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Factors associated with intimacy in female Taiwanese patients with systemic lupus erythematosus: a cross-sectional study

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ABSTRACT

Objective The aim of this study was to investigate the association of demographic factors, clinical manifestations and disease activity of systemic lupus erythematosus (SLE) with intimate relationships in female patients with SLE.

Design This was a cross-sectional study based on questionnaires.

Setting This study was conducted at a regional teaching hospital in southern Taiwan from April to September 2019.

Participants Adult patients with SLE recruited from the outpatient rheumatology clinics of the study hospital.

Primary outcome measure Disease-specific quality of life assessed using the Lupus Quality of Life questionnaire (LupusQoL).

Results A total of 243 female patients with SLE were enrolled. The results of the multiple linear regression analysis indicated that the independent factors associated with a higher score in the intimate relationships domain of the LupusQoL included the age group under 40 years (p=0.001), education level of college or above (p=0.005), being employed (p<0.001), a better self-reported health status (p=0.012) and a lower SLE-Disease Activity Score (SLE-DAS) score (p=0.010). In addition, the intimate relationships domain was significantly and independently associated physical health (p=0.001), fatigue (p=0.006) and burden to others (p=0.002) domains of the LupusQoL.

Conclusions Physicians should be vigilant regarding the intimate relationships aspect of the health-related quality of life in female patients with SLE, especially in those who are older, unemployed, have a low educational level, poor self-reported health status, higher SLE-DAS, fatigue, and feeling of burden to others.

Strengths and limitations of this study

- ► This study explored the association of comprehensive factors including demographic data and clinical manifestations with intimacy in female patients with systemic lupus erythematosus (SLE).
- ► This study involved a large sample of female patients with SLE and SLE disease activity was measured with newly developed SLE-Disease Activity Score.
- ► All participants were recruited from a single regional hospital and thus limited the generalisability of the results.

INTRODUCTION

Systemic lupus erythematosus (SLE) is a chronic autoimmune disease that affects multiple organ systems, including the kidney, lung, musculoskeletal system and the skin.[1] SLE is known to be associated with a shorter life expectancy and poor health-related quality of life.[2 3] Since patients with SLE are predominantly women of childbearing age, it may impact on their intimate relationships and sexual functioning. A cross-sectional study in Taiwan showed that 52.5% of the sexually active patients with SLE had impaired sexual function. Vascular disease was found to be a significant and independent risk factor for impaired sexual function.[4] A meta-analysis of 8 studies involving 758 patients in the SLE group and 1724 individuals in the control group showed that SLE was significantly associated with an increased risk of sexual dysfunction.[5] However, a few studies have explored the association of demographic data and clinical manifestations with intimacy in patients with SLE, especially in Asian populations.[4 6] We hypothesised that demographic factors, clinical manifestations and disease activity of SLE would affect the intimate relationships in female patients with SLE. Therefore, the aim of this study was to investigate the association of these factors with intimate relationships in female patients with SLE.

MATERIALS AND METHODS

The data of this study were based on our previous study that compared the correlation of the Systemic Lupus Erythematosus Disease Activity Index 2000 and the SLE-Disease Activity Score (SLE-DAS) with health-related quality of life in patients with SLE.[7] In brief, a cross-sectional study was conducted

Table 1 Baseline characteristics of the study participants (N=243)

Variable	n (%)
Age interval (years)	
≥40	146 (60.1)
20–39	97 (39.9)
Body mass index (kg/m^2)	
Normal (≥18.5 and <24.0)	127 (52.3)
Other	116 (47.7)
Educational level	
High school or below	121 (49.8)
College or above	122 (50.2)
Marital status	
Married	168 (69.1)
Single, widowed, divorced	75 (30.9)
Employment status	
Unemployed	80 (32.9)
Employed	163 (67.1)
Job change related to SLE	69 (28.4)
Self-reported health status	
Not healthy	175 (72.0)
Healthy	68 (28.0)
Smoking habit	18 (7.4)
Alcohol use	59 (24.3)
Regular exercise	204 (84.0)
Length of sleep, hours	
≤7	204 (84.0)
≥8	39 (16.0)
Sleeping medication use	66 (27.2)
Age at diagnosis, years	
≥30	105 (43.2)
≤29	138 (56.8)
Disease duration, years	
≥10	163 (67.1)
≤9	80 (32.9)
SLE-DAS (median, IQR)	2.08 (1.12, 7.23)
Arthritis	54 (22.2)
Malar rash	31 (12.8)
Photosensitivity	118 (48.6)
Discoid rash	2 (0.8)
Alopecia	28 (11.5)
Oral ulcer	32 (13.2)
Vasculitis, skin	7 (2.9)
Sjögren's syndrome	64 (26.3)
Raynaud phenomenon	152 (62.6)
Nephropathy	34 (14.0)
Dialysis	4 (1.6)
Hypocomplementaemia	139 (57.2)
Anti-dsDNA (+)	87 (35.8)
Thrombocytopenia	8 (3.3)
Leucopenia	14 (5.8)
Anaemia	105 (43.2)

SLE, systemic lupus erythematosus; SLE-DAS, Systemic Lupus Erythematosus-Disease Activity Score.

in the rheumatology outpatient department at a regional hospital in southern Taiwan from April to September 2019. Patients, who were aged 20 years and above with physician diagnosed SLE based on the 1997 American College of Rheumatology revised criteria of SLE[8] or the 2012 Systemic Lupus International Collaborating Clinics Classification Criteria[9] according to the time of diagnosis, were enrolled. Exclusion criteria included patients who had previously diagnosed with rheumatoid arthritis, polymyositis, dermatomyositis, systemic sclerosis, spondyloarthritis and juvenile idiopathic arthritis. Male patients with SLE and those with active infection were also excluded from this study.

Intimacy-related quality of life was assessed based on the intimate relationships domain of the Lupus Quality of Life questionnaire (LupusQoL).[10] The LupusQoL is a disease-specific measurement for health-related quality in patients with SLE and consists of eight domains, including physical health, emotional health, body image, pain, planning, fatigue, intimate relationships and burden to others. The questions in the intimate relationship contain two questions that are (1) Because of the pain I experience due to Lupus I am less interested in a sexual relationship and (2) Because of my Lupus I am not interested in sex. Raw score was transformed to a range from 0 to 100, with higher scores indicating intimacy-related better quality of life. The internal reliability (Cronbach's alpha) for the intimate relationships domain was 0.96 in the present study. Clinical parameters of SLE were obtained based on clinical evaluation, laboratory data and questionnaires. SLE disease activity was assessed using the SLE-DAS.[11]

Patient and public involvement

To avoid biases, patients were not involved in the study design, conduct, analysis, reporting or dissemination plans of this research.

Statistical analysis

Simple and multiple linear regression analyses were used to evaluate factors associated with intimate relationships among female patients with SLE. The stepwise variable selection method was used to determine the independent factors in the multiple linear regression analysis. All statistical analyses were performed using IBM SPSS Statistics

Table 2 Simple and multiple linear regression analyses of factors associated with the intimate relationships domain of the LupusQoL in female patients with systemic lupus erythematosus

Variable	Simple linear regression			Multiple linear regression		
	β (95% CI)	Std β	P value	β (95% CI)	Std β	P value
Age interval (years)						
≥40	Ref			Ref		
20–39	24.02 (16.04 to 32.00)	0.36	<0.001	14.52 (6.33 to 22.71)	0.22	0.001
Body mass index (kg/m^2)						
Normal (≥18.5 and <24.0)	Ref					
Other	0.52 (–7.85 to 8.90)	0.01	0.902			
Educational level						
High school or below	Ref			Ref		
College or above	24.29 (16.51 to 32.07)	0.37	<0.001	11.64 (3.51 to 19.76)	0.18	0.005
Marital status						
Married	Ref					
Single, widowed, divorced	16.44 (7.62 to 25.25)	–0.26	<0.001			
Employment status						
Unemployed	Ref			Ref		
Employed	28.75 (20.63 to 36.87)	0.41	<0.001	19.48 (11.33 to 27.62)	0.28	<0.001
Job change related to SLE	–7.55 (–14.91 to –0.19)	–0.13	0.044			
Self-report health status						
Not healthy	Ref			Ref		
Healthy	14.19 (5.05 to 23.33)	0.19	0.002	10.25 (2.26 to 18.23)	0.14	0.012
Smoking habit	–5.64 (–21.60 to 10.32)	–0.04	0.487			
Alcohol use	7.51 (–2.20 to 17.22)	0.10	0.129			
Regular exercise	7.17 (–4.19 to 18.53)	0.08	0.215			
Length of sleep, hours						
≥8	Ref					
≤7	0.30 (–11.10 to 11.70)	0.003	0.958			
Sleeping medication use	–17.57 (–26.71 to –8.43)	–0.24	<0.001			
Age at diagnosis, years						
≥30	Ref					
≤29	20.83 (12.81 to 28.85)	0.31	<0.001			
Disease duration, years						
≥10	Ref					
≤9	3.86 (–5.02 to 12.75)	0.06	0.393			
SLE-DAS	–0.45 (–0.91 to 0.02)	–0.12	0.060	–0.66 (–1.16 to –0.16)	–0.14	0.010
Arthritis	–10.88 (–20.85 to –0.91)	–0.14	0.033			
Malar rash	3.49 (–9.04 to 16.02)	0.04	0.584			
Photosensitivity	–4.38 (–12.74 to 3.97)	–0.07	0.302			
Discoid rash	–24.17 (–70.37 to 22.03)	–0.07	0.304			
Alopecia	–10.95 (–23.98 to 2.08)	–0.11	0.099			
Oral ulcer	–9.61 (–21.92 to 2.70)	–0.10	0.125			
Vasculitis (Skin)	–2.62 (–27.63 to 22.39)	–0.01	0.837			
Sjögren's syndrome	–13.19 (–22.54 to –3.84)	–0.18	0.006			
Raynaud phenomenon	–2.96 (–11.60 to 5.67)	–0.04	0.500			
Nephropathy	4.62 (–7.43 to 16.66)	0.05	0.451			

Continued

Table 2 Continued

Variable	Simple linear regression			Multiple linear regression		
	β (95% CI)	Std β	P value	β (95% CI)	Std β	P value
Dialysis	13.76 (–19.08 to 46.59)	0.05	0.410			
Hypocomplementaemia	5.35 (–3.08 to 13.77)	0.08	0.213			
Anti-dsDNA (+)	7.20 (–1.48 to 15.88)	0.10	0.104			
Thrombocytopaenia	18.84 (–4.49 to 42.16)	0.10	0.113			
Leucopenia	2.04 (–15.91 to 19.99)	0.01	0.823			
Anaemia	0.34 (–8.10 to 8.79)	0.01	0.936			

LupusQoL, Lupus Quality of Life questionnaire; SLE-DAS, Systemic lupus erythematosus disease activity score; Std β, standardised beta coefficient.

for Windows, V.24.0 (IBM). A p<0.05 was considered statistically significant.

RESULTS

A total of 243 female patients with SLE were enrolled in this study. The mean and median score of the intimate relationship domain of the LupusQoL was 74.0 (SD 33.0) and 87.5 (IQR 62.5–100), respectively. The demographic and clinical variables of the patients are presented in table 1. In brief, 60.1% were over 40 years old and 52.3% of the patients had a normal body mass index.

Table 2 shows the factors associated with the intimate relationship domains of the LupusQoL in the simple and multiple linear regression analyses. A younger age group (20–39 years) (standardised (std) β=0.22, p=0.001), education level of college or above (std β=0.18, p=0.005), being employed (std β=0.28, p<0.001), a better self-reported health status (std β=0.14, p=0.012) and a lower SLE-DAS score (std β = –0.14, p=0.010) were significantly and independently associated with a higher score of the intimate relationships domain of the LupusQoL among female patients with SLE.

Table 3 shows the association between the intimate relationships domain with the other seven domains of the LupusQoL, including physical health, emotional health, body image, pain, planning, fatigue and burden to others. Results from the simple linear regression analysis showed that all seven domains were significantly associated with the intimate relationships domain of the LupusQoL. However, results from the multiple linear regression analysis indicated that only physical health (std β=0.13, p=0.048), fatigue (std β=0.18, p=0.006) and burden to others (std β=0.20, p=0.002) were significantly and independently associated with the intimate relationships domain of the LupusQoL among female patients with SLE.

DISCUSSION

Our study in Taiwanese female patients with SLE showed that a younger age, higher educational level, being employed, better self-reported health status and a lower SLE-DAS score were significantly and independently associated with a better intimacy-related quality of life, as measured by the intimate relationships domain of

Table 3 Simple and multiple linear regression analyses of the intimate relationships domain associated with the other seven domains of the LupusQoL in female patients with systemic lupus erythematosus

Domain of LupusQoL (except the intimate relationships)	Simple linear regression			Multiple linear regression*		
	β (95% CI)	Std β	P value	β (95% CI)	Std β	P value
Physical health	0.82 (0.61 to 1.03)	0.45	<0.001	0.24 (0.002 to 0.48)	0.13	0.048
Emotional health	0.66 (0.45 to 0.88)	0.37	<0.001			
Body image	0.42 (0.24 to 0.59)	0.29	<0.001			
Pain	0.49 (0.34 to 0.64)	0.38	<0.001			
Planning	0.49 (0.32 to 0.66)	0.35	<0.001			
Fatigue	0.52 (0.35 to 0.68)	0.37	<0.001	0.25 (0.07 to 0.43)	0.18	0.006
Burden to others	0.42 (0.29 to 0.56)	0.36	<0.001	0.23 (0.09 to 0.38)	0.20	0.002

*Adjusted for age interval, educational level, self-report health status, SLE-DAS and employment status.
LupusQoL, Lupus Quality of Life questionnaire; SLE-DAS, Systemic Lupus Erythematosus-Disease Activity Score; Std β, standardised beta coefficient.

the LupusQoL. A cross-sectional study of 279 Taiwanese female outpatients with SLE showed that only vascular comorbidities in SLE, but not the disease activity of SLE, had a negative impact on women's sexual functioning. However, the details of the other clinical manifestations of SLE were not explored in the study.[4] In contrast, several studies in China,[6] Iran,[12] and India[13] showed that the disease activities of SLE were associated with sexual dysfunction. In our study, among the SLE-specific parameters, the presence of arthritis and a diagnosis of Sjögren's syndrome were significantly associated with a lower score of intimate relationships domain of the LupusQoL in the simple linear regression analysis. However, only a lower SLE-DAS remained significantly associated with a higher score in intimate relationships domain of the LupusQoL in the multiple regression analysis. This finding is consistent with the findings from several other studies.[6 12 13] The cause of impaired intimate relationships in patients with SLE is a very complex issue, in which biological factors, psychological states and individual characteristics can all play a role. Therefore, studies on patients in different countries with different culture might affect the results.

Our study also showed that a younger age, a higher educational level, being employed, better self-reported health status were associated with an intimacy-related quality of life. A survey study on 168 Chinese patients with SLE and 210 healthy individuals also found that older age and lower educational levels were among the predictors of impaired partner relationships and impaired sexual function.[6] Similarly, a cross-sectional study of 340 Iranian women reported that age, disease activity, depression and life status had the strongest independent correlation with sexual dysfunction in women with SLE.[12] Because poor sexual function can lead to a low health-related quality of life,[14 15] it is plausible that factors associated with impaired sexual function could be similar to those involved with a poor intimacy-related quality of life. Furthermore, intimate relationships can be affected by many social, emotional and physical factors, including depression, stress, fatigue and body image.[16–18] These factors and other SLE-specific factors, such as complex pregnancy-related comorbidities and infection wound, can also lead to intimacy problems in female patients with SLE.[19] We used the seven domains of LupusQoL, including physical health, emotional health, body image, pain, planning, fatigue, burden to others as surrogates for these potential affecting factors. We found that physical health, fatigue and burden to others were the main factors associated with intimacy in female patients with SLE, and the results were consistent with those observed in the general population.[16–18]

We noted several limitations in this study. First, the effect of SLE on intimacy-related quality of life was assessed based on the questions on the intimate relationships domain of the LupusQoL. The questions focused mainly on whether the interest in sex and sex relationship was affected by SLE. Other domains of the intimate relationships, such arousal, lubrication, orgasm or satisfaction that contribute to sexual responses and feelings, are not measured. Second, the participants in our study were outpatients at the rheumatology outpatient clinic in a regional hospital in southern Taiwan, which could limit the generalisability of the study results. Third, a number of potential important factors, such as fatigue, body image and emotional health, were also obtained from questions in the LupusQoL rather than questionnaires specifically designed to measure these variables.

CONCLUSIONS

Intimacy-related quality of life is a frequently neglected domain for the quality of life in patients with SLE. To improve the health-related quality of life of female patients with SLE, physicians should assess the intimate relationships domain of these patients, especially in those who are older, unemployed, have a lower educational level, worse self-reported health status, high disease activity, fatigue and feeling of burden to others.

Collaborators NA.

Contributors Conceptualisation: C-WH, B-BH, MK and M-CL. Data curation: B-BH and M-CL. Formal analysis: C-WH and MK. Funding acquisition: M-CL. Investigation: MK and M-CL. Methodology: C-WH and MK. Project administration: M-CL. Supervision: MK and M-CL. Writing—original draft preparation: C-WH and M-CL. Writing—review and editing: C-WH, B-BH, MK and M-CL. M-CL is the author responsible for the overall content as the guarantor.

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Competing interests None declared.

Patient and public involvement Patients and/or the public were not involved in the design, or conduct, or reporting, or dissemination plans of this research.

Patient consent for publication Consent obtained directly from patient(s)

Ethics approval All the participants signed informed consent under a study protocol approved by the institutional review board of Dalin Tzu Chi Hospital, Buddhist Tzu Chi Medical Foundation (No. B10801017).

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