Newman, 2012). The underlying etiology remains elusive but likely involves multiple factors related to disease, behavior, or psychological aspects. In fact, fatigue on SLE is multi-dimensional and multi-determined, which can be separated into several domains, such as physical and mental domains, with physical and mental aspects likely having different etiologies. Disease activity and depressive symptom are two of widely mentioned contributors of fatigue among reference, and the symptom is long-existed even the relief of disease severity. Studies have proved that there is significantly more fatigue symptom comparing with control group (Tench et al., 2002), and the phenotype of fatigue on SLE patients varies from normal people. Unfortunately, broadly and pervasively persisted fatigue also has a robust negative correlation to daily functions, even said to be the primary contributor to functional disability (Wolfe, Hawley, & Wilson, 1996). Pettersson et al. tried to find out the most distressing symptoms on SLE and determine how symptoms relate to HRQOL. They found out in approximately half of the patients, they even emphasize the importance of further intervention to ease their fatigue symptom (Pettersson et al., 2012). LUMINA, a multiethnic US cohort targeting on SLE patients, also showed relationships between fatigue and QOL. High level fatigue predicted lower QOL was what they found in this study also (Sanchez et al., 2009).

2.3 Pain

Pain is one of the most complain symptoms on SLE patients, nearly 95% of SLE patients experiences musculoskeletal-related pain during the course of their disease (Ahn & Ramsey-Goldman, 2012). The origin of pain comes from several symptoms, such as headache (32% to 66 %), abdominal pain, chest pain and fibromyalgia (Greco, Rudy, & Manzi, 2003). Through medication treatment, they can get slight relief. However, the influence on their mood and daily life participation is what we cannot overlook. Studies reported that illness-induced and activity-induced pain are attributed to their dysfunction in daily life (Greco et al., 2003; Johnsson, Sandqvist, Bengtsson, & Nived, 2008), and they sense more pain than healthy controls (Waldheim et al., 2013). A research hoping to find out the frequently reported symptoms identified 23 symptoms categories for patient with SLE to choose. Result showed there were 50% patients regard pain was the most frequently reported symptom. But pain was only associated with PSC score in SF-36 rather than MSC score (Pettersson et al., 2012). Similar result was shown in a Germany study (Tamayo, Fischer-Betz, Beer, Winkler-Rohlfing, & Schneider, 2010). There were also controversy studies revealed disconnection between pain and QOL (Hyphantis, T. et al., 2011; Sanchez et al., 2009).

2.4 Depression

The existence of psychiatric disorders is commonly seen on patients with SLE, among these psychiatric manifestations, depression is one of the most prevalent disorder as a secondary symptom (Maneeton, Maneeton, & Louthrenoo, 2013). In a review done by Palagini et al. in 2013, it concluded that 17% to 75% of prevalence rates were found in 17 studies comparing to lower prevalence rate of general population (Palagini et al., 2013). Besides, 20% to 30% of SLE patient having comorbid with depression were even in a severe status (Huang, Chou, Lin, & Chao, 2007). In a follow-up study, depressed mood were

correlated with changes in functional ability over the 8-month period (Da Costa et al., 1999). Most studies have proved that depression plays a key role on patients' quality of life. . One studies suggested psychological morbidity has correlated with quality of life (Medeiros et al., 2008). Within the last 5 years, three studies done in Chine (Shen et al., 2013) and the US (Moldovan et al., 2011; Sanchez et al., 2009) had the same result on whether depression is one of the predictors of QOL. By using different evaluation tools to depressed symptom (SDS, PHQ-9, and U.S. Preventive Services Task Force questionnaire), we can still have the same results indicated that depression has large to do with QOL. One of the two study done in the US indicated depression as a latent variable to negatively influence QOL on both Caucasians (r:-0.488~-0.660) and Hispanics (r: -0.456~-0.723) (Moldovan et al., 2011).

2.5 Anxiety

Anxiety disorders is one of the most frequently observed psychiatric disorders in female SLE patients (Nery et al., 2008). In a prevalence study, 65% of SLE patient has received a lifetime mood or anxiety diagnosis (Bachen, Chesney, & Criswell, 2009) (Schmeding & Schneider, 2013). Anxiety was found to have an impact on life performance and QOL (Adams Jr, Dammers, Saia, Brantley, & Gaydos, 1994; Dobkin et al., 1998). Indeed, the negative correlations between QOL and anxiety confirmed the great impact of anxiety on HRQOL (Doria et al., 2004). For example, a research done on Chinese patients with SLE showed correlation between anxiety and QOL (Tam et al., 2008). Partial correlation between anxiety and QOL were found in research done in China (Shen et al., 2013) and Singapore (Mak, Tang, Chan, Cheak, & Ho, 2011).

2.6 Sense of Competence

Occupational performance results from the dynamic relationship between people, their occupations and roles, and the environments in which they live, work and play (Law et al., 1996). Performance limitation is another troublesome problem and there is a considerable

evidence to verify its severity on SLE (Alarcon et al., 2004; Benitha & Tikly, 2007; Da Costa et al., 1999; Tench et al., 2002). Performance limitation means one cannot executive daily activities well as previously in their daily lives. In their view, working, running a household and looking after children are their crucial aims, however, not available in practice. Among patients having daily activity limitations, the more number of days with limitations, the lower their well-being. Besides, patients who reported daily activity limitations had lower score on quality of life. Actually, patients' attitudes toward their fatigue and pain have greater impact on self-perceived performance levels (Friedman et al., 1999). Taking work, one of the most important occupational performance, for example, it is reported that the rates patients stopped working after 5, 10, 15, and 20 years of disease duration were 15%, 36%, 51%, and 63%, respectively (Yelin et al., 2012). Mok. et al. also showed 9%, 21%, 25%, 31% and 36% of the cumulative incidences of work disability at 1, 2, 3, 4, 5 years (Mok, Cheung, Ho, Yu, & To, 2008). Patients who had the prevalence of work disability got a lower quality of life (Baker, K. et al., 2009). They suggest making patients be able to work, to regain their participation, could augment the chance to regain well-being from working (Almehed et al., 2010).

2.7 Mastery

Mastery, same as locus of control and sense of control, is in definition of "the extent to which one regards one's life chances as being under one's own control in contrast to being fatalistically ruled" (Pearlin & Schooler, 1978) or "the extent to which people see themselves as being in control of the forces that importantly affect their lives" by Brady (Brady, 2003). The sense of control of one's life has large to do with the circumstances of illness (Brady, 2003). Engaging in daily activity is the creator of an experience of mastery and control (Pi et al., 2002). People lose the sense of mastery can decrease the strength to exploration, influence the functions that daily required and thus reduce the frequency to engage in daily

life (kielhofner, 2008). SLE patients expressed more dissatisfaction with their perceived control over their bodies, moreover, they even mentioned it as causes of their lower quality of life (Archenholtz, Burckhardt, & Segesten, 1999).

2.8 Disease Activity

Nearly 80 percentage of research would discuss the relationship between disease activity and QOL. Disease activity is evaluated by biomarkers such as compliments (C3, C4), blood cells, or DNA binding. The common used evaluation tool is SLEDAI–2000, a clinician–reported questionnaire. Although large evidence tried to reveal whether disease activity is a critical factor to decrease QOL, we still cannot depict the truth. Actually, controversy evidences had proposed to the correlation between disease activity and quality of life (Doria et al., 2004). Several reference confirmed they indeed had relationship (Almehed et al., 2010; Garcia-Carrasco et al., 2012; Kulczycka et al., 2010; Kulczycka et al., 2008; Mok et al., 2009; Sliem et al., 2010; Zheng et al., 2009), whereas others disapproved (Moldovan et al., 2011; Gilboe, Kvien, & Husby, 1999; Gladman, Urowitz, Ong, Gough, & MacKinnon, 1996a, 1996b; Hanly, 1997; Jolly & Utset, 2004). On suspicion of the deterioration of mediators, we can examine the direct and indirect influence on quality of life by disease activity.

3. Path Analysis

Although many factors which have impact on QOL have been discovered, the actual mechanisms of how these factors affect QOL are still not clear. Besides, those factors are dependent to each other apparently, and the relationships between them are not clear either. Many researchers thus have devoted to such kind research recently.

Actually, a few conceptual models were proposed to provide the holistic view of the casual relationship of HRQOL on SLE. Through interviewing and collecting perspective of patients, Gallop et al. developed a model illustrating how SLE impacts on HRQOL (Gallop et al., 2012). Symptoms are suggested as the start of a deteriorating processing on HRQOL. Fatigue, pain, depression, anxiety, and lots comorbid have direct impact on function of daily life, such as work, daily activities, leisure and independence. Limitation of those functions is thus the crucial point to directly change the well-being of SLE. Sutanto et al. gave a thematic schema in 2013 in order to represent how SLE may impact on patients' lifestyle and sense of mastery (Sutanto et al., 2013). It pointed out that the debilitating fatigue and pervasive pain are two of the factors contributing to restrictive lifestyle and losing sense of mastery come to happen further. There are few quantitative research. A path model proposed in 2004 firstly described the relationship between disease activity, pain, and distress on activity limitations on patient with SLE (Greco, Rudy, & Manzi, 2004). Result found that only the level of pain had the significant direct influence on activity limitation and it didn't describe how these variables affected on QOL. In 2013, a path-analytic models analysis suggested that the main influencing factors of health-related QOL are the following: depression, anxiety, disease activity, and work status (Shen et al., 2014). However, it mainly focused on the impact of psychiatric disorders and demographic status. What we discover previously is that fatigue, occupational performance, and sense of mastery cannot be overlooked for the well-being of people is obtained by a complicate process. Although many hypothesis had been proposed, much of the present research had rarely guided by theoretical models (Seawell & Danoff-Burg, 2004).

4. Predictive Model of Quality of Life on Patient with SLE

In order to find out the nature of quality of life in SLE, 4 predictive domains of QOL model were proposed based on literature review and concepts of occupational therapy. The independent variables, mediating variables, and dependent variables we consider in our models are shown in Figure 1, 2, 3, and 4. The causal relationship between each two variables was presented by one-head arrows.

In our model, we choose 4 of the most mentioned and concerned symptoms, social-demographic characteristics, and disease activity as independent variables. These variables have either direct or indirect influence on 4 domains of QOL. We assume that limited performance is attributed by symptoms (fatigue, pain, depression, and anxiety), social-demographic characteristics (age, education level, living status, work status, and work satisfaction), and disease activity. Patients facing with limited performance may not sense mastery in their lives, and life is fatalistically ruled either under one's control. Quality of life, one's well-being, is thus influenced. Hypotheses were as follow:

Hypothesis 1

Physical health QOL model: fatigue, pain, education level, sense of competence, and sense of mastery may directly influence on physical health QOL. Higher disease activity indirectly causes a drop on physical health QOL through higher level of fatigue and pain. More severe fatigue and pain level will indirectly lower down physical health QOL through decreased sense of competence and sense of mastery. Lower education level may decrease physical health QOL via sense of competence (Figure 1).

Hypothesis 2

Psychological health QOL model: depression, anxiety, sense of competence, and sense of mastery may directly influence on psychological health QOL. Higher disease activity

indirectly causes a drop on psychological health QOL through higher level of depression and anxiety. More severe depression and anxiety level will indirectly lower down psychological health QOL through decreased sense of competence and sense of mastery (Figure 2).

Hypothesis 3

Social relationships QOL model: Living status, depression, fatigue, sense of competence, and sense of mastery directly influence on social relationships QOL. Higher level of disease activity indirectly causes lower social relationships QOL through two steps. First, severe depression and fatigue symptoms decreased sense of competence and sense of mastery. Lower sense of competence and sense of mastery further cause lower social relationships QOL. Living alone (living status) indirectly decreases social relationships QOL through lower sense of competence and sense of mastery (Figure 3).

Hypothesis 4

Environmental QOL model: Living status, work status, work satisfaction, environmental impact, education level, depression and sense of mastery directly influence on environmental QOL. Higher level of disease activity indirectly causes lower environmental QOL through two steps. First, unemployed work status and lower work satisfaction decreased environmental impact and sense of mastery. Lower environmental impact and sense of mastery further cause lower environmental QOL. Living alone (living status) indirectly decreases environmental QOL through lower environmental impact and sense of mastery. Lower education level and depression may decrease environmental QOL via environmental impact further decreases environmental QOL (Figure 4).

The relationship between symptoms, disease activity, sense of competence, sense of mastery, and quality of life will be validated by statistical method, path analysis. Path

analysis, one of the causal interpretation theories, was firstly introduced by geneticist Sewall Wright in 1918 to apply in the area of population genetics and sociology (Duncan, 1966). By using mathematical calculation to solve a combination of a few equations into a single model, path analysis elucidates the direct and indirect casual relevancy of variables. Path analysis provides an available method to find out the effects among a series of variables within a causal model. We try to use statistical methods to confirm the goodness-of fit of the predictive model. It gives researcher a picture toward the origins and consequences of phenomena and provides evidences to interpret inexplicable things.

METHODOLOGY

Reliable data is crucial for any statistical analyses, and thus the enrollment procedure and data collection need carefully designed.

1. Subjects

Subjects were adult outpatients with SLE regularly followed up at the clinic, division of Rheumatology of the National Taiwan University Hospital (NTUH) in northern Taiwan. All participants should be voluntary to participate in the research and having the ability to fill in all the questionnaires in the survey. Patients all meet at least 4 of the 11 American College of Rheumatology (ACR) revised criteria for the classification of SLE (Hochberg, 1997). The inclusion criteria were age above 20 and with education level at least fifth grade of elementary school. The excluded criterion is insufficient cognitive function. We use Mini-Mental State Examination-Chinese Version (MMSE-C) to evaluation cognitive function. Scoring lower than 24 will be excluded from this study (Folstein, Folstein, & McHugh, 1975).

2. Procedure

In this cross-sectional study, outpatients were enrolled in a clinic in NTUH from July to December in 2014. All of the patients gave written informed consent for study participation, and the procedures were approved by the National Taiwan University institutional review board (Number: 201405046RIN) (Appendix. P). First, verbal explanation was given to ensure the participant understood the information provided. After participants signed the informed consent, they would firstly be evaluated on their disease activity by physician using the paper-based SLEDAI-2000 assessment. Participants would

then conduct a computer-based Google Doc online survey consisting of 3 components: one interview-based instrument (MMSE), demographic and disease-related questions, and 7 questionnaires. Patients were first evaluated MMSE for screening the cognitive function for 5 minutes, followed by self-reported demographic disease-related questions, FACIT-Fatigue, pain-NRS, BDI-II, BAI, OSA, Mastery scale, and WHOQOL-BREF-TW with the tablet PC. In average, 30 to 40 minutes were spent on filling all the questionnaires. The enrollment procedure is shown in Figure 5.

The demographic data includes age, sex, marital status, duration of disease, education level, and so on. The 7 administrated questionnaires were Functional Assessment of Chronic Illness Therapy-fatigue (FACIT-Fatigue), Pain-Numerical Rating Scale (NRS), Beck depression inventory-II (BDI-II), Beck anxiety inventory (BAI), Occupation self assessment (OSA), Mastery scale (MS), and the World Health Organization Quality of Life-BREF-Taiwan version (WHOQOL-BREF-TW). The contents of the instruments were presented in Appendix C~I, and the permission to apply these instruments was included in Appendix J~O.

3. Measures

To verify our model in quantitative way, several evaluation tools are applied to quantify the degree of each factor. The corresponding tools and the detail descriptions of each tool are described as follows:

3.1 Mini –Mental State Examination –Chinese Version (MMSE-C)

The MMSE was developed by Folstein and McHugh to differentiate organic from functional psychiatric patients. It consists of 11 questions relating to cognitive function. The maximum score is 30 point and it can be administered within 5 to 10 minutes. Many

cognitive functions were included in MMSE, such as orientation to time (5 points), orientation to place (5 points), registration of 3 words (3 points), attention and calculation (5 points), recall of 3 words (3 point), language (8 points), and visual construction (1 point) (Tombaugh & McIntyre, 1992). The level of cut-off score was generated: 30 to 24 with no cognitive impairment, 23 to 18 with mild cognitive impairment, and 17 to 0 with severe cognitive impairment. The Chinese version of MMSE (MMSE–C) was translated by Guo et al. in 1988 (Guo et al., 1988). It was found the score was easily influenced by the education level of client. Thus it suggests to discriminate the education level of client before the beginning of test. The criteria vary between formal education experiences. Client who has of less than 2 years and 2 to 10 year should have a score of at less 13/14 and 23/24. This instrument should be conducted carefully. The MMSE-C is used to screen the cognitive function of SLE patients, to ensure they have sufficient cognitive level to understand all the questionnaires.

3.2 The Systemic Lupus Erythematosus Disease Activity Index 2000 (SLEDAI-2000)

The SLEDAI was first introduced in 1958 and constructed by a panel of experts of rheumatology (Bombardier, Gladman, Urowitz, Caron, & Chang, 1992). Clinicians had pointed out that persistence active symptoms and chronic but active symptoms couldn't be illustrated and recorded in the SLEDAI for the assessment only aimed at evaluating at their first occurrence, or upon recurrence. Thus, the SLEDAI-2000 came out to be the modification version of the SLEDAI. The correlation between them was r=0.97 (p=0.0001) and it was proved that both of them can be the predictor of mortality and had sensitivity toward change.

The SLEDAI-2000 has 4 modified items as below: rash, alopecia, mucous membrane ulcers, and proteinuria. It is recommended to be the assessment of global disease activity

than SLEDAI for the more precise and accurate items in the assessment. Twenty-four items are listed in the assessment and every item has been limited to the maximum rating. Total score is one hundred and five and the higher the rating, the higher the disease activity. There are two cut-off points to distinguish the disease activity based on SLEDAI. Total score below 6 indicates inactive or mild disease, between 6 and 12 represents moderately active disease, and score above 12 are considered severe disease (Gladman, Ibanez, & Urowitz, 2002).

3.3 Functional Assessment of Chronic Illness Therapy–Fatigue Scale (FACIT-F)

The FACIT, a measurement system composed of quality of life questionnaires, targets to the health-related quality of life on patient with chronic illness in 1997. The FACIT is derived from the functional assessment of cancer therapy (FACT), a measurement system applied only on cancer patients, in view of the diversity clinically-relevant conditions and problems (Webster, Cella, & Yost, 2003).

The FACIT-F scale was developed through three steps, first, a few items in the FACIT-fatigue scale were adopted from the Functional Assessment of Cancer Therapy-General (FACT-G) (Yellen, Cella, Webster, Blendowski, & Kaplan, 1997). Second, interviewing patients and accumulating experts' opinions with these questions. The last step was to real test on patients to validate the test-retest reliability and construct validity of final version which obtains thirteen questions. In the same study, the FACIT-F scale had shown good test–retest reliability ($r = 0.90$) and internal consistency (alphas = 0.93 and 0.95) (Yellen et al., 1997).

There are multi-facet to evaluate fatigue, such as intensity, frequency, and types of fatigue. In the FACIT-F, it mainly targets on evaluating different dimensions of fatigue which obtains physical, functional, emotional, and social consequences of fatigue. It is easy for

administrators to administer and score the FACIT-F scale for every item is based on a four-point scale, 0 point indicates “not at all” while 4 point represents “very much”. A total ranges from 0 to 52, more higher the score, more fatigue patient perceives.

3.4 Pain – Numerical Rating Scale (Pain---NRS)

The most widely used evaluation tool for pain is the numerical rating scale (NRS) which commonly composes a 100 millimeter horizon line with descriptions on both sides, 0 point indicates “no pain” and 10 point indicates “I’ve never experienced that kind of pain” (Ho, Spence, & Murphy, 1996; Wewers & Lowe, 1990). It possesses excellent clinical utility for convenient, easy, and rapidly application (Wewers & Lowe, 1990). Sufficient reliability was found to assess client with both acute and chronic pain (Bijur, Silver, & Gallagher, 2001; Price, McGrath, Rafii, & Buckingham, 1983). Researchers have suggested that the NRS can be applied as a reliable and valid evaluation tool not only intensity of pain but unpleasantness (Price et al., 1983). A systematic review which examined the use and performance of unidimensional pain scales also suggested that NRSs are applicable for unidimensional assessment of PI in most settings (Hjermstad et al., 2011). The British Pain Society is a company involving in all aspects of pain and its management through the work of the Council, Committees and Working Parties (The British Pain Society, 2008). The Pain---NRS is free downloaded and printed free of charge from web page. Its psychometrics also had been proved to be excellent and clinical significant (Coghill, McHaffie, & Yen, 2003).

3.5 Beck Depression Inventory-Second Version *(*BDI-II)

The structure and concept of the BDI were proposed by Aaron T. Beck in 1961 (Beck, A. T., Ward, Mendelson, Mock, & Erbaugh, 1961). In order to fit into the construct of DSM-IV (Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition), the revised version of BDI, Beck depression Inventory-Second Version (BDI-II), was thus come out

(Steer, Robert A, Clark, Beck, & Ranieri, 1999). In the BDI-II, a somatic-affective (12 items) and a cognitive (9 items) dimension of depression are measured by twenty-one symptoms and attitudes observed on patients with depression without predetermining a theory (Beck et al., 1996). During the test, client is asked to score the intensity of questions on a 4-point rating scale. By self-administration or structured interview, the sum of the highest score from 0 to 3 in each item turns to be the outcome of depression level, and the total score ranges from 0 to 63 (Storch, Roberti, & Roth, 2004).

Many findings suggest that the BDI-II shows good reliability. The internal consistency of total score, somatic factor, and cognitive-affective factor is 0.9, 0.74, and 0.87 respectively (Storch et al., 2004). High internal consistency was also found by Steer et al. (coefficient α= .92) (Steer, R. A., Kumar, Ranieri, & Beck, 1998).

The Taiwanese version of BDI-II was issued in 2000. It was proved to have acceptable internal consistency (Cronbach α .92), construct validity, and sensitivity by applying Rasch analysis (Pan, A. W. & Hsu, 2008). In a study with 180 samples in clinical psychiatry, it was also tested to obtain good split-half reliability (Cronbach α .91) and constructed two domains – cognitive-affective and body, separately (Lu, Che, Chang, & Shen, 2002).

3.6 Beck Anxiety Inventory (BAI)

The Beck anxiety inventory (BAI) was originally developed for measuring common symptoms of clinical anxiety, such as nervousness and fear of losing control by Aaron T. Beck (Beck, Aaron T., Epstein, Brown, & Steer, 1988). It is a 21-item Likert scale self-report questionnaire and the each item range from 0 to 3, corresponding “not at all” to “severely, I could barely stand it”. The higher score indicates to higher severity of anxiety. There is 3 dimensions within BAI, 13 items describing physical or physiological symptoms

(e.g., heart pounding), 5 evaluating clearly cognitive aspects of anxiety (fear of the worst), and 3 having both a physical and cognitive meaning (e.g., terrified). It had proved to have good to very good internal consistency with coefficient alpha values of at least .83 and mean alphas of .88 or better by a review done in 2005 (Fydrich, Dowdall, & Chambless, 1992; Kabacoff, Segal, Hersen, & Van Hasselt, 1997). Test-retest values ranging from .35 to .83 was present at the same study.

The Chinese version of BAI showed excellent internal consistency Cronbach's α=0.95 and two dimensions and its factor loadings were found similar as English version (Che, Lu, Chen, Chang, & Lee, 2006). Higher correlation with Hamilton Anxiety Rating Scale, HAM-A), one of the most applied anxiety evaluation tools, was also shown in the same study.

3.7 Occupational Self Assessment (OSA)

The OSA, which has two parts-the myself part and environmental impact, is an assessment designed to be used as a client-centered assessment to identify sense of competence and environmental impact from the client's perspective (Baron et al 2006). The uni-dimensional construct originally concepts from the model of human occupation (MOHO) (Kielhofner, Forsyth, Kramer, & Iyenger, 2009). The 'Myself' items is designed to understand one's volition, habituation, and occupational performance in their living. If ones can successfully well-adapted toward obstacles and barriers, they are believed to fulfil personal and external expectations and responsibilities related to their occupational competency. In other words, subjects have well occupational performance in their living. The 'environmental impact' part is design to evaluation how environment impacts on one's life. The items evaluate how subjects feel about their physical and social environment. 2 parts, myself and environmental impact, include a series of 21 and 8 statements. All

statements are four-point scale. The values categories range from 1 to 4, indicating very difficult, difficult, easy, and very easy, separately. The higher score represents the greater the person sense its competence in his life, the greater their environment affordance.

The Chinese version of OSA has been tested to acquire well psychometric properties by Pan et al. (Pan, A. W., Chung, & Hong, 2002; Pan, A.W. et al., 2011). It showed good construct validity and moderate test-retest reliability. Moderate concurrent validity had also been proved.

3.8 Mastery Scale

Mastery, or called locus of control, self-efficacy, and sense of control, is a level of perception that reflects one's mastery or control toward life events, and it has been defined as the "extent to which one regards one's life-chances as being under one's own control in contrast to being fatalistically ruled" (Pearlin & Schooler, 1978). The mastery scale (MS) was introduced by Pearlin and Schooler in 1987 (Pearlin & Schooler, 1978), and total of seven items were included, two positive items and five negative items. Five-point scale is used to rate the agreement of items, 1 indicates "strongly disagree" and 5 indicates "strongly agree", higher score thus presents a higher level of mastery (Majer, Jason, & Olson, 2004).

The Taiwanese version of mastery scale was translated by Hsiung et al. The psychometric property had been estimated to be acceptable and sound. It shows uni-dimensional construct and well clinical utility among different groups of patients (Chen, Hsiung, Chung, Chen, & Pan, 2013).

3.9 The World Health Organization Quality of Life – BREF– Taiwan Version (WHOQOL – BREF – TW)

The development of the WHOQOL was exactly a project led by the World Health Organization (WHO) to build a cross-cultural assessment in order to improve the efficiency

to compare outcomes in different settings (WHO, 1995). 100 items were eventually selected on behave of the final version from a pilot testing of 236 items by testing the psychometric properties. Through validate and rough translation methodology, unbiased quality of life assessment can be utilizes around the world and makes it a comparable tool for researchers. The WHOQOL is comprised of twenty-five facets and facets are separated into six domains. The WHOQOL has built comprehensive norm and manual which are specific to different populations, all level of age, education level, and gender.

The WHOQOL – BREF is originated from the WHOQOL and it is a lengthier version of WHOQOL which reduces the number of item from one hundred to twenty-eight in order to increase clinical utility. Twenty-six items and two national items are grouped into four domains which includes physical and independence, spiritual, religion, and personal belief, social relationship, environment. All the questions are inquired with five point Likert-like rating scale to estimate the capacity, frequency, intensity of quality of life related issues. The higher the total score indicates the better the quality of life. Different perspectives such as objective and subjective feelings and positive and negative affective are included in the WHOQOL – BREF. It has been proved that WHOQOL and WHOQOL – BREF are highly correlated and both possess acceptable test-retest reliability (O'Carroll, Smith, Couston, Cossar, & Hayes, 2000).

The Taiwanese version of WHOQOL – BREF was translated and validated in 1991. It takes about eleven minutes to complete the self-administer questionnaire. In order to be cultural relevant, two national items were generated to construct a comprehensive perspective of quality of life. In the same study, it also assessed psychometric properties to test the reliability and validity of the WHOQOL – BREF – TW. Exploratory factor analysis revealed a four-domain model and these domains can explain 88% of the variance of the

quality of life. It can be concluded that the questionnaire has well-built construct validity (Yao, Chung, Yu, & Wang, 2002). In a 1200 community-dwelling older people study, excellent discriminant validity, construct validity, and responsiveness were also verified (Hwang, Liang, Chiu, & Lin, 2003).

4. Statistical Analyses

We conduct the data analyses by the following procedures (Suhr, 2008). Descriptive statistics are used to describe the central tendency and divergent trend, which includes demographic data (i.e. age, gender, educational level, marital status, living status, and working status), disease-related information (onset age, onset duration years, clinic visit frequency, and drug used), and all data deriving from 7 instruments (FACIT-F, Pain-NRS, BDI-II, BAI, OSA, Mastery scale, WHOQOL-BREF-TW, and SLEDAI-2000). Categorical data will be presented with the amount and percentage, and the continuous data will be presented with mean, standard deviation (SD) and range of raw score by SPSS version 19.0 software.

After collecting the sufficient data, statistical analyses were carried out by LISREL version 8.5.2 software and SPSS 19.0 software (Joreskog & Sorbom, 1996). In order to examine how symptoms and disease activity impact on different domains of QOL, the 4 domains of QOL (physical health, psychological health, social relationships, and environment) will be analyzed separately. First, we calculate the correlation matrix of all variables in our study and draw path diagrams of 4 QOL models. Second, we use the correlation matrix to compute the model fit indexes for each model. In our study, we examine Chi-square ($\chi 2$) and the significance level of *p*-value in each model. The chi-square test indicates the amount of difference between expected and observed covariance matrices. A chi-square value closes to zero indicates little difference between the expected and observed covariance

matrices (Suhr, 2008). Thus, the smaller the chi-square, the better the model fitness we have. If the *p*-value is higher than 0.05, in this research, we define the collected data well explained the predictive models.

The best strategy for evaluating model fit is to examine multiple tests. The goodness of fit index (GFI) is the index to look at the variance and covariance accounted for by the model it shows how closely the model comes to replicating the observed covariance matrix. Adjusted goodness of fit index (AGFI) is the adjustment of the GFI based upon degrees of freedom, with more saturated models reducing fit. Normed fit index (NFI), the statistic assesses the model by comparing the $\chi 2$ value of the model to the $\chi 2$ of the null model. It is not suggested to use alone. Comparative fit index (CFI) is a revised form of the NFI which performs well even when sample size is small. All of these indexes have its advantages and disadvantages, thus, we all take into consideration to validate our models. In our study, the GFI, AGFI, CFI, and NFI should be greater than 0.9 to prove the goodness-of-fit of the 4 predictive QOL models (Suhr, 2008; Chung, Pan, & Hsiung, 2009; Hsiung et al., 2010).

If model fit is acceptable, we continue on examining the parameter estimation in 4 models. The ratio of each parameter estimate to its standard error is distributed as a z statistic and we define significant at the 0.05 level if its t-value exceeds 1.96 (Suhr, 2008). The negative value of path parameter represents a negative correlation within two variables. In our study, all the paths should be significant in 4 models. Standardized path coefficients with absolute values less than 0.10 will indicate a “small” effect, values around 0.30 represents a “medium” effect, and values greater than 0.50 means a “large” effect on this parameter (Suhr, 2008).

The direct and indirect effect of variables in the 4 predictive models will be presented in a table to examine which variable contribute the largest magnitude in its model. The causal

effect includes direct and indirect effects between two variables while the non-causal effect is the difference between correlation coefficient and causal effect coefficient. The larger the causal effect, the more magnitude of variable impacted in the model.

In our study, we examine the R square in 4 predictive models. The R square represents the proportion the collected data explains the predictive models. The larger the R square of outcome measures, which are physical health QOL, psychological health QOL, social relationships QOL, and environmental QOL, the more the explained variance of 4 models. We also examine the residual of each variable. The residual of each variable shows to which extend the variable is not explained in this model. The less the residual, the more proportion the variable is explained by other indicators.

Independent t-test is applied to examine the relationships between QOL (physical health QOL, psychological health QOL, social relationships QOL, environmental QOL, overall QOL, and health QOL) and variables (hospitalized frequency, work status, marital status, steroid dosage, and disease activity). All the variables were separated into two groups to conduct statistical analysis. Hospitalized frequency is separated into hospitalized<4 times and hospitalized≧4 times. Work status is split into two groups: those who have job and have no job. Marital status is separated into married and singled groups. Steroid dosage is divided by dosage of steroid: dosage above/equal and lower 15mg per day. Disease activity is split into two groups: SLEDAI score<6 and SLEDAI score≧6. The significance level of *p*-value is 0.05.

RESULTS

1. The characteristics of subjects

The demographic data describing this purposive sample are presented in Table 1. Among 105 patients admitted for the study, 11 were subsequently excluded in accordance with recruitment criteria, resulting in 94 participants. The rejection rate for the subject recruitment was relatively low of 3.2%. The reasons for drop-out were unwilling to participate (n=3), age lower than 20 (n=1), insufficient education level (n=3), and insufficient cognitive function (n=3). The sample were aged between 20.32 and 70.42 years, with a mean age of 49.47 years (Standard deviation = 11.03 years). Most subjects were female (92.6%), completed college education (46.8%), and were married (68.1%). Results showed half of the subjects were full time employed (51.1%), and the remaining 48.9% subjects were either part-time employed (5.3%), non-working (11.7%), or retired (31.9%). Most of the subjects lived with their family members (95%), seldom lived with friends (2%) or lived alone (1%). The average onset age of SLE is 34.7 year-old (SD=13.06, range=13.8~60.4), with an average onset duration of 14.77 years (SD=8.84, range=1~42 years). About medication, nearly every subject is under medication treatment (97%). The average dosage of steroid is 1.57 tablets per day, and the average dosage of quinine is 1.32 tablets per day. Among subjects, nearly 25.5% of them were prescribed hypnotic, and 36.2% subjects took immunosuppressant. The average number of hospitalizations is 2.5 times, with 34% of the subjects were not hospitalized ever. Nearly half of the subjects visit clinic once a month (51.1%), followed by two month (35.1%) and three month (13.8%).

2. The associations between the predictors on each domain of QOL

The descriptive and inferential analyses of variables are presented in Table 2. The FACIT-Fatigue total scores ranged from 1 to 45 with a mean of 14.36 (SD = 8.26) and a mode of 12. The pain-NRS impact has a mean of 2.21 (SD = 2.85) with a total of 46 participants ranked no pain impact. The BDI-II total scores ranged from 0 to 48 with a mean of 10.31 (SD = 10.30). The number of participants with minimal, mild, and severe severity of depression is 11 (11.7%), 9 (9.6%), and 6 (6.4%), respectively. There are 68 (72.3%) participants scored within the normal range of BDI-II. The average BAI total score was 10.69, with a range of 0 to 55 and a standard deviation of 10.35. The number of participants with minimal, mild, and severe severity of anxiety is 30 (31.9%), 12 (12.8%), and 8 (8.5%), respectively. There are 44 (46.6%) participants scored within the normal range of BAI. For OSA, the mean and SD for the OSA-myself and the OSA-environmental impact are 63.20 (SD = 9.56) and 25.07 (SD = 4.29), respectively. The range of raw scores on the Mastery scale is from 11 to 28 with a mean of 19.35 (SD=3.23). Participants ranked highest on environmental QOL with a mean of 14.34, and the lowest is psychological health QOL with a mean of 12.72.

3. The final 4 QOL models

The Figure 6, 7, 8, and 9 illustrate each final version of the 4 path diagrams, and the Figure 10 shows the final QOL model for SLE. The correlational matrix was shown in Table 3, and the decomposition of the 4 final path models for the 4 QOL domains was present in Table 12. The results of the path analysis for the initial physical health QOL model are presented in Figure 1 and Table 4. In the initial physical domain of QOL model, disease activity has no predictive relationships with fatigue (r=0.17), pain impact was found to have weakly association with disease activity and levels of mastery (r=0.21; r=-0.12), and sense of mastery had insignificant relationship with physical health QOL (r=0.12). The model fit

indices were all substandard with Chi-Square=41.72 (p<0.0000), *df*=9, GFI=0.89, AGFI=0.65, CFI=0.81, and NFI=0.78. The total explained variance is 56%. Disease activity and sense of mastery were found to be insignificant predictors of QOL (Figure 6). Removing disease activity and sense of mastery from the physical health QOL model, the remaining variables showed a well model fit with Chi-Square=4.76 (*p*-value=0.09), *df*=2, GFI>0.9, AGFI<0.9, NFI>0.9, and CFI>0.9 (Table 8). Final model showed that fatigue, sense of competence, and education level has direct effects on physical health QOL, while pain and fatigue have indirect effects on physical health QOL through sense of competence. Among dependent variables, the proportion of the variance explained by sense of competence was 40%, and the total explained variance is 60%. Among variables, fatigue has the highest total effect in the model (-0.63), followed by sense of competence (0.41), education level (0.17), and pain (-0.10) (Table 12). In this model, fatigue and sense of competence, fatigue and physical health QOL, and sense of competence and physical health QOL are moderately correlated (r=-0.49; r=-0.43; r=0.41), while other paths are modestly correlated (r=-0.24~0.17).

The results of the path analysis for the initial psychological health QOL model are presented in Figure 2 and Table 5. In the model of psychological domain of QOL, the proportion of the explained variance is 63%. The misfit model indices were Chi-Square=52.68 (p=0.00), *df*=5, GFI=0.84, AGFI=0.33, CFI=0.75, NFI=0.74. Among paths in this model, disease activity had no correlation with anxiety (r=-0.17), and anxiety had no association with sense of mastery and psychological QOL (r=-0.013; r=0.011). Removing disease activity from the psychological health QOL model, the remaining variables showed a well model fit with Chi-Square=7.41 (*p*-value=0.06), *df*=3, GFI>0.9, AGFI=0.85, NFI>0.9, and CFI>0.9 (Table 9). Final model showed that depression, sense of competence, and sense of mastery have direct effects on psychological health QOL, while anxiety and depression have indirect effects on psychological health QOL through sense of

competence and depression has indirect effect through sense of mastery. Among dependent variables, the proportion of the variance explained by sense of competence and sense of mastery were 40% and 30% separately, and the total explained variance is 65%. Among variables, depression has the highest total effect in the model (-0.70), followed by sense of competence (0.30), sense of mastery (0.18), and anxiety (-0.07) (Table 12). In this model, all the paths are significant. Path from depression to mastery is highly correlated (r=-0.54), and path from depression to sense of competence and to psychological health QOL were moderately correlated (r=-0.45; r=-0.47). Other paths were modestly correlated (r=-0.23~0.30) (Table 9).

The results of the path analysis for the initial social relationships QOL model are presented in Figure 3 and Table 6. In the social relationships of QOL model, disease activity has no predictive relationships with fatigue (r=-0.17), fatigue has weakly correlation with sense of mastery and social relationships QOL (r=-0.048; r=-0.09), and sense of mastery and living status were found to have no association with social relationships QOL (r=-0.071; r=0.13). The model fit indices were all substandard with Chi-Square=76.34 (p=0.00), GFI=0.81, AGFI=0.24, CFI=0.65, and NFI=0.65. The total explained variance is 38%. Removing disease activity and sense of mastery from the social relationships QOL model, the remaining variables showed a well model fit with Chi-Square=0.38 (*p*-value=0.54), *df*=1, GFI>0.9, AGFI>0.9, NFI>0.9, and CFI>0.9 (Table 10). Final model showed that depression, sense of competence, and functional status have direct effects on social relationships QOL, while fatigue and depression have indirect effects on social relationships QOL through sense of competence. Among dependent variables, the proportion of the variance explained by sense of competence was 44%, and the total explained variance is 40% (Table 10). Among variables, depression symptom has the highest total effect in the model

(-0.46), followed by sense of competence (0.38), and fatigue (-0.13) (Table 12). In this model, all the paths are modestly correlated (r=-0.38~0.38).

The results of the path analysis for the initial environmental QOL model are presented in Table 7, and Figure 4. In the model of environmental domain of QOL, the proportion of the explained variance is 38%. The misfit model indices were Chi-Square=55.66 (p=0.00), *df*=15, GFI=0.88, AGFI=0.65, CFI=0.67, NFI=0.66. Among paths in this model, disease activity had no correlation with neither work status nor work satisfaction (r=0.19; r=-0.19), work status had no association with sense of mastery and environmental QOL (r=-0.14; r=-0.026), work satisfaction, work status, and living status had no significant relationship with environmental impact (r=-0.011; r=-0.13; r=-0.0005), and living status and work status had no relationships with environmental QOL (r=-0.073; r=-0.026). Removing disease activity and sense of mastery from the environmental QOL model, the remaining variables showed a well model fit with Chi-Square=6.4 (*p*-value=0.09), *df*=3, GFI>0.9, AGFI<0.9, NFI>0.9, and CFI>0.9 (Table 11). Final model showed that environmental impact and work satisfaction have direct effects on environmental QOL, while education level and depression have indirect effects on environmental QOL through environmental impact. Among dependent variables, the proportion of the variance explained by environmental impact was 21%, and the total explained variance is 41%. Among variables, environmental impact has the highest total effect in the model (0.57), followed by depression (-0.21), work satisfaction (0.21), and education level (0.13) (Table 12). In this model, environmental impact and environmental QOL is moderately correlated (r=0.57), while other paths are modestly correlated (r=-0.37~0.23) (Table 11).

4. The relationships between QOL and variables

The association between QOL and variables was shown in Table 13. Significant overall QOL difference was found between less frequent hospitalized group and higher frequent hospitalized group (p=0.024) which the first group demonstrated higher overall quality of life. There is also significant difference of the overall quality of life between group with high (15mg/per day) dosage of steroid intake and low use group (p=0.032). The low use group demonstrated better overall quality of life.

DISCUSSION

1. The characteristic of sample in the research

In our study, the subjects were patients with systemic lupus erythematosus with the mean disease duration of 14.77 years. The sex ratio is 1: 12.4 in this study, as similar to that of global, with a marked female predominance. A high rate of unemployment (43.6%) in patients with SLE was observed in our study. In a review of work disability in SLE, they mentioned 47.1% SLE are employed and 32.54% are work disability, which aligned with our results. In Taiwan, the average employment rate in age between 45 to 64 year old female is 46%, which is lower than SLE patients' employment rate in our study. The result may be explained by the recruitment hospital is in Taipei, which is the capital of Taiwan, with more job openings. A previous study had reported the unemployment status with the reason of the existence of disease (55%). The cause of work disability may associate with the increased physical demands and increased psychological demands accompanied by decreased control (Baker, Kim & Pope, 2009). The limited ability to change working situation in case of disease onset in older patients is another reason that they cannot re-enter into workforce (Bultink, Turkstra, Dijkmans, & Voskuyl, 2008).

Demographic data had shown that nearly one of forth (25.5%) patients have taken hypnotics medication. It had reminded us the sleep problem in patient with SLE. It has been reported that women with SLE has experienced a high frequency of sleep disturbance (61%) (Gudbjornsson & Hetta, 2001). Comparing with healthy controls, SLE patients had more impaired sleep efficacy and higher arousal frequencies (Iaboni, Ibanez, Gladman, Urowitz, & Moldofsky, 2006). Some of the

symptoms such as tiredness or limited daily activities on SLE patients also attributes to the sleep deficit. Thus, some of SLE patients may take hypnotics to have good sleep quality and to maintain their daily participation.

2. The QOL in person with systemic lupus erythematosus

The findings from the study indicate that the patients with SLE are more satisfied with the environmental domain, and are less satisfied with the psychological health domain of QOL. The subjects in this study pointed out they were satisfied with medical resources, their living status, and the easy-accessed of transportation. It may show that they have sufficient resource to maintain their environmental QOL during their daily living. However, results indicated they were dissatisfied with their sleep condition, concentration ability, and they felt they couldn't enjoy their lives. In fact, subjects with SLE often worry about their health condition and have negative feelings toward their changed-appearance and ability to deal with lives circumstances. These worries and concerns may explain their low score responses on items of psychological health domain of QOL. Studies done by Khanna et al. also points out the QOL score was the lowest in the domain for the psychological QOL, with a mean of 12.94 as similar to our study of 12.6 (Khanna et al., 2004).

We also found that patients who prescribed more steroids may think their overall health QOL worse than patients taking less steroids. Besides, if patients need to be hospitalized more, they showed worse overall QOL than those who seldom be hospitalized. Steroids dosage and the number of hospitalization are said to be the indicators of flare of disease (Zhu, T. Y. et al., 2010). We may conclude the fluctuation of disease is the indicator of patients' self-perceived wellness.

3. Critical predictors influencing QOL

In four models of QOL, disease activity has insignificant relationships with QOL. The relationship between disease duration and QOL holds a contradictory proposition among previous research, and some of them had explained the result for the discrepancy on methods of evaluation. In a cohort study, doctors and patients have nearly 58% significant disagreement on disease activity evaluation (Yazdany & Yelin, 2010). Owing to the SLEDAI-2000 is the only one assessment that is not self-reported by SLE patient in our study, the scoring of disease activity differing from doctors and patients may vary the result depends on their definition and perception toward disease activity. Second, the explanation of weak correlation between disease activity and QOL may be all the patients are outpatients with a relative stable disease condition, thus has less impact on QOL (Maeshima et al., 2007). In our study, disease activity was the only variable evaluated by clinician rather than self-reported. Besides, all the patients were recruited from clinics which have a relative lower disease activity than other similar research (Alarcon et al., 2004). It may be these reasons to interfere the results in our study.

Sense of mastery has initially proposed to be the predictor of four QOL models. In this study, however, sense of mastery has only been proved to be the predictor in psychological QOL. Mastery is so called sense of control and locus of control, to describe how one senses its ability to seize life on its own. Depression symptom on patients with SLE may give them a feeling of loss control of life further decrease their psychological QOL in our study. In a research done in 2013, the author pointed out some SLE patients has learned to master their stress or received emotional supports from family members or friends to avoid psychological symptoms that could prevent

them from a sense of loss control (Sutanto et al., 2013). Thus, one possible explanation for this finding is that sense of mastery is a psychological feeling in nature. Adams et al. had examined the relationships between depressed symptom, locus of control, and quality of life. Results found depression was a variable led to lower locus of control. However, controversial to our result, locus of control significantly impacted physical domain of quality of life in SF-12 (Adams et al., 2004). In Paschalides's study, psychological distress such as depression and anxiety, accompany with sense of control, accounted for 57% of the total variance to the mental domain of quality of life in SF-36 in patient with diabetes, which is also a chronic illness (Paschalides et al., 2004).

Sense of competence, evaluating by the occupational self assessment, was found to be a decisive predictor to determine the perception of well-being in patients with SLE. From our results, symptoms such as fatigue, pain, depression, anxiety all indirectly manipulate QOL through sense of competence. In the occupational self assessment, they scored lowest in items such as "finish the things that I plan to do", "make efforts toward my goals", and "relax and enjoy life". From patients' perspective, they felt they couldn't do what they want and what they wish to do, and SLE makes them hard to enjoy their lives. Previous research had interviewed on person with SLE. From the descriptive analysis, SLE patients mostly address the distracting problems of physical illness and psychological distress which makes them hard to strike a balance in daily living and work. These limitations to participate reduced their sense of well-being (Sutanto et al., 2013). We may conclude the existence of symptoms is what we need to be attention to, but whether the symptoms have deteriorated their daily participation in work, home, or social activities is exactly the critical issue that we have to address and deal with in clinics.

Fatigue symptom is one of the most complained symptoms among SLE patients. In our physical QOL model, in agreement with those reported by others (Baker, Kim & Pope, 2009; Hyphantis, T. et al., 2011), fatigue symptom has great impact on one's daily participation and further influences on physical health QOL. Patients with SLE scores highest on item "I can do the daily activities that I use to do" and "I have energy", which means they have insufficient energy to participate in life activities. The lack of energy to engage in daily lives further decreases their sense of well-being. A study done in Taiwan had highlighted the importance of facilitating both fatigue and health-promoting lifestyle as a mean to improve physical health QOL (Huang et al., 2007).

In physical health domain QOL model, pain symptom has only indirect influence on physical QOL through a mediator of sense of competence. Actually, in previous study, Emine Handan Tüzün had found patients who have a better quality of life showed a greater level of acceptance of pain and a willingness to engage in activities despite the existence of pain. The result addressed the importance of engagement than the existence of pain symptom. In fact, there were some evidence mentioned chronic musculoskeletal pain impacts negatively on physical health QOL in several ways instead of directly influence of QOL. In a review of QOL in chronic musculoskeletal pain, pain was found to lead to disability, and disability eventually decreases physical QOL in patients with osteoarthritis, rheumatoid arthritis, and low back pain (Tüzün, 2007). Thus, the pain symptom may not direct impact on physical QOL until pain interferes with their daily participation. Doria et al. had suggested the presence of a more complex model between pain, psychological distress, and QOL. The existence of chronic pain may have reciprocal influence on psychological distress

and, in turn, reduces QOL. Accordingly, study indicated that patients with SLE need to focus on what they can do rather than the existence of pain.

Depression were said to show a high prevalence among SLE patients. In our study, 27.7% of participants had scored above 13 points in Beck depression inventory-II (BDI-II), which indicates their depressive symptom are higher than health control norms. Understanding the underlying components of psychological distress in SLE patients would be an important avenue in developing the best treatment regimes. In patients with SLE, the depressed mood may come from several factors: high doses of corticosteroids used in SLE treatment, the concern of rejecting by others for the change appearance of side effects of medication, physical damage, and chronic joint pain (Nery et al., 2007). The presence of negative life events was the stressors of SLE patients, and they face the demand of adaption. However, the use of disengaging and emotional coping styles may be the reason that further makes people distressed. Kozora et al. had examined the relationships between stressors, coping styles, and social support on SLE patients. What they found was the experience of a life-threatening adverse event within the prior 6 months and use of more avoidant coping styles related to severely psychological distress (Kozora, Ellison, Waxmonsky, Wamboldt, & Patterson, 2005).

Patients with SLE are anxiety about the disease activity fluctuation, side effects of medication, the face appearance, or the acceptance by others. In our study, anxiety symptom has only indirect effect on psychological QOL. The result was similar in a Greece study that anxiety was not an independent predictor of psychological health QOL evaluating by WHOQOL-BREF (Hyphantis, Thomas et al., 2009). Previous research has suggested a possible mechanism leading to the result.

Researchers had demonstrated that the presence of anxiety symptom may increase the likelihood of physical illness, causing some physical problems. These physical problems reduce the capacity to deal with daily living challenges and associated with the poorer functional outcomes. In combination with anxiety and anxiety-led poor functional outcomes, the psychological health QOL decreased (Sareen et al., 2006). Thus, anxiety symptom may indirectly impact on psychological QOL through variables such as physical illnesses and functional limitation rather than directly influence on psychological QOL.

Psychological distress was a constant variable correlates of SLE patients' social relationships and depression was one of the major determinants of social QOL reduction in our model. In a Japan study comparing SLE with health control and other autoimmune disease, depression had a negative correlation with social relationships QOL. What they found was the significant relation between depression and life-style activities in SLE suggests that detection and treatment of psychological distress is crucial for improving both the life-style activities participation and social relationships QOL on SLE patients (Maeshima et al., 2007). An intervention had found similar result after cognitive behavioral therapy. Patient's social life had improved along with the improvement in the patient's mental areas. The result addressed the importance of maintaining social life through reducing emotional distress (Navarrete-Navarrete et al., 2010). Actually, depression symptom had already been observed in patients with some autoimmune diseases. Not only SLE, but also cancer, glaucoma, and rheumatoid arthritis had led to depression, which found to generate large effect on social relationships QOL (Hyphantis, Thomas et al., 2009).

Most studies had applied SF-36 to evaluation QOL in patients with SLE, however, the lack of environmental domain QOL limits its' application. Previous research has highlighted the need for such studies in a wide variety of socio-cultural contexts. In our study, we applied WHOQOL-BREF-TW as the measurement of QOL, which has the merit of evaluating environmental domain of QOL. WHOQOL-BREF environmental domain is also said to be particularly appropriate in Asian countries where environmental factors play important role in determining access to health-care and health condition (Khanna et al., 2004). Among environmental QOL model, education level has indirectly influence on environmental QOL through environmental impact. A study done in Midwest Brazil examined the correlation between education level and environmental QOL. Education level was separated into three groups as primary, high, and superior. Result revealed higher levels of education perceived better environmental QOL. It was explained by that higher level education may adopt better cognitive or behavior coping strategies to deal with disease thus can represent better mental preparation and emotion control (dos Reis & da Costa, 2010). Similar result had shown in an Israel study that education level was suggested to be a contributing variable to general QOL in WHOQOL-BREF (Abu-Shakra et al., 2006). In a review of 26 studies with a total of 9886 SLE patients, lower education level was described as one of the patient characteristics led to work disability, which has profound effects on both daily participation and stemming from financial hardship (Baker, Kim & Pope, 2009). These changes would not only lower their self-esteem but also decrease their quality of life in general.

Many studies had mentioned social-economic status is a crucial factor to influence on QOL. In our result, high work satisfaction can indirectly increase the

level of environmental QOL. Model showed the more patients satisfy with their work, the less the impact on their environment. A positive work place and well job satisfaction play important roles in improving environmental QOL. It may attribute to the stable work condition to maintain their lives and to have access to gain life's necessities. The less fluctuation of environment and the less uncertainty of environment make they perceive higher environmental QOL.

Among patients with SLE, fatigue, depression, anxiety, and pain were all correlated with sense of competence in daily participation and quality of life. Nonetheless, only fatigue, pain, depression were independent predictors of quality of life in this sample. These findings are an important first step toward identifying potentially clinical factors that contribute to the result of lower quality of life and reduced daily participation.

4. The clinical applications

In the future, the medical professions can refer some results in our study. From the result, 4 domains of QOL were impacted by different variables. Thus, the most important thing in the clinical practice is to find out the most dissatisfied domain on each SLE patient. Professions could provide therapies to deal with SLE patients' physical or psychological problems based on their self-reported questionnaires.

According to path analysis in this study, fatigue, depression, and sense of competence are three variables that have largest magnitude to interfere with patients' daily participation and quality of life. Thus, early intervention targeting on these symptoms may be the way to lead to the optimal outcome of disease along with the chronic illness duration. For example, we can apply assessments in the clinics to

evaluation patients' level of sense of competence in daily activity and work status to monitor their life participation. The severity of their symptoms could also be assessed in order to refer further treatments for the prevention of lower QOL and disengagement in their work status and daily living.

Second, according to the findings in the current sample seem plausible, and if validated, may be useful to identify assessments and interventions for lupus rehabilitation. Literature underscores the importance of interventions to help SLE patients modifying their inappropriate behaviors to cope with illness, not merely targets on the conventional pharmacologic or biologic therapy. For example, a supervised cardiovascular training program may shed light on the improvement in exercise tolerance, aerobic capacity, quality of life, and reduce fatigue symptom in patients with SLE (Carvalho et al., 2005). Existing randomized clinical trials such as SLE self-help course, telephone counseling, UVA-1 cold light treatment, or psycho-educational intervention could be adapted and provided for patients in the community and hospital clinics to deal with psychological distress such as depression and anxiety (Thumboo & Strand, 2007).

Third, comparing with normal people, just under half of working age adults with SLE is employed (Yazdany & Yelin, 2010). Withdrawal from the workforce may lead to lowered self-esteem, reduced income, and social isolation, further attributes to more medical cost to deal with psychological issue (Bultink et al., 2008). Accordingly, adopting working modification and encouraging communication with employers are important to prevent from work loss and to increase work satisfaction to improve environmental QOL. It is also worth noting that helping persons with SLE retain employment is crucial to their welfare.

5. The limitations in this study

In this study, we have insufficient sample size to address the accuracy of model fit that we only included 94 subjects to apply path analysis. It may decrease the validity of model results. Second, since inpatients were not included and patients were only included in a clinic in a hospital, the sample is not necessarily representative of the general lupus population. Furthermore, it is a cross-sectional study that only recruits data among short period of time. Since the disease activity and symptoms fluctuates among this population, we may not ensure it is the whole picture of SLE patients (Zhu, L. W., Zhang, Pan, Li, & Ye, 2010). Third, some critical factors influencing QOL on patients with SLE are not included in our study such as coping strategy, social support, social-economic status, side effects of medication, and stress. Since only a few of the potential important predictors were assessed, our conclusions are limited by the number of variables studied. These variables may contribute to lower social relationships QOL and environmental QOL that we did not detect. Final, the cross-section design of our study limits its examination of time change effect on QOL. Since SLE is a chronic disease with fluctuated disease activity and swing emotion, the periods of remission and exacerbation of disease activity may change patients' perception of their quality of life further vary the result of evaluation.

6. Future suggestions

In our study, we found the discordance between physician and patient report of disease activity may vary the outcome of medical care (Pons-Estel et al., 2010). However, there are little Chinese version self-reported assessments of disease activity for SLE patients. The development of Chinese version patient-reported assessments

with sound psychometric properties for disease activity and disease damage is what deserve in further research.

Second, there are many regimens targeting on dealing with depression in the reference, however, little efforts had targeted on anxiety treatment for patient with SLE. Thus, similar efforts should be examined and suggested in the future studies for anxiety symptoms. Besides, we can observe symptoms vary among SLE patients. However, treatments often design for the whole SLE group rather than personalization. The effects of individualized motivationally tailored interventions must be examined in the future.

The last, from self-reported medication, we could find sleep a critical problem to interfere with patients' QOL. The existence of chronic illness is also said to generate personality change. Whether anxiety and depressed mood are secondary symptoms cause by sleep disturbance and the existence of chronic illness is what we can examine in the future.

CONCLUSION

The cross-sectional study of QOL in patients with systemic lupus erythematosus built 4 domains of QOL and examined by path analysis, showing diverse variables contributed to lower QOL. Patients were satisfied with their environmental QOL, followed by social relationships, physical health, and the last psychological health QOL. As literature suggested, the most complained symptoms on SLE patients are also predictors of QOL. Fatigue, depression, and sense of competence are variables that present the largest magnitude effects on QOL. Social-demographic characteristics like education level and work status also either direct or indirectly impact on physical health or environmental QOL. However, disease activity, age, and disease duration are not as important variables as we previous thought. We may conclude patients with longer disease duration or higher disease activity could still have good QOL despite of the existence of illness.

The present study provides a holistic picture of QOL in patients with SLE. Each domain QOL presents diverse problem existing on SLE patients. In physical health domain, SLE patients reported they have insufficient energy to do what they use to do in daily lives. Pain symptom also impacts on physical health QOL indirectly via their decreased sense of competence. Patients with higher education level even sense better physical health QOL. What we proved is both symptoms and personality characteristics are crucial for evaluating patients' QOL.

In psychological health domain, psychological distress such as depression, anxiety, and sense of mastery explained a large portion of total variance. We could confirm the severity of emotional distress may tend to change patients' perception toward their well-being and enjoyment of life. With regard to social relationships domain, depression and fatigue still pose a threat on patients' sense of competence. It happened to us the relevant roles of depressive mood and insufficient energy in the maintenance their social relationships.

Results also remind us there may have interactions between psychological health status and social relationships in patients with SLE.

Environmental QOL is seldom largely discussed in previous studies. In our study, we apply the WHOQOL-BREF-TW to evaluate the environmental domain QOL to examine correlational variables. The environmental domain of QOL is relatively more complicated for depression, work satisfaction, and education level all have much effect on QOL. The result shows mental distress and social-demographic variables are crucial to maintain a patients' well-being. In particular, environmental impact presents the largest magnitude among all the variables, indicating both the change of physical and social environmental could impact on patients' perception on QOL.

Nowadays, many clinical trials and treatments are developed to support SLE patients' mental health. The existence of clinical trials such as self-help course, telephone counseling, or psycho-educational intervention may help patients with SLE dealing with psychological distress, regaining their sense of mastery in life, and facilitating engagement. The aerobic exercise could also provide strength and energy to maintain daily engagement.

The finding of our study may provide us suggestions that it could be useful to identify assessments and interventions for lupus rehabilitation. Although medication and biochemical index in blood test are important to maintain patients' health condition and inflammation, it is noteworthy that patients' self-reported symptoms and daily participation are crucial to their sense of well-being. With regard to daily participation, adopting work or life modification and encouraging communication with employers and family members are important to prevent from work loss and limitation to improve QOL.

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FIGURES

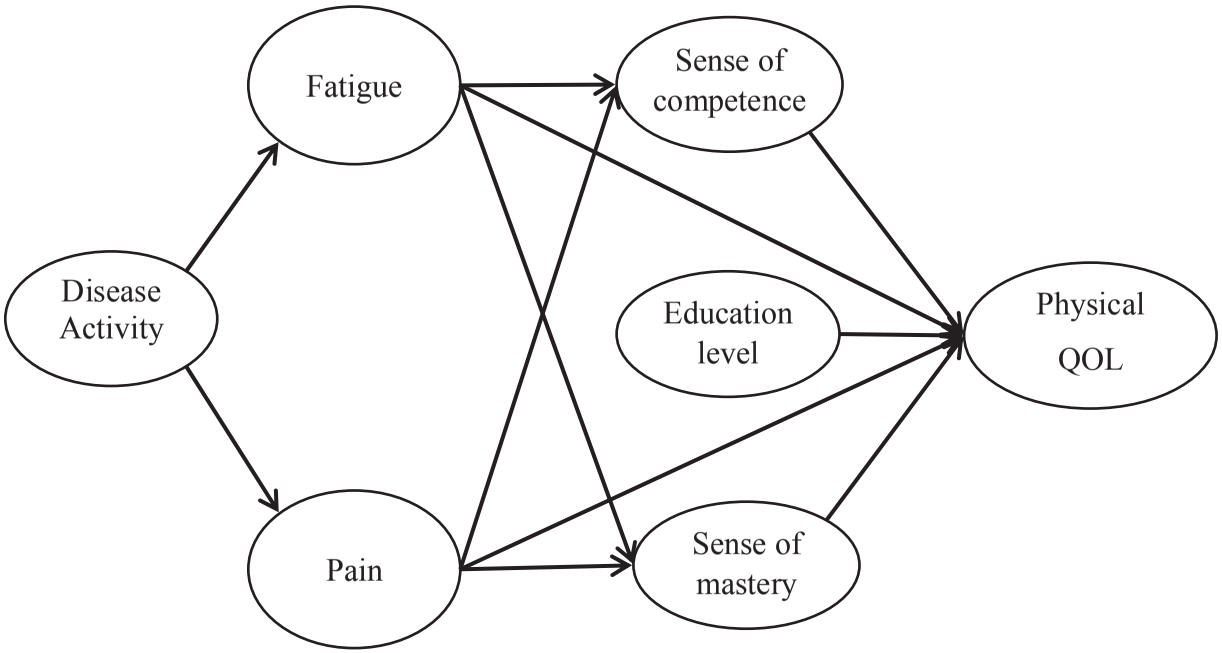


Figure 1 The initial model of physical health domain QOL

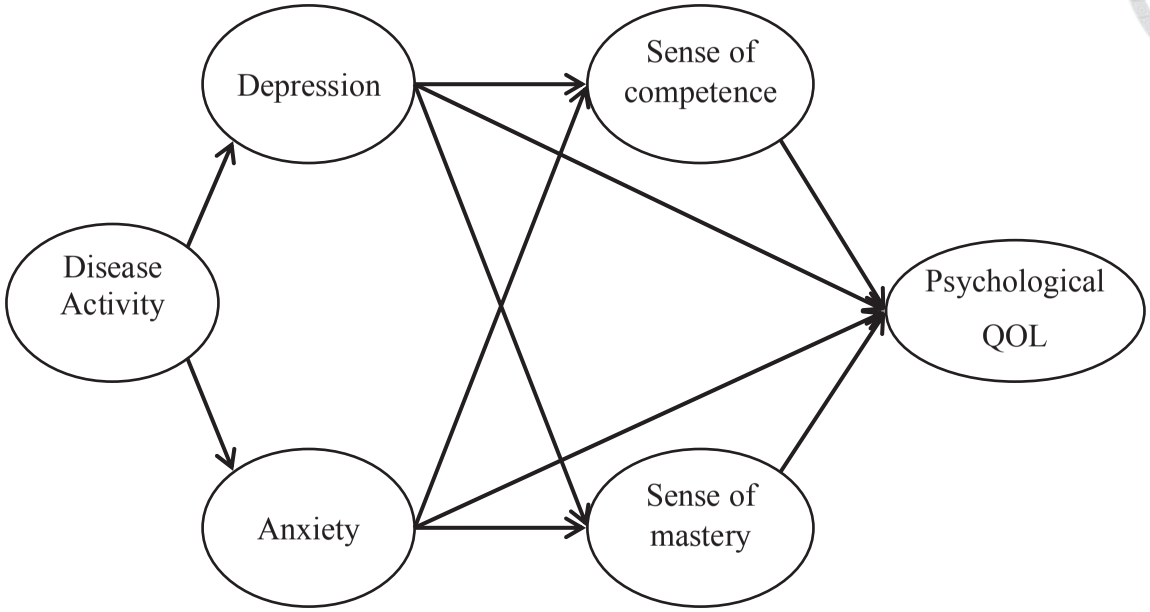


Figure 2 The initial model of psychological health domain QOL

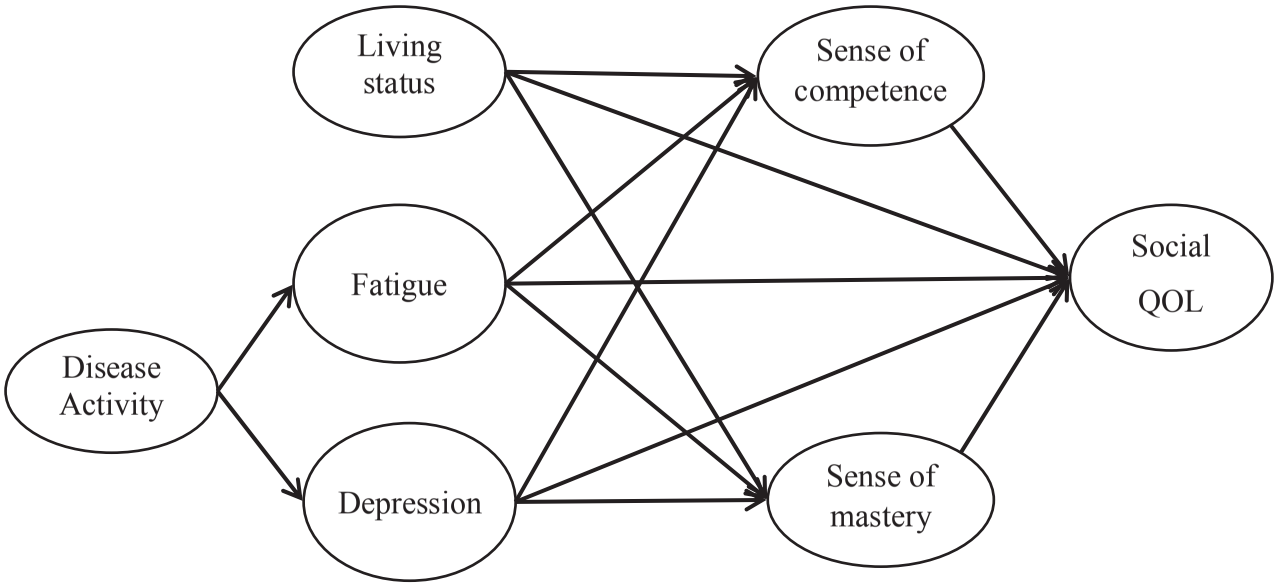


Figure 3 The initial model of social relationships domain QOL

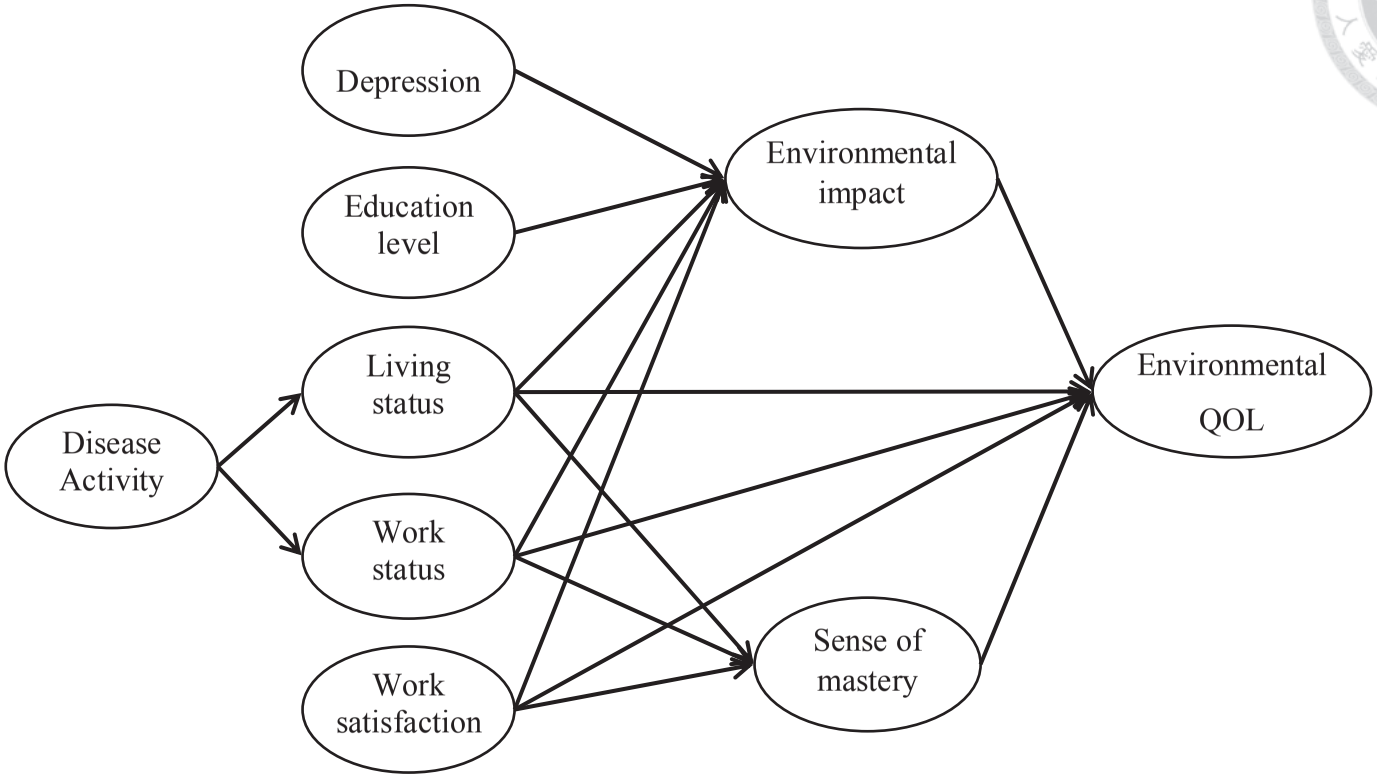


Figure 4 The initial model of environmental domain QOL

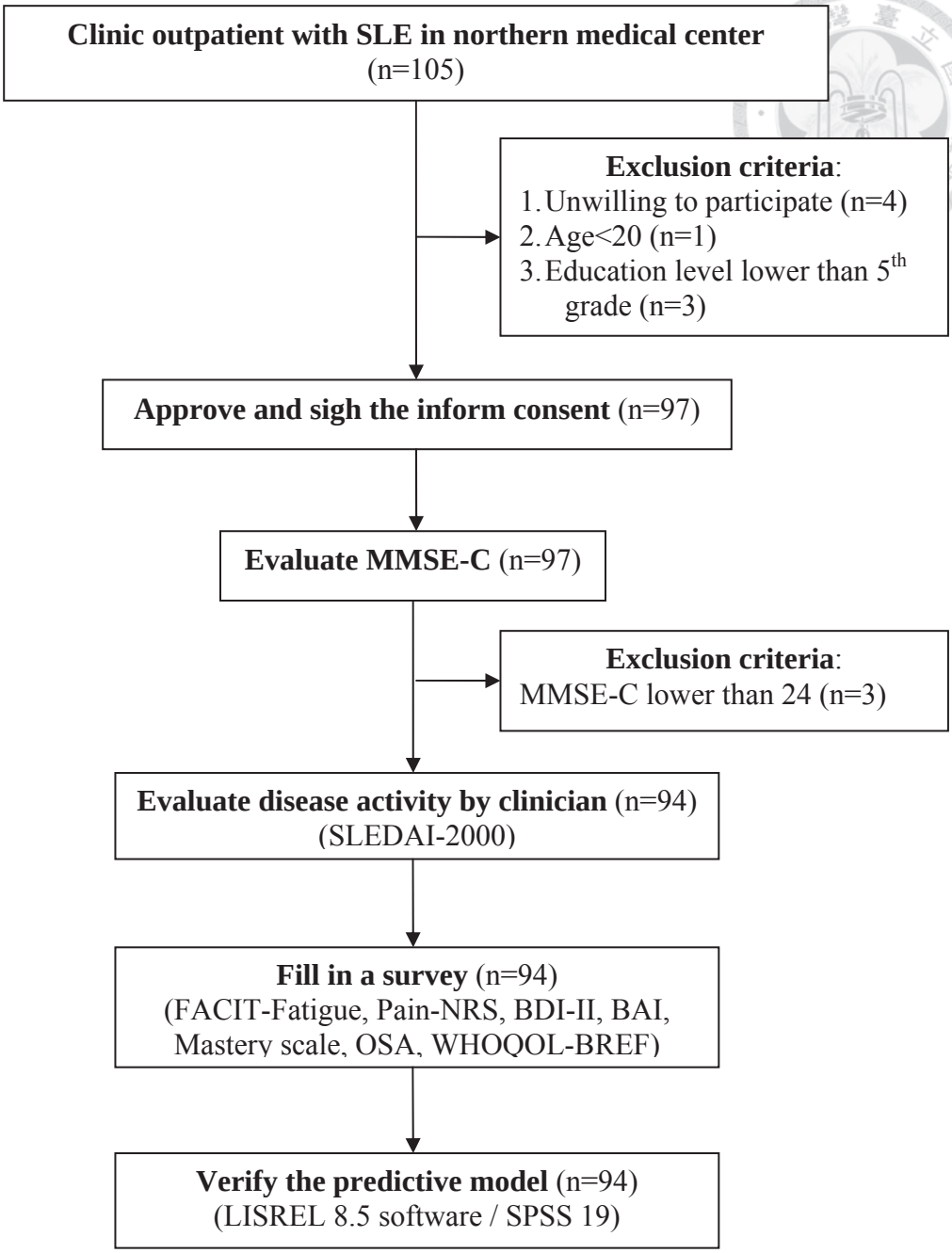


Figure 5 Enrollment procedure

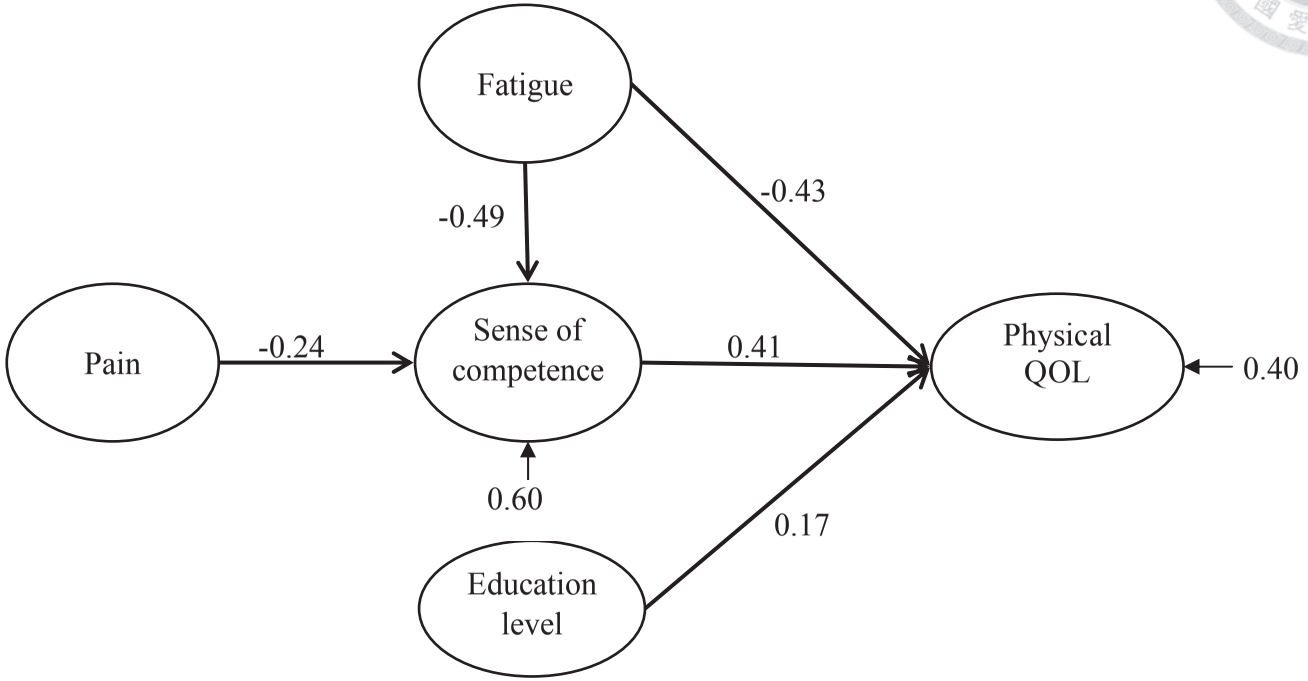


Figure 6 The final model of physical health domain QOL

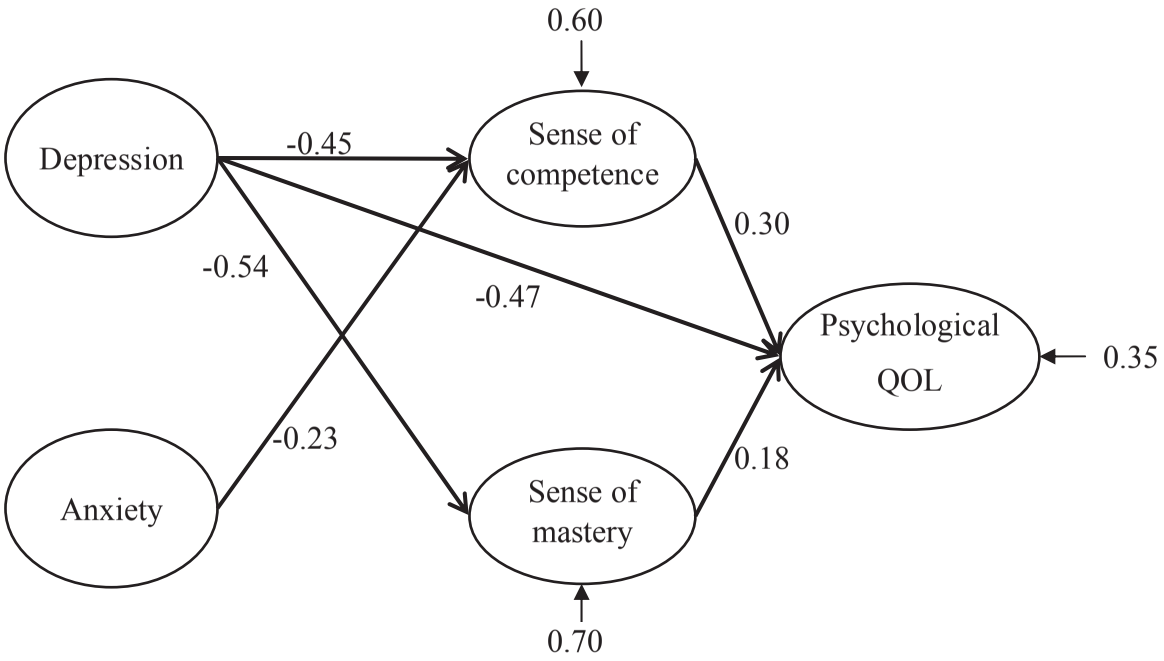


Figure 7 The final model of psychological health domain QOL

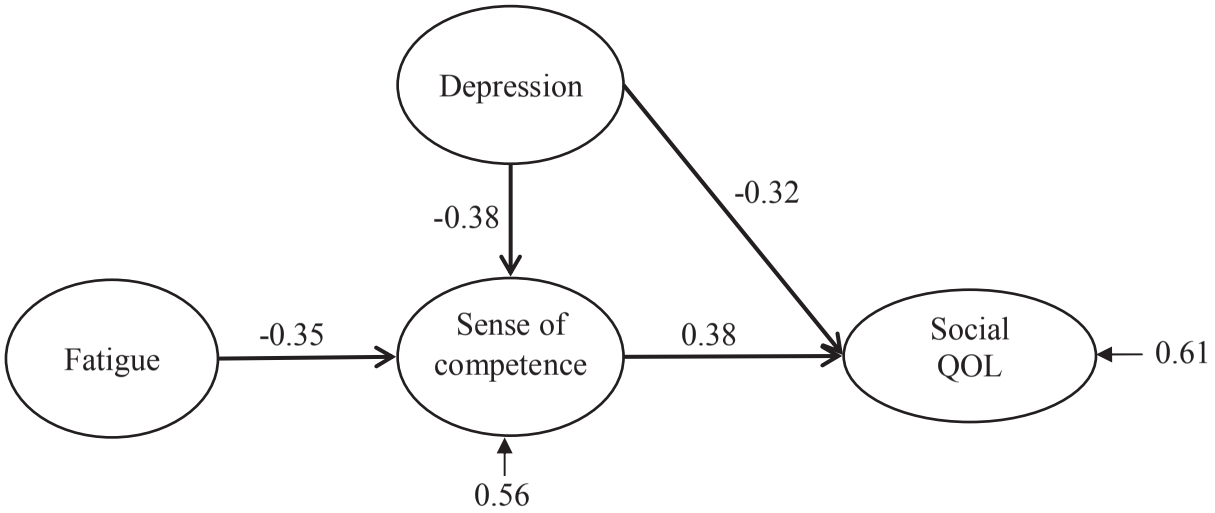


Figure 8 The final model of social relationships domain QOL

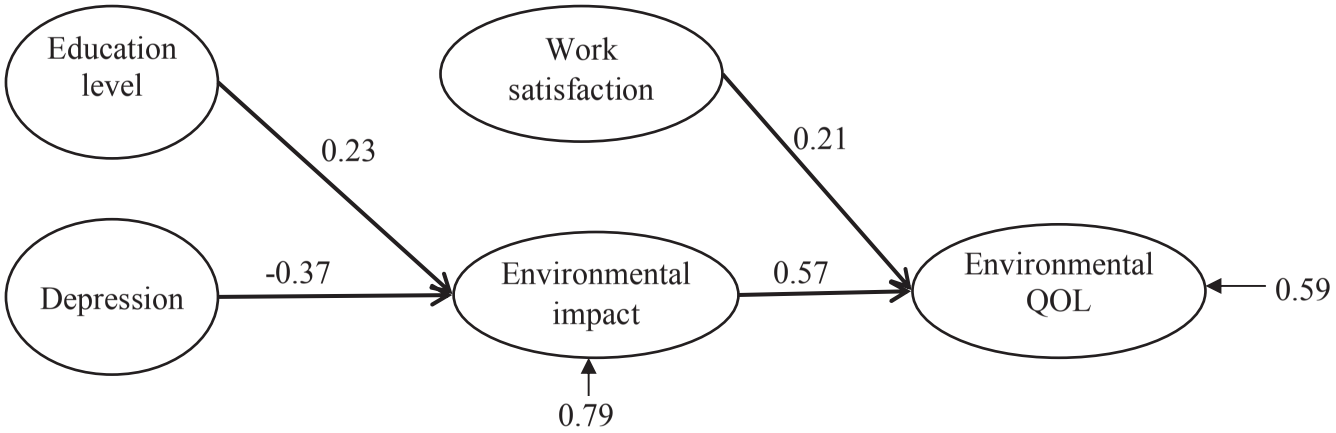


Figure 9 The final model of environmental domain QOL

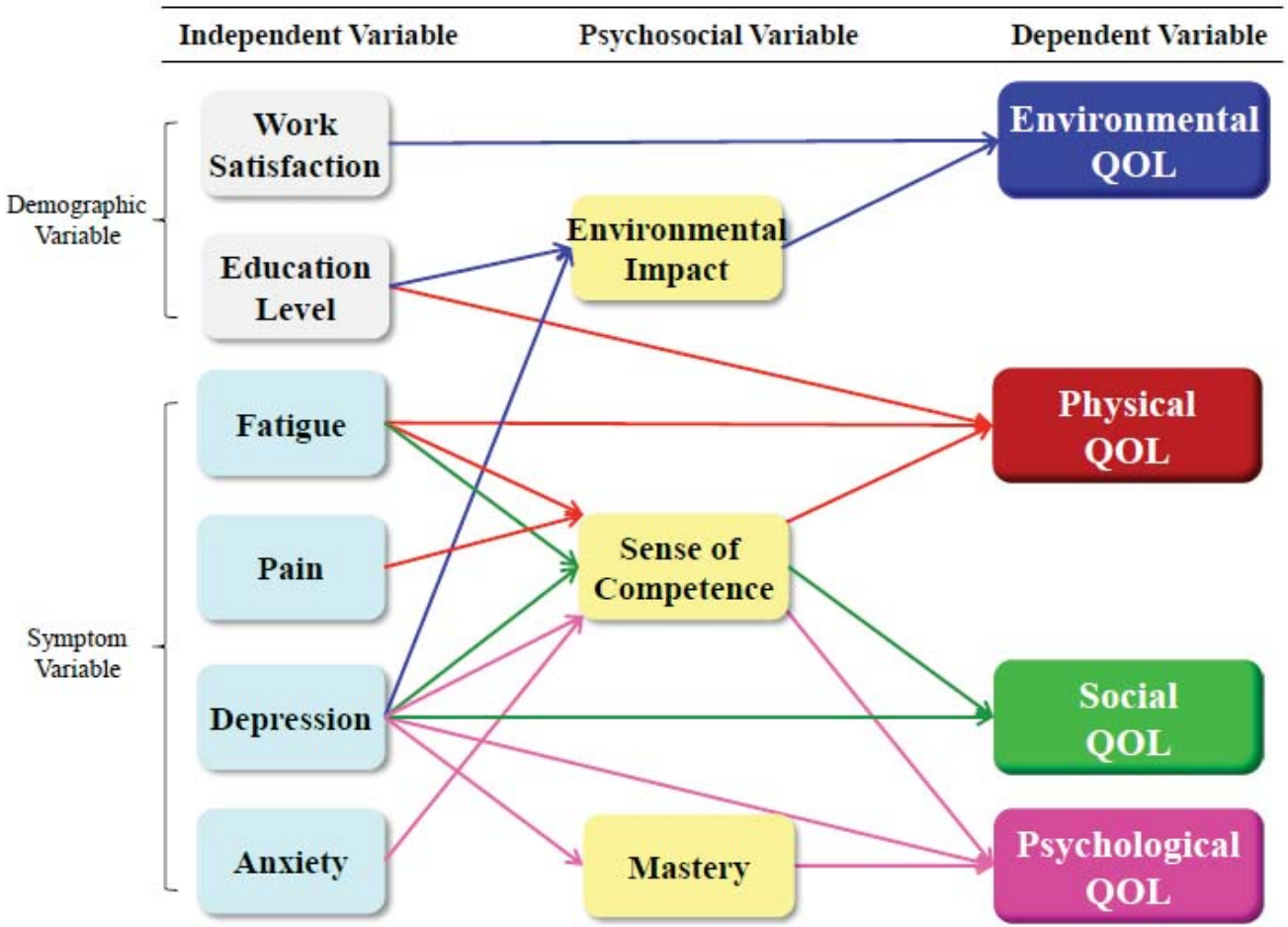


Figure 10 The final QOL model for SLE

TABLES

Table 1 Characteristics of subjects (n=94)

Demographics	
Age (range, mean ± SD years)	20.32~70.42, 49.47±11.03
Gender (no, %)	
Men	7, 7.4%
Female	87, 92.6%
Education level (no, %)	
Elementary school	3, 3.2%
Junior high	10, 10.6%
Senior high	29, 30.9%
College	44, 46.8%
Higher education	8, 8.5%
Disease duration (range, mean ± SD years)	1~42, 14.77 ±8.84
Onset age (range, mean ± SD years)	13.8~60.4, 34.7 ±13.06
Marital status (no, %)	
Single	24, 25.5%
Married	64, 68.1%
Divorced	5, 5.3%
Widowed	1, 1.1%
Working status (no, %)	
Full-time	48, 51.1%
Part-time	5, 5.3%
Unemployed	11, 11.7%
Retire	30, 31.9%
Number of hospitalizations (no, %)	
0 time	32, 34.0%
1 time	19, 20.2%
2 times	10, 10.6%
3 times	5, 5.3%
4 times	3, 3.2%
5 and above 5 times	25, 26.6%
Clinics frequency (mean ± SD)	1.63±0.72
1 month (no, %)	48, 51.1%
2 months	33, 35.1%

3 months	13, 13.8%
Steroid (range, mean ± SD mg per day)	0~30, 7.85 ±6.55
Quinine per day (range, mean ± SD)	0~4, 1.32±0.79
Immunosuppressant (no, %)	
Yes	34, 36.2%
No	60, 63.8%
Hypnotics (no, %)	
Yes	24, 25.5%
No	70, 74.5%
Independence level (no, %)	
Independent	75, 79.8%
Need little assistant	18, 19.1%
Need large assistant	1, 1.1%
Life satisfaction (range, mean ± SD)	2~100, 77.94±15.07
Satisfaction toward work or study (range, mean ± SD)	30~100, 79.55±13.48

Table 2 Raw scores of the assessments in the study (n=94)

Instrument	Mean	Range	Standard Deviation
MMSE	28.37	24~30	1.59
FACIT-F	14.36	1~45	8.26
Pain-NRS	2.21	0~10	2.85
BDI-II	10.31	0~48	10.30
BAI	10.69	0~55	10.35
OSA-My self	63.20	30~84	9.56
OSA-Environmental impact	25.07	11~32	4.29
Mastery	19.35	11~28	3.23
SLEDAI-2000	5.12	0~12	2.66
WHOQOLBREF-TW			
Physical health	13.29	4.57~20	2.72
Psychological health	12.72	5.33~18.67	2.95
Social relationships	13.52	9~17	2.05
Environmental	14.34	8~19.56	2.08

Table 3 Correlation matrix of 4 domains of QOL

	Fatigue	Pain	Depression	Anxiety	Sense of competence	Environmental impact	Mastery	Disease activity	Work satisfaction	Education level	Work status
Fatigue	1.000										
Pain	0.431*	1.000									
Depression	0.646*	0.498*	1.000								
Anxiety	0.720*	0.453*	0.676*	1.000							
Sense of competence	-0.594*	-0.452*	-0.606*	-0.533*	1.000						
Environmental impact	-0.288*	-0.454*	-0.401*	-0.216*	0.715*	1.000					
Mastery	-0.381*	-0.263*	-0.544*	-0.375*	0.515*	0.527*	1.000				
Disease activity	0.166	0.208*	0.262*	0.169	-0.282*	-0.271*	-0.233*	1.000			
Work satisfaction	-0.475*	-0.368*	-0.400*	-0.345*	0.355*	0.134	0.229*	-0.172	1.000		
Education level	0.041	-0.218*	-0.120	0.005	0.162	0.271*	0.082	-0.098	0.000	1.000	
Work status	0.067	0.114	0.093	-0.001	-0.107	-0.221*	-0.150	0.188	0.026	-0.288*	1.000
Physical QOL	-0.663*	-0.483*	-0.566*	-0.522*	0.689*	0.479*	0.473*	-0.219*	0.451*	0.219*	-0.181
Psychological QOL	-0.568*	-0.438*	-0.748*	-0.539*	0.679*	0.479*	0.589*	-0.286*	0.455*	0.118	-0.153
Social QOL	-0.467*	-0.380*	-0.548*	-0.320*	0.572*	0.536*	0.409*	-0.213*	0.383*	0.219*	-0.194
Environmental QOL	-0.329*	-0.394*	-0.468*	-0.341*	0.612*	0.602*	0.537*	-0.182	0.284*	0.244*	-0.159

Table 4 Path analysis for the initial physical health QOL model

Dependent Variable	Independent Variable	Regression Coefficient	Standard Error	t value	R^2
Physical QOL	Fatigue	-0.38*	0.080	-4.21*	0.56
	Pain	-0.11	0.068	-1.54	
	Sense of competence	0.33*	0.083	3.95*	
	Mastery	0.12	0.070	1.67	
	Education level	0.15	0.065	2.31	
Sense of competence	Fatigue	-0.49*	0.081	-6.07*	0.34
	Pain	-0.24*	0.081	-2.99*	
Mastery	Fatigue	-0.33*	0.096	-3.42*	0.13
	Pain	-0.12	0.096	-1.27	
Fatigue	Disease Activity	0.17	0.10	1.60	0.03
Pain	Disease Activity	0.21*	0.10	2.03*	0.04
*significant: p<0.05					

Index	Value	Criteria	Fitness
Chi-Square	41.72	N/A	N/A
p-value	p=0.0000	p>0.05	Substandard
df	9	N/A	N/A
GFI	0.89	>0.9	Substandard
AGFI	0.65	>0.9	Substandard
CFI	0.81	>0.9	Substandard
NFI	0.79	>0.9	Substandard

Table 5 Path analysis for the initial psychological health QOL model

Dependent Variable	Independent Variable	Regression Coefficient	Standard Error	t value	R^2
Psychological QOL	Depression	-0.47*	0.080	-5.90*	0.63
	Anxiety	0.011	0.063	0.17	
	Sense of competence	0.31*	0.078	3.92*	
	Mastery	0.18*	0.072	2.45*	
Sense of competence	Depression	-0.45*	0.081	-5.57*	0.31
	Anxiety	-0.23*	0.081	-2.8*	
Mastery	Depression	-0.54*	0.088	-6.11*	0.29
	Anxiety	-0.013	0.088	-0.15	
Depression	Disease Activity	0.26*	0.10	2.60*	0.07
Anxiety	Disease Activity	0.17	0.10	1.65	0.03
*significant: $p<0.05$					

Index	Value	Criteria	Fitness
Chi-Square	52.68	N/A	N/A
p-value	p=0.00	p>0.05	Substandard
df	5	N/A	N/A
GFI	0.84	>0.9	Substandard
AGFI	0.33	>0.9	Substandard
CFI	0.75	>0.9	Substandard
NFI	0.74	>0.9	Substandard

Table 6 Path analysis for the initial social relationships QOL model

Dependent Variable	Independent Variable	Regression Coefficient	Standard Error	t value	R^2
Social QOL	Living status	0.13	0.081	1.61	0.38
	Depression	-0.30*	0.10	-2.95*	
	Fatigue	-0.09	0.09	-1.01	
	Sense of competence	0.33*	0.11	3.06*	
	Mastery	0.071	0.096	0.73	
Sense of competence	Living status	0.035	0.079	0.44	0.34
	Depression	-0.39*	0.079	-5.00*	
	Fatigue	-0.35*	0.079	-4.47*	
Mastery	Living status	-0.022	0.088	-0.25	0.27
	Depression	-0.50*	0.088	-5.73*	
	Fatigue	-0.048	0.088	-0.54	
Depression	Disease Activity	0.26*	0.10	2.59*	0.07
Fatigue	Disease Activity	0.17	0.10	1.60	0.03
*significant: p<0.05					

Index	Value	Criteria	Fitness
Chi-Square	76.34	N/A	N/A
p-value	p=0.00	p>0.05	Substandard
df	7	N/A	N/A
GFI	0.81	>0.9	Substandard
AGFI	0.24	>0.9	Substandard
CFI	0.65	>0.9	Substandard
NFI	0.65	>0.9	Substandard

Table 7 Path analysis for the initial environmental QOL model

Dependent Variable	Independent Variable	Regression Coefficient	Standard Error	t value	R^2
Environmental QOL	Work Satisfaction	0.16*	0.080	2.01*	0.38
	Work status	-0.026	0.080	-0.32	
	Living status	-0.073	-0.081	-0.90	
	Environmental impact	0.43*	0.08	5.35*	
	Mastery	0.25*	0.083	3.05*	
Environmental impact	Work Satisfaction	-0.011	0.093	-0.11	0.22
	Work status	-0.13	0.093	-1.42	
	Living status	-0.0005	0.10	-0.005	
	Depression	-0.37*	0.10	-3.59*	
	Education level	0.19*	0.094	2.01*	
Mastery	Work Satisfaction	0.21*	0.10	-2.08*	0.11
	Work status	-0.14	0.10	-1.42	
	Living status	-0.21*	0.10	-2.08*	
Work Satisfaction	Disease Activity	-0.19	0.10	-1.80	0.035
Work status	Disease Activity	0.19	0.10	1.81	0.036
*significant: p<0.05					

Index	Value	Criteria	Fitness
Chi-Square	55.66	N/A	N/A
p-value	p=0.00	p>0.05	Substandard
df	15	N/A	N/A
GFI	0.88	>0.9	Substandard
AGFI	0.65	>0.9	Substandard
CFI	0.67	>0.9	Substandard
NFI	0.66	>0.9	Substandard

Table 8 Path analysis for the final physical health QOL model

Dependent Variable	**Independent Variable**	**Regression Coefficient**	**Standard Error**	**t value**	**R^2**
Physical QOL	Sense of competence	0.41*	0.083	4.92*	0.60
	Fatigue	-0.43*	0.083	-5.17*	
	Education level	0.17*	0.067	2.56*	
Sense of competence	Fatigue	-0.49*	0.090	-5.42*	0.40
	Pain	-0.24*	0.090	-2.67*	
*significant: $p<0.05$					
Index		**Criteria**	**Fitness**		
Chi-Square	4.76	N/A	N/A		
p-value	p=0.09	p>0.05	Meet standard		
df	2	N/A	N/A		
GFI	0.98	>0.9	Meet standard		
AGFI	0.85	>0.9	Substandard		
CFI	0.98	>0.9	Meet standard		
NFI	0.97	>0.9	Meet standard		

Table 9 Path analysis for the final psychological health QOL model

Dependent Variable	Independent Variable	Regression Coefficient	Standard Error	t value	R^2
Psychological QOL	Sense of competence	0.30*	0.077	3.96*	0.65
	Depression	-0.47*	0.086	-5.41*	
	Mastery	0.18*	0.073	2.44*	
Sense of competence	Depression	-0.45*	0.11	-4.09*	0.40
	Anxiety	-0.23*	0.11	-2.05*	
Mastery	Depression	-0.54*	0.088	-6.18*	0.30

*significant: $p<0.05$

Index	Value	Criteria	Fitness
Chi-Square	7.41		N/A
p-value	p=0.06		Meet standard
df	3		N/A
GFI	0.97	>0.9	Meet standard
AGFI	0.85	>0.9	Substandard
CFI	0.98	>0.9	Meet standard
NFI	0.97	>0.9	Meet standard

Table 10 Path analysis for the final social relationships QOL model

Dependent Variable	Independent Variable	Regression Coefficient	Standard Error	t value	R^2
Social QOL	Sense of competence	0.38*	0.10	3.70*	0.39
	Depression	-0.32*	0.10	-3.09*	
Sense of competence	Depression	-0.38*	0.10	-3.71*	0.44
	Fatigue	-0.35*	0.10	-3.38*	

*significant: $p<0.05$

Index	Value	Criteria	Fitness
Chi-Square	0.38	N/A	N/A
p-value	p=0.54	p>0.05	Meet standard
df	1	N/A	N/A
GFI	1.00	>0.9	Meet standard
AGFI	0.98	>0.9	Meet standard
CFI	1.00	>0.9	Meet standard
NFI	1.00	>0.9	Meet standard

Table 11 Path analysis for the final environmental QOL model

Dependent Variable	Independent Variable	Regression Coefficient	Standard Error	t value	R^2
Environmental QOL	Environmental impact	0.57*	0.082	6.98*	0.41
	Work Satisfaction	0.21*	0.082	2.52*	
Environmental impact	Depression	-0.37*	0.094	-3.97*	0.21
	Education level	0.23*	0.094	2.40*	

*significant: $p<0.05$

Index	Value	Criteria	Fitness
Chi-Square	6.4	N/A	N/A
p-value	p=0.09	p>0.05	Meet standard
df	3	N/A	N/A
GFI	0.97	>0.9	Meet standard
AGFI	0.87	>0.9	Substandard
CFI	0.96	>0.9	Meet standard
NFI	0.93	>0.9	Meet standard

Table 12 Decomposition of the final path model for the 4 QOL domains

QOL Domain Bivariate Relationships	Direct	Indirect	Casual	Non-casual	Correlation Coefficient
Physical health QOL					
Sense of competence	0.41	—	0.41	0.28	0.69
Fatigue	-0.43	-0.20	-0.63	-0.03	-0.66
Pain	—	-0.10	-0.10	-0.38	-0.48
Education level	0.17	—	0.17	0.05	0.22
Psychological health QOL					
Sense of competence	0.30	—	0.30	0.38	0.68
Sense of mastery	0.18	—	0.18	0.41	0.59
Depression	-0.47	-0.23	-0.70	-0.05	-0.75
Anxiety	—	-0.07	-0.07	-0.47	-0.54
Social relationships QOL					
Sense of competence	0.38	—	0.38	0.19	0.57
Depression	-0.32	-0.14	-0.46	-0.09	-0.55
Fatigue	—	-0.13	-0.13	-0.34	-0.47
Environmental QOL					
Environmental impact	0.57	—	0.57	0.03	0.60
Depression	—	-0.21	-0.21	-0.26	-0.47
Education level	—	0.13	0.13	0.11	0.24
Work satisfaction	0.21	—	0.21	0.07	0.28

Table 13 The relationships between QOL and variables (independent t-test)

Variables	Groups	Physical QOL	Psychological QOL	Social QOL	Environmental QOL	Overall QOL	Overall health QOL
SLEDAI (raw score)	≧6 < 6	0.482	0.351	0.223	0.195	0.217	0.252
Hospitalized (times)	≧4 < 4	0.891	0.339	0.887	0.725	0.024*	0.371
Steroid (mg/day)	≧15 < 15	0.709	0.686	0.441	0.535	0.577	0.032*
Work status	Have job No job	0.849	0.828	0.999	0.911	0.277	0.567
Marital status	Singled Married	0.955	0.632	0.681	0.913	0.413	1.000

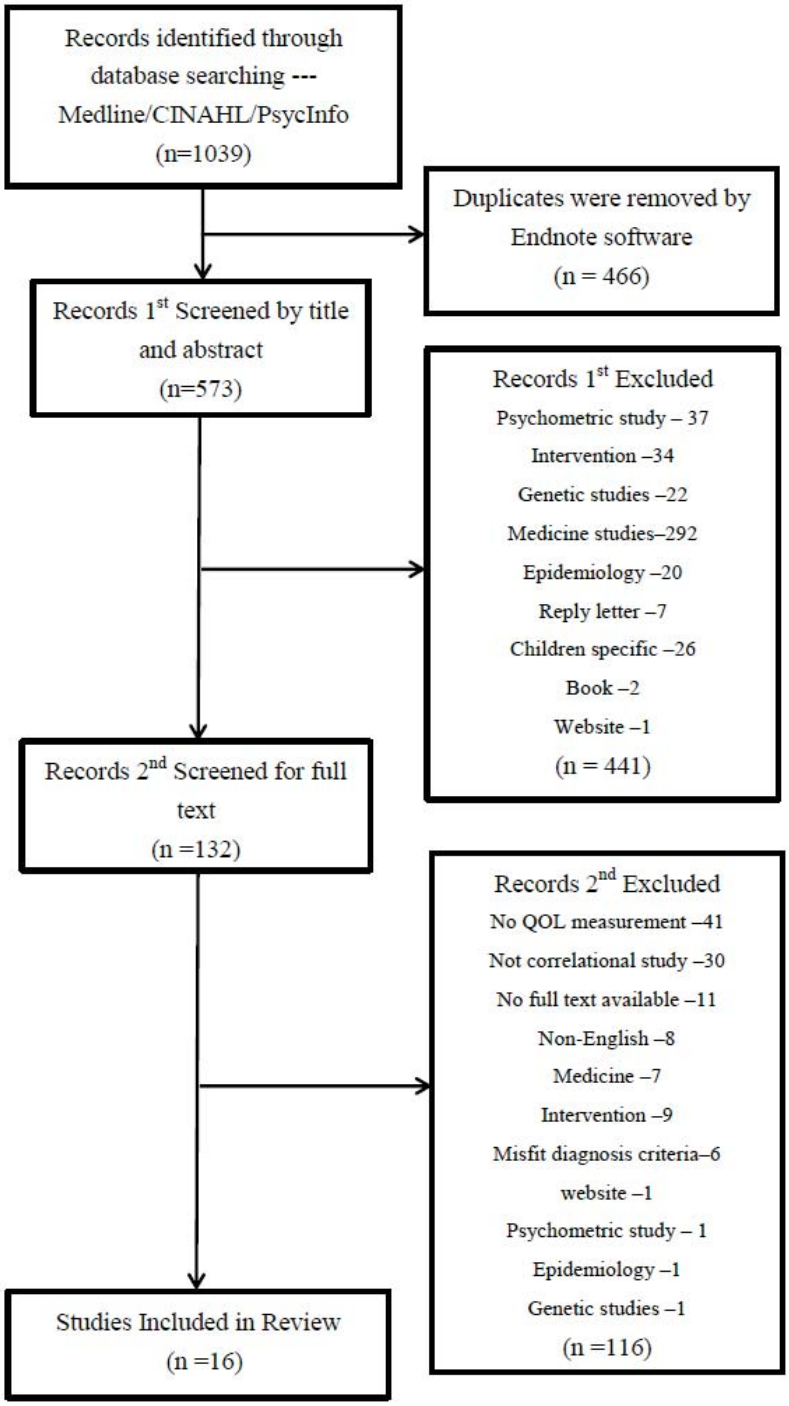
***significant level : p<0.05**

Table 14 Demographic table

姓名	
身分證字號	
病歷號碼	
生日	_____年_____月_____日 ____歲
性別	□男 □女
教育程度	□不識字 □國小(含肄業) □國中/初中(含肄業) □高中/高職 □大學/大專 □研究所以上
婚姻狀況	□已婚 □未婚 □分居 □離婚 □鰥寡/喪偶
職業	□全職就業 □兼職就業 □待業中 □退休
職業別	□公教 □軍 □工 □商 □服務業 □家管 □學生 □其他____
發病年紀	_____歲(民國_____年)
曾因紅斑性狼瘡住院次數	□0 次 □1 次 □2 次 □3 次 □4 次 □5 次 (包括以上)
門診頻率	____□月□週 ____次
類固醇服用數量	____天____顆
免疫抑制劑服用數量	____天____顆 藥名_____
奎寧服用數量	____天____顆
安眠藥服用數量	□是(____天____顆) 藥名_____ □否
是否使用生物製劑	□是(____天____支) 製劑名_____ □否
自評功能獨立程度	□獨立 □需他人一些協助 □需他人大量協助 □依賴
自評生活滿意度	_____分(0 至 100 分)
連絡電話	

APPENDIX

Appendix A. Systematic review procedure



Appendix B. Summary of the correlational studies related to QOL in patients with SLE

Symptom	Author	Country	Sample Size (M:F)	QOL Measurement	Symptom Measurement	Significance	Note
Fatigue							
	*Pettersson, S. et al.	Sweden	324 (14:144)	SF-36	Yes-no question	Fatigue was associated with PSC and MSC score ($p < 0.001$)	predictor
	*Sanchez, M. L.et al.	USA	588 (10:90)	SF-6D	FSS	Fatigue was associated with PSC, MSC and total SF-6D score ($p<0.0001$)	Increased fatigue predicts lower QOL
Depression							
	*Shen, Biyu. et al.	China	158 (14:144)	SF-36	SDS	Four domains were associated with SDS, VT, PF, SF, and RE ($p=0.04$~0.001)	Stepwise regression
	*Moldovan, I. et al.	USA	125 (6:119)	SF-36	PHQ-9	All domains were associated with PHQ-9 except GH(general health) ($p=0.07$)	regression
	*Sanchez, M. L.et al.	USA	588 (10:90)	SF-6D	U.S. Preventive Services Task Force questionnaire	Depression was associated with SF-6D ($p<0.0001$)	Univariable
Pain							
	Hyphantis, T. et al.	Greece	56 (1:8.2)	WHOQOL-BREF	visual analogue scale (VAS)	No association between pain severity and physical health QOL ($r=-0.22$, $p=0.076$)	
	*Pettersson, S. et al.	Sweden	324 (14:144)	SF-36	Yes-no question	Pain was only associated with PSC score ($p < 0.001$)	predictor
	*Tamayo, T. et al.	Germany	317 (18:299)	SF-12	Scale of 1-10	Pain was associated with PSC and MSC scores ($p < 0.01$)	

	Sanchez, M. L.et al.	USA	588 (10:90)	SF-6D	Didn't mention	No association between pain and SF-6D (p=0.3479)	Univariable
Disease activity							
	*Almehed, K. et al.	Sweden	163 (0:163)	SF-36 (Swedish version)	SLEDAI-2K	Low SLEDAI-2K was associated with the PCS(r=0.23, p<0.01)	predictor
	*Kulczycka, L.et al.	Poland	83 (5:78)	SF-36	SLAM	PF, MH and VT was associated with the SLAM	Spearman's rank correlation
	Chaiamnuay, S. et al.	Thailand	95 (2:93)	SF-36	MEX-SLEDAI	No association between MEX-SLEDAI and SF-36	
	Hyphantis, T. et al.	Greece	56 (1:8.2)	WHOQOL-BREF	SLEDAI	No association between SLEDAI and WHOQOL-BREF (β=0.035, p=0.723)	
	Mok, C. C. et al.	China	155 (6:94)	SF-36	SELENA-SLEDAI	No association between SELENA-SLEDAI and SF-36(p=0.97)	
	Moldovan, I. et al.	USA	125 (6:119)	SF-36	SLEDAI	No association between SLEDAI and SF-36 every domains (p=0.24~0.64)	regression
	*Tamayo, T. et al.	Germany	317 (18:299)	SF-12	SLAQ	SLAQ was associated with PSC and MSC scores (p < 0.01)	
	*Sanchez, M. L.et al.	USA	588 (10:90)	SF-6D	SLAM-R	SLAM-R was associated with the SF-6D (p<0.0001)	Multivariate
	*Zhu, Tracy Y. et al.	China	303 (12:291)	SF-36	A revised SELENA flare tool	Only PSC had significant differences between patients with and without flares	
	*Zheng, Y. et al.	China	202 (26:176)	SF-36	SLEDAI	MSC and PSC domains were associated with SLEDAI (p=0.04, 0.026)	predictor
	Garcia-Carrasco. et al.	Mexico	127 (0:127)	LupusQOL	Mex-SLEDAI	Mex-SLEDAI was not associated with QOL (r=-0.149; p=0.095)	Pearson's correlation
	*Zhu, L. W. et al.	China	384 (42:342)	SF-36	SLEDAI	MSC and PSC domains were negative associated with SLEDAI (r=−0.56, p=0.043; r=−0.42, p=0.031)	predictor
Anxiety							
	*Shen, Biyu. et al.	China	158 (14:144)	SF-36	SAS	Only three domains were associated with SAS, VT, PF, and RP (p=0.026~0.0001)	Stepwise regression

	*Mak, Anselm. et al.	Singapore	60 (7:53)	SF-12	HADS-anxiety	PCS-12 (not MCS-12) was associated with anxiety (p=0.014)	Multivariate predictor
Disease Damage							
	*Mok, C. C. et al.	China	155 (6:94)	SF-36	SDI	SDI was independently associated with SF-36 total score (p=0.004)	Linear regression model
	*Sanchez, M. L.et al.	USA	588 (10:90)	SF-6D	SDI	SDI was associated with SF-6D total score (p=0.04)	Multivariable
	Hanly, J. G. et al.	Canada	209 (26:183)	SF-36	SDI	No association between SDI score and SF-36 total score	
	*Garcia-Carrasco. et al.	Mexico	127 (0:127)	LupusQOL	SDI	SDI was associated with QOL total score (r=-0.31; p=0.000)	Pearson's correlation

Note:
*There is total or partial association between variable and QOL
HAQ: Health Assessment Questionnaire
SDS: The Revised Self-Rating Depression Scale
HADS: The Hospital Anxiety and Depression Scale
PCS-12: Physical component score of SF-12
SDI: Systemic Lupus International Collaborating Clinics (SLICC) Damage Index
SLAQ: Systemic Lupus Activity Questionnaire
PHQ-9: Patient Health Questionnaire
FSS: Fatigue Severity Scale
SLAMR: Systemic Lupus Activity Measure-Revised

Appendix C. The World Health Organization Quality of Life-BREF-Taiwan Version (WHOQOL-BREF-TW)

勾選說明：

這份問卷詢問您對於自己的生活品質、健康、以及其他生活領域的感覺。請您回答所有的問題。如果您對某一問題的回答不確定，請選出五個答案中最適合的一個，通常會是您最早想的那個答案。

我們的問題所關心的是您**最近兩星期內**的生活情形，請您用自己的標準、希望、愉快、以及關注點來回答問題。請參考下面的例題：

例題一：整體來說，您滿意自己的健康嗎？
□極不滿意 □不滿意 □中等程度滿意 □滿意 □極滿意

請選出最適合您在**最近兩星期內**對自己健康的滿意程度，如果您極滿意自己的健康，就在「極滿意」前的□內打「✓」。請詳細閱讀每個題目，並想想您自己的感覺，然後就每一個題目選出最適合您的答案。謝謝您的協助！

1. 整體來說，您如何評價您的生活品質？

□極不好 □不好 □中等程度好 □好 □極好

2. 整體來說，您滿意自己的健康嗎？

□極不滿意 □不滿意 □中等程度滿意 □滿意 □極滿意

3. 您覺得身體疼痛會妨礙您處理需要做的事情嗎？

□完全沒有妨礙 □有一點妨礙 □中等程度妨礙 □很妨礙 □極妨礙

4. 您需要靠醫療的幫助應付日常生活嗎？

□完全沒有需要 □有一點需要 □中等程度需要 □很需要 □極需要

5. 您享受生活嗎？

□完全沒有享受 □有一點享受 □中等程度享受 □很享受 □極享受

6. 您覺得自己的生命有意義嗎？

□完全沒有 □有一點有 □中等程度有 □很有 □極有

7. 您集中精神的能力有多好？

□完全不好 □有一點好 □中等程度好 □很好 □極好

8. 在日常生活中，您感到安全嗎？

□完全不安全 □有一點安全 □中等程度安全 □很安全 □極安全

9. 您所處的環境健康嗎？(如污染、噪音、氣候、景觀)

□完全不健康 □有一點健康 □中等程度健康 □很健康 □極健康

10. 您每天的生活有足夠的精力嗎？

□完全不足夠 □少許足夠 □中等程度足夠 □很足夠 □完全足夠

11. 您能接受自己的外表嗎？

□完全不能夠 □少許能夠 □中等程度能夠 □很能夠 □完全能夠

12. 您有足夠的金錢應付所需嗎？

□完全不足夠 □少許足夠 □中等程度足夠 □很足夠 □完全足夠

13. 您能方便得到每日生活所需的資訊嗎？

□完全不方便 □少許方便 □中等程度方便 □很方便 □完全方便

14. 您有機會從事休閒活動嗎？

□完全沒有機會□少許機會□中等程度機會 □很有機會 □完全有機會

15. 您四處行動的能力好嗎？

□完全不好 □有一點好 □中等程度好 □很好 □極好

16. 您滿意自己的睡眠狀況嗎？

□極不滿意□不滿意 □中等程度滿意 □滿意 □極滿意

17. 您對自己從事日常活動的能力滿意嗎？

□極不滿意 □不滿意 □中等程度滿意 □滿意 □極滿意

18. 您滿意自己的工作能力嗎？

□極不滿意 □不滿意 □中等程度滿意 □滿意 □極滿意

19. 您對自己滿意嗎？

□極不滿意 □不滿意 □中等程度滿意 □滿意 □極滿意

20. 您滿意自己的人際關係嗎？

□極不滿意 □不滿意 □中等程度滿意 □滿意 □極滿意

21. 您滿意自己的性生活嗎？

□極不滿意 □不滿意 □中等程度滿意 □滿意 □極滿意

22. 您滿意朋友給您的支持嗎？

□極不滿意 □不滿意 □中等程度滿意 □滿意 □極滿意

23. 您滿意自己住所的狀況嗎？

□極不滿意 □不滿意 □中等程度滿意 □滿意 □極滿意

24. 您對醫療保健服務的方便程度滿意嗎？

□極不滿意 □不滿意 □中等程度滿意 □滿意 □極滿意

25. 您滿意所使用的交通運輸方式嗎？

□極不滿意 □不滿意 □中等程度滿意 □滿意 □極滿意

26. 您常有負面的感受嗎？（如傷心、緊張、焦慮、憂鬱等）

□從來沒有 □不常有 □一半有一半沒有 □很常有 □一直都有

27. 您覺得自己有面子或被尊重嗎？

□完全沒有 □有一點有 □中等程度有 □很有 □極有

28. 您想吃的食物通常都能吃到嗎？

□從來沒有 □不常有 □一半有一半沒有 □很常有 □一直都有

Appendix D. The Functional Assessment of Chronic Illness Therapy-Fatigue (FACIT-F)

FACIT疲乏量表（第四版）

以下是那些跟您有同樣疾病的人所認爲重要的一些陳述。請在每一行圈出或標出一個數字，以表達適用於您過去7天的回答。

		一點也不	有一點	有些	相當	非常
HI7	我感到疲乏	0	1	2	3	4
HI 12	我感到全身無力	0	1	2	3	4
An1	我感到倦怠(無精打采)	0	1	2	3	4
An2	我感到疲倦	0	1	2	3	4
An3	我因爲疲倦而難以開始去做任何事情	0	1	2	3	4
An4	我因爲疲倦而難以完成所做的事	0	1	2	3	4
An5	我有精力	0	1	2	3	4
An7	我能夠從事平常做的活動	0	1	2	3	4
An8	我白天需要睡覺	0	1	2	3	4
An 12	我因太疲倦而不想吃	0	1	2	3	4
An 14	我做平常的活動時需要幫助	0	1	2	3	4
An 15	我因爲太疲倦而無法做我想做的事，這讓我感到很挫折	0	1	2	3	4
An 16	我因爲疲倦而必須限制自己的社交活動	0	1	2	3	4

Traditional Chinese

18 September 2009
Page 1 of 1

Appendix E. The Systemic Lupus Erythematosus Disease Activity Index-2000 (SLEDAI-2000)

Study No.: _____ Patient Name: _____ _____ Visit Date: ___

(Enter weight in SLEDAI Score column if descriptor is present at the time of the visit or in the preceding 10 days.)

Weight	SLEDAI SCORE	Descriptor	Definition
8	_____	Seizure	Recent onset, exclude metabolic, infectious or drug causes.
8	_____	Psychosis	Altered ability to function in normal activity due to severe disturbance in the perception of reality. Include hallucinations, incoherence, marked loose associations, impoverished thought content, marked illogical thinking, bizarre, disorganized, or catatonic behavior. Exclude uremia and drug causes.
8	_____	Organic brain syndrome	Altered mental function with impaired orientation, memory, or other intellectual function, with rapid onset and fluctuating clinical features, inability to sustain attention to environment, plus at least 2 of the following: perceptual disturbance, incoherent speech, insomnia or daytime drowsiness, or increased or decreased psychomotor activity. Exclude metabolic, infectious, or drug causes.
8	_____	Visual disturbance	Retinal changes of SLE. Include cytoid bodies, retinal hemorrhages, serous exudate or hemorrhages in the choroid, or optic neuritis. Exclude hypertension, infection, or drug causes.
8	_____	Cranial nerve disorder	New onset of sensory or motor neuropathy involving cranial nerves.
8	_____	Lupus headache	Severe, persistent headache; may be migrainous, but must be nonresponsive to narcotic analgesia.
8	_____	CVA	New onset of cerebrovascular accident(s). Exclude arteriosclerosis.
8	_____	Vasculitis	Ulceration, gangrene, tender finger nodules, periungual infarction, splinter hemorrhages, or biopsy or angiogram proof of vasculitis.
4	_____	Arthritis	≥ 2 joints with pain and signs of inflammation (i.e., tenderness, swelling or effusion).
4	_____	Myositis	Proximal muscle aching/weakness, associated with elevated creatine phosphokinase/aldolase or electromyogram changes or a biopsy showing myositis.
4	_____	Urinary casts	Heme-granular or red blood cell casts.
4	_____	Hematuria	>5 red blood cells/high power field. Exclude stone, infection or other cause.
4	_____	Proteinuria	>0.5 gram/24 hours
4	_____	Pyuria	>5 white blood cells/high power field. Exclude infection.
2	_____	Rash	Inflammatory type rash.
2	_____	Alopecia	Abnormal, patchy or diffuse loss of hair.
2	_____	Mucosal ulcers	Oral or nasal ulcerations.
2	_____	Pleurisy	Pleuritic chest pain with pleural rub or effusion, or pleural thickening.
2	_____	Pericarditis	Pericardial pain with at least 1 of the following: rub, effusion, or electrocardiogram or echocardiogram confirmation.
2	_____	Low complement	Decrease in CH50, C3, or C4 below the lower limit of normal for testing laboratory
2	_____	Increased DNA binding	Increased DNA binding by Farr assay above normal range for testing laboratory.
1	_____	Fever	>38° C. Exclude infectious cause.
1	_____	Thrombocytopenia	<100,000 platelets / $x10^9$/L, exclude drug causes.
1	_____	Leukopenia	< 3,000 white blood cells / $x10^9$/L, exclude drug causes.
TOTAL SLEDAI SCORE _____			

Appendix F. The Occupational Self Assessment (OSA)

我自己	能力			
	許多困難	一些困難	可以做好	做得非常好
專注於我的活動或工作上				
實際從事我需要做的活動或工作				
打理居家環境				
自我照顧				
照顧我有責任扶養的人				
到我需要去的地方				
管理我的財務				
處理我的基本需求（飲食、服藥）				
向別人表達我的想法				
與別人相處				
找出問題並解決問題				
放鬆並享受生活的樂趣				
整理記錄下我需要做的事				
有一個滿意的規律生活習慣				
盡我應盡的責任				
擔任學生/工作者/志工/或家庭成員的角色				
做我喜歡的活動				
朝向我的目標努力				
以我的價值觀為標準來作決定				
完成我所計畫的事				
有效率地運用自己的技能				

Appendix G. The Mastery Scale (MS)

Mastery (Personal Control) Scale (7 題)

說明：

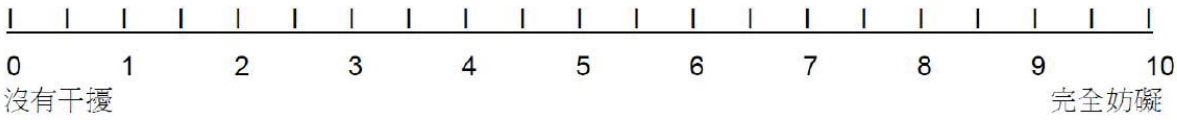
這些問題是關於您現在如何看待您的生活情況，圈選最近兩週最恰當描述您感覺的數字，指出您有多同意或不同意以下這些敘述。

	極為同意	同意	不同意	極不同意
1. 真的已經沒有方法可以解決一些我現有的問題。	1	2	3	4
2. 有時候我覺得在生活中被牽著鼻子走。	1	2	3	4
3. 我對於發生在我身上的事完全無能為力。	1	2	3	4
4. 我可以做任何我定意要做的事。	1	2	3	4
5. 我在處理生活的問題時常有無力感。	1	2	3	4
6. 未來發生在我身上的事多半取決於我。	1	2	3	4
7. 若想改變生命中許多重要的事情，我實在無能為力	1	2	3	4

PCS

Appendix H. The Pain-Numerical Rating Scale (Pain-NRS)

請根據疼痛對您的日常生活的干擾程度，在下面的比例尺上做記號。
零(0)代表沒有干擾 十(10)代表完全妨礙



Appendix I. The Mini-Mental State Examination-Chinese Version (MMSE-C)

簡易智能狀態測驗（中文版）

錯誤	正確	不明		
0	1	9	1）	今年是那一年？
0	1	9	2）	現在是什麼季節？
0	1	9	3）	今天是幾號？
0	1	9	4）	今天是禮拜幾？
0	1	9	5）	現在是那一個月份？
0	1	9	6）	我們現在是在那一個省？
0	1	9	7）	我們現在是在那一個縣、市？
0	1	9	8）	這間醫院（診所）的名稱？
0	1	9	9）	現在我們是在幾樓？
0	1	9	10）	這裡是哪一科？
0	1	9	11）	藍色 ***請重複這三個名稱，按第一次複述結果計分，***
0	1	9		悲傷 ***最多只能重複練習三次；練習次數：_____***
0	1	9		火車
			12）	請從 100 開始連續減 7，一直減 7 直到我說停爲止。
				（每減對一次得一分）
				93_____; 86_____; 79_____; 72_____; 65_____;
0	1	9	13）	***(5 分鐘後請說出剛才請你記住的三樣東西,每對一項得一分,不論順序）***
0	1	9	14）	悲傷
0	1	9	15）	火車
0	1	9	16）	（拿出手錶）這是什麼？_____
0	1	9	17）	（拿出鉛筆）這是什麼？_____
0	1	9	18）	請跟我唸一句話　『白紙真正寫黑字』
0	1	9	19）	請唸一遍並做做看　『請閉上眼睛』

0　1　9　20）請用左/右手（非利手）拿這張紙

（三步驟指令,每對一步驟得一分）

0　1　9　把它折成對半

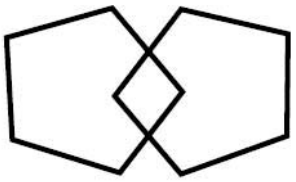
0　1　9　然後置於大腿上面

0　1　9　21）請在紙上寫一句語意完整的句子。

（含主詞動詞且語意完整的句子）

0　1　9　22）請畫出一個相同的圖形。

（兩五邊形,交一四邊形,有兩交點,則給分）



總分

（圈選 9 的部分不予計入，並說明無法施測之原因）

Appendix J.The permission for using WHOQOL-BREF-TW

臺灣版世界衛生組織生活品質問卷
(WHOQOL-BREF 臺灣簡明版)使用授權書

本人代表臺灣版世界衛生組織生活品質問卷發展小組，同意台灣大學職能治療所研究生吳昭儀，在其研究「紅斑性狼瘡的生活品質：運用路徑分析」中，使用臺灣版世界衛生組織生活品質問卷發展小組所發展出的臺灣簡明版世界衛生組織生活品質問卷（WHOQOL-BREF 台灣簡明版），做為研究之一部分。

授權人

單位：國立臺灣大學心理系姚開屏教授

日期：2014 年 2 月 19 日

簽章：姚開屏

Appendix K. The permission for using FACIT–Fatigue

FACIT.org FACIT trans

PROVIDING A VOICE FOR PATIENTS WORLDWIDE

FUNCTIONAL ASSESSMENT OF CHRONIC ILLNESS THERAPY (FACIT) LICENSING AGREEMENT

February 10, 2014

The Functional Assessment of Chronic Illness Therapy system of Quality of Life questionnaires and all related subscales, translations, and adaptations ("FACIT System") are owned and copyrighted by David Cella, Ph.D. The ownership and copyright of the FACIT System - resides strictly with Dr. Cella. Dr. Cella has granted FACIT.org (Licensor) the right to license usage of the FACIT System to other parties. Licensor represents and warrants that it has the right to grant the License contemplated by this agreement. Licensor provides to ***Chao-Yi Wu*** *the licensing agreement outlined below.*

This letter serves notice that ***Chao-Yi Wu*****("**INDIVIDUAL**")** is granted license to use the **Traditional Chinese** version of the **FACIT-Fatigue** in one study.

This current license extends to (INDIVIDUAL) subject to the following terms:

1) (INDIVIDUAL) agrees to provide Licensor with copies of any publications which come about as the result of collecting data with any FACIT questionnaire.

2) Due to the ongoing nature of cross-cultural linguistic research, Licensor reserves the right to make adaptations or revisions to wording in the FACIT, and/or related translations as necessary. If such changes occur, (INDIVIDUAL) will have the option of using either previous or updated versions according to its own research objectives.

3) (INDIVIDUAL) and associated vendors may not change the wording or phrasing of any FACIT document without previous permission from Licensor. If any changes are made to the wording or phrasing of any FACIT item without permission, the document cannot be considered the FACIT, and subsequent analyses and/or comparisons to other FACIT data will not be considered appropriate. Permission to use the name "FACIT" will not be granted for any unauthorized translations of the FACIT items. Any analyses or publications of unauthorized changes or translated versions may not use the FACIT name. Any unauthorized translation will be considered a violation of copyright protection.

4) In all publications and on every page of the FACIT used in data collection, Licensor requires the copyright information be listed precisely as it is listed on the questionnaire itself.

5) This license is not extended to electronic data capture vendors of (INDIVIDUAL). Electronic versions of the FACIT questionnaires are considered derivative works and are not covered under this license. Permission for use of an electronic version of the FACIT must be covered under separate agreement between the electronic data capture vendor and FACIT.org

6) This license is only extended for use on the internet on servers internal to (INDIVIDUAL). This FACIT license may not be used with online data capture unless specifically agreed to by Licensor in writing. Such agreement will only be provided in cases where access is password protected.

7) Licensor reserves the right to withdraw this license if (INDIVIDUAL) engages in scientific or copyright misuse of the FACIT system of questionnaires.

8) There are no fees associated with this license.

Appendix L.The permission for using SLEDAI–2000

RE: copyright of SLEDAI-2000

Violet Turalba (vturalba@jrheum.com) 新增至連絡人 2014/2/19
收件者： '吳 昭儀'
副本： Domenica

GLADMAN D. D. et al: Systemic Lupus Erythematosus Disease Activity Index 2000 J Rheumatol 2002;29(2):288-291 Table 2. SLEDAI- 2K data collection form p. 289

Dear Chao-Yi Wu,

Thank you to getting in touch with The Journal of Rheumatology and your permission request.

A one-time full permission is granted to use Table 2 from the above article for thesis purposes, you may use this permission anytime at your convenience. Please print a copy of this e-mail as proof of your permission, should you need original signed copy please provide preferred mailing address.

We appreciate full acknowledgement to The Journal of Rheumatology for the use of the material.

Yours truly,

Violet Turalba
Admin, Promotions & Exchange
The Journal of Rheumatology
365 Bloor Street East, Suite 901, Toronto, ON CANADA M4W 3L4
Tel: 416-967-5155 ext 221 / Fax: 416-967-7556 vturalba@jrheum.com / http://www.jrheum.org/

Appendix M. The permission for using OSA

Re: 使用OSA量表之授權

aywoan 2014/3/4
收件者： 吳 昭儀

Dear Chao-I
You can purchase the manual and read thoroughly before you use it. Please use proper citation when you write your thesis or paper.

Good Luck

Ay-Woan Pan

From my iPhone

吳 昭儀 <immunocytes@hotmail.com> 於 2014/3/3 下午1:16 寫道：

潘老師您好

由於學生碩論研究關於紅斑性狼瘡患者之生活品質
希望能夠探討職能表現與生活品質的關係
不知道能否與您取得Occupational self assessment量表的授權使用?

謝謝老師

吳昭儀
台灣大學職能治療學系
immunocytes@hotmail.com

Appendix N. The permission for using MS

Mastery Scale 中文版 使用同意書

編號_____

To: 熊秉荃
Cc: 潘瓊琬
台大社會工作學系
台北市羅斯福路四段一號
電話（02）33661244
pchsiung@ntu.edu.tw

本人有興趣使用 Mastery Scale 中文版，本人同意在使用過程中不會對此問卷之題目、量尺，以及題目的順序做任何的更改，並於研究論中正確引述 Chen, Y.L., Hsiung, P.C. & Pan, A.W. (2007). The study of the construct validity of the personal control scale with Rasch measurement model. Paper presented at the Pacific Rim Objective Measurement Symposium in June 16-19, Tao-Yuan, Taiwan. 為量表出處。

以下簡單說明本人將使用此問卷的研究：

研究題目：Using path analysis to investigate the quality of life on SLE patients

研究計畫主持人/論文指導教授：潘瓊琬 教授

研究性質：（請圈選） 臨床試驗 流行病學調查 計畫評估 單一受試調查 臨床工具 其他形式研究 問卷調查

受測對象及估計樣本數：紅斑性狼瘡患者 (SLE) / 60人

簡述研究內容：

利用 path analysis，找出 SLE 患者 mastery 與 QOL 之間是否有因果關係，依文獻回顧來假設，患者的 function 會影響其 sense of mastery，進而影響 QOL.

開始日期：102年年底

預計完成日期：103年年初

簽名：吳明儀

Appendix O. The permission for using Pain–NRS

Pain scales in multiple languages

The Society has produced a series of pain scales in multiple languages to assist an encourage improved assessment both by the healthcare professional and the patient, for whom English is not their first language. Difficulty in assessing pain is one common barrier that can inhibit effective treatment, particularly when the patient's first language is not English, so it is hoped that these pain scales will go some way to combat this.

The pain scales are recommended to be used by GP's and Accident and Emergency staff and may well also prove useful in a wider range of situations in which the communication of pain is necessary.

The pain scales we present on the website are judged to be easiest to use and best understood of the simple scales available for adults with no cognitive impairment. The scales assess different, partly separable, aspects of pain, plus pain relief. They are not intended to be combined in total or averaged. The best source of information about them is in a chapter: Jensen MP, Karoly P, Self-report scales and procedures for assessing pain in adults, in Turk DC and Melzack R (eds.), Handbook of Pain Assessment, 2nd edition, New York: Guilford Press, 2001, pp 15-34.

The translations were done professionally into the languages most often used in the UK by adults.

Reliability and validity

Because pain often fluctuates over time, a high index of test-retest reliability is not the goal - it might indicate insensitivity to change rather than reliability across time. As single item scales, there is no question of internal consistency, and as self-report, there is no inter-rater reliability. What helps to achieve reliability is that the scale and the response options are easy to understand, and in this it is somewhat better than the visual analogue scale.

Because pain is a subjective experience there is no "gold standard" criterion for validity. However, in a broad sense these pain ratings do bear the expected relationships to related variables, such as disability and mood, and are also correlated with the amount of activation in certain areas of the brain concerned with pain processing [Coghill RC, McHaffie JG, Yen Y-F (2003) Neural correlates of interindividual differences in the subjective experience of pain. Proceedings of the National Academy of Sciences 100 8538-8542].

Printing and downloading

The following pain scales can be downloaded and printed free of charge from this web page. Arabic and Urdu are read from left to right, instructions and scales, so have additional instructions. Both of these languages, and Gujurati, have numerals unlike those used in English and the 12 other scales.

Please Note: All the pain scales consist of the foreign language scale followed by the English language translation. The English scale at the top of the list is provided for information only.

English
Albanian
Arabic
Bengali
Chinese, Simplified
Chinese, Traditional
Greek
Gujurati
Hindi
Polish
Punjabi
Somali
Swahili
Turkish
Urdu
Vietnamese
Welsh

Appendix P. Inform consent

研究倫理委員會案號：201405046RIN NTUHREC_Version：AF-097/02.0

國立台灣大學醫學院附設醫院
研究受訪者說明及同意書

您被邀請參與此研究，這份表格提供您本研究之相關資訊，本研究已取得研究倫理委員會審查通過，研究主持人或其授權人員將會為您說明研究內容並回答您的任何疑問，請您經過慎重考慮後方予簽名。您須簽署同意書後才能參與本研究。

中文計畫名稱: 紅斑性狼瘡患者的生活品質預測模式－運用路徑分析 **英文計畫名稱: The Predictive Model of Quality of Life for Systemic Lupus Erythematosus – A Path Analysis**
執行單位：國立臺灣大學醫學院職能治療學系 委託單位/藥廠：無 **經費來源：無** **主要主持人：潘瓊琬 職稱：副教授/職能治療師 電話：(02)33668168** **協同主持人：許秉寧 職稱：教授 電話：(02)23123456#68635** **協同主持人：吳昭儀 職稱：碩士研究生/職能治療師 電話：(02)33668169** **※二十四小時緊急聯絡人：吳昭儀 電話：0928466688**
受訪者姓名： **性別： 出生日期：** **病歷號碼：** **通訊地址：** **聯絡電話：**

法定代理人、輔助人或有同意權人之姓名：

與受訪者關係：與受訪者關係：

性別：　　出生日期：

身分證字號：

通訊地址：

聯絡電話：

一、研究目的：

紅斑性狼瘡是一個會影響生活品質的疾病，因此我們希望透過問券調查，找出生活品質與症狀(疲勞、疼痛、憂鬱、焦慮等)的相關性。因此希望能邀請您參與這項問卷研究，透過驗證症狀與生活品質的關係，更加了解紅斑性狼瘡患者的感受，幫助臨床人員更加了解紅斑性狼瘡患者。

二、受訪者之參加條件：

負責本研究的人員會幫您做評估，並與您討論參加本研究所必需的條件。您必須在進入研究前簽署本受試者說明及同意書。

納入條件：

您必須符合以下所有條件方能參加本研究：

1. 經由風濕免疫科醫師診斷為紅斑性狼瘡
2. 正參與本院風濕免疫科門診追蹤治療
3. 年齡 20 歲以上成人
4. 教育程度小學五年級以上

排除條件：

若有下列任何情況者，不能參加本研究：

1. 認知功能不足(MMSE-C 測驗分數低於 24 分)
2. 未達美國風濕病醫學會疾病診斷標準

三、研究方法、程序及受訪者應配合之事項：

整個研究需要花費您半小時至一小時的時間，整個研究預計收錄 150 名紅斑性狼瘡患者參加。

1. 研究人員將在台大內科門診時間與您見面(禮拜一下午 12 診或禮拜二早上 25 診)。
2. 風濕科醫師許秉寧與研究人員會向您解釋研究目的並邀請您參與研究。
3. 您同意後會請您簽署受試者同意書。醫師許秉寧會當場使用紅斑性狼瘡疾病活性量表(SLEDAI-2000)評估您現在的紅斑性狼瘡疾病活性，約 3 分鐘。
4. 接下來會進行基本資料的填寫以及一份簡式智能評估，簡式智能評估(Mini-Mental State Examination-Chinese, MMSE-C)是使用會談的方式，由評估者評估您現在的心智狀況，大約

會占用您 15 分鐘時間。

5.最後將請您填寫七個評估量表，這七個量表評估紅斑性狼瘡患者常有的症狀，如疲勞、疼痛、憂鬱、焦慮等。分別為疲乏量表、疼痛量表、貝氏憂鬱量表(第二版)、貝氏焦慮量表、職能自我評估量表、自我掌控感量表，以及台灣簡明版世界衛生組織生活品質量表，以上皆為中文的問卷，整個過程約半小時至一小時的時間，地點會在醫院診間。

請您遵照研究人員的指示，配合回答或填寫相關問題。在進行調查時務必請您放輕鬆，不要有任何壓力。您的回答不會對您的權益產生任何影響。

四、研究材料之保存期限及運用規劃：

本研究資料將會以去連結方式保存 2 年。所有的資料將使用統計方法進行分析，用以評估紅斑性狼瘡患者的社會心理層面狀態。

五、可預見之風險及補救措施：

若因填寫問卷時間冗長，讓您身心感到不適，請隨時與研究主持人或研究人員連絡，尋求說明或協助。您也可隨時提出退出本研究，我們將會尊重您意願。

六、研究預期效益：

由於您的熱心參與，此研究或許能夠因而找出影響紅斑性狼瘡患者生活品質的症狀，並幫助醫療人員同理紅斑性狼瘡患者感受。並期許未來能夠針對紅斑性狼瘡患者特定的症狀進行介入。

七、機密性：

臺大醫院將依法把任何可辨識您的身分之記錄與您的個人隱私資料視為機密來處理，不會公開。如果發表試驗/研究結果，您的身分仍將保密。您亦瞭解若簽署同意書即同意您的原始醫療紀錄可直接受監測者、稽核者、研究倫理委員會及主管機關。

八、損害補償：

(一) 如依本研究進行因而發生不良反應或損害，本院願意提供必要的協助。

(二) 除前項協助外，本研究不提供其他形式之補償。若您不願意接受這樣的風險，請勿參加本研究。

(三) 您不會因為簽署本同意書，而喪失在法律上應有的權利。

九、受訪者權利：

(一) 研究過程中，與您的健康或是疾病有關，可能影響您繼續接受本研究的任何重大發現，都將即時提供給您。

(二) 本研究已經過本院研究倫理委員會審查，並已獲得核准。本院研究倫理委員會委員由醫事專業人員、法律專家、社會工作人員及其他社會公正人士所組成，每月開會一次，審查內容包含試驗之利益及風險評估、受訪者照護及隱私保護等。如果您在研究過程中對研究工作性質產生疑問，對身為受訪者之權利有意見或懷疑因參與研究而受害時，可與本院之研究倫理委員會聯絡請求諮詢，其電話號碼為：__

02-2312-3456 轉 63155 。

(三) 如果您現在或於研究期間有任何問題或狀況，請不必客氣，可與 職能治療碩士研究生 吳昭儀 聯絡(24 小時聯繫電話：0928466688)。

本同意書一式 2 份，主持人或其授權人員已將同意書副本交給您，並已完整說明本研究之性質與目的。職能治療碩士研究生 吳昭儀 已回答您有關本研究的問題。

(四) 本研究預期不會衍生專利權或其他商業利益。

十、研究之退出與中止：

您可自由決定是否參加本研究；研究過程中也可隨時撤銷同意，退出研究，不需任何理由，且不會引起任何不愉快或影響日後醫師對您的醫療照顧。研究主持人亦可能於必要時中止該研究之進行。

您在退出後，即不再繼續收集資料。

十一、簽名

(一) 主要主持人、協同主持人已詳細解釋有關本研究計畫中上述研究方法的性質與目的，及可能產生的危險與利益。

主要主持人/協同主持人簽名：

日期：□□□□年□□月□□日

(二) 受訪者已詳細瞭解上述研究方法及其所可能產生的危險與利益，有關本研究計畫的疑問，業經計畫主持人詳細予以解釋。本人同意接受研究計畫的自願受訪者。

受訪者簽名：

日期：□□□□年□□月□□日