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Quality of Life among Patients with Systemic Lupus Erythematosus in Karbala Governorate 2023

A thesis

submitted to the council of College of Medicine – University of Kerbala as partial fulfillment for the degree of Higher Diploma (two calendar years) in Family Medicine

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بسم الله الرحمن الرحيم

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صدق الله العلي العظيم

{الاسراء (85)}

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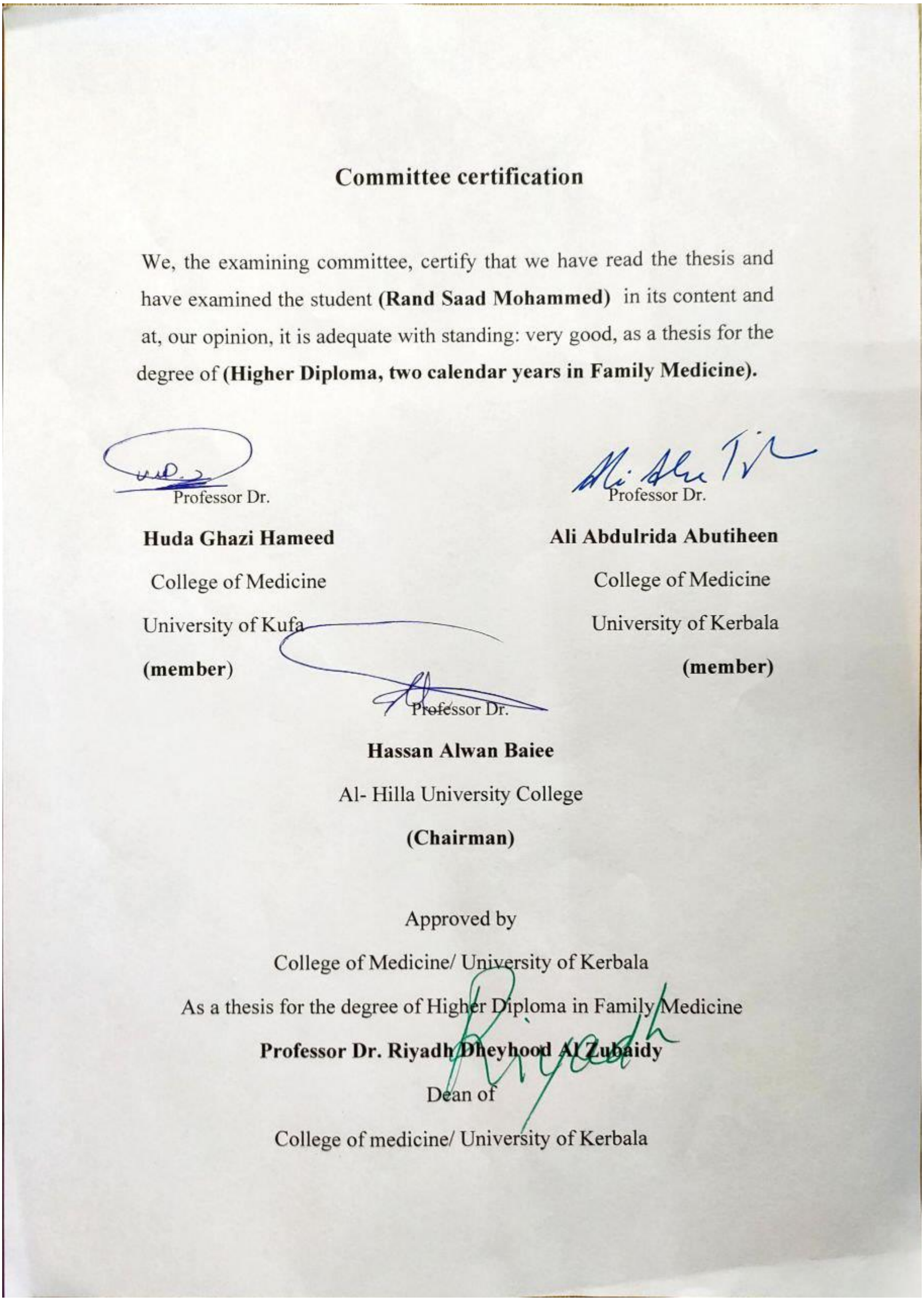

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We, the examining committee, certify that we have read the thesis and have examined the student **(Rand Saad Mohammed)** in its content and at, our opinion, it is adequate with standing: very good, as a thesis for the degree of **(Higher Diploma, two calendar years in Family Medicine).**

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Dedications

I dedicated this thesis paper to:

My parents, thanks for the kindness, support and love. You are my best supporters.

My husband, thanks for the support and advice

My source of love and happiness, my daughter and my son.

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Table of Contents

List of Abbreviations

Abbreviations	**Meaning**
ACR	American College of Rheumatology
BILAG index	British Isles Lupus Assessment Group index
CDC	Centers for disease control and prevention
ESR	Erythrocytes Sedimentation Rate
EULAR	European Alliance of Associations for Rheumatology
HRQOL	Health related quality of life
IQR	Interquartile range
OA	Osteoarthritis
RA	Rheumatoid arthritis
SF-36	Short form -36
SLE	Systemic Lupus Erythematosus
SLEDAI	Systemic Lupus Erythematosus Disease Activity Index
SLICC	Systemic Lupus International Collaborating Clinics
WHO	World Health Organization

List of Figures

List of Tables

ABSTRACT

Background: Systemic lupus erythematosus (SLE) is a chronic, multisystemic, heterogeneous, autoimmune disease with a variety of clinical symptoms that primarily affect young women of childbearing age. SLE is associated with a significant patient burden.

Objectives: To assess health-related quality of life (HRQOL) among patients with SLE and to evaluate its association with different sociodemographic and clinical characteristics of SLE patients.

Methods: Seventy-five patients with SLE who attended the Rheumatology outpatient clinics of Imam Al-Hassan Al-Mujtaba Teaching Hospital in Karbala, Iraq, participated in a cross- sectional study. The period of time for this study was January 2023–March 2024. Data were collected through direct interviews and the using of structured questionnaires. Lupus quality of life (lupusQoL) questionnaire was used to assess disease-specific health related quality of life; and SLE disease activity index (SLEDAI-2K) was recorded.

Results: This study included 75 SLE patients with the mean age of 38.12 ± 11.70 years, who were 97.3% females, and disease duration was (71.29±65.65 months). All LupusQol domains were reduced. The total mean Score of QOL was 43.44±22.75. Intimate relationship accounted for the highest Qol score (55.05±38.45), whereas fatigue represented the lowest score (35.51±29.61). There was no significant statistical differences of Total mean score of QOL and the demographic characteristics of the study patients. Younger age groups, employee and patients of an urban residence significantly scored higher than older age groups and housewives in Physical Health domain. The patients with

Kidney/ Neuropsychiatric involvement significantly scored higher than the patients with no Kidney/ Neuropsychiatric involvement. Result of multiple regression analysis revealed that age was the strongest predictor in the Physical Health domain of QOL ($\beta = -0.8$).

Conclusions: patients with SLE had low scores of all LupusQoL domains. Physicians should focus on QoL and on how to improve it through regular monitoring of the quality of life of SLE as standard care, and managing the disease should be centered on the patients, not only on the disease, with collaborative work between internists, rheumatologists, and psychologists, in order to provide holistic treatment, including psychological care

CHAPTER ONE

Introduction

Introduction

Systemic lupus erythematosus (SLE) is a chronic, multisystemic autoimmune disorder that could affect many different body organs with a variety of clinical symptoms and course **(Barber et al. , 2021**). It primarily affects young women of childbearing age **(Cattalini et al., 2019)**. The pathogenesis of SLE is highly complicated, involves both innate and adaptive immunity, and primarily caused by two important families of mediators: autoantibodies that target nucleic acids and nucleic acid-binding proteins and type I interferon (IFN-I**) (Crow, 2023)**. The exact etiological cause of SLE is still unknown. Genetic predisposition, environmental variables, hormonal, and immunological factors all interplay in disease development and activity **(Fava and Petri, 2019)**. The strongest epidemiological evidence exists for increased risk of SLE associated with exposure to silica, cigarette smoking, use of contraceptives and postmenopausal hormonal therapy, UV light, certain infections, and heavy metals **(Parks et al., 2017)**.

Systemic lupus erythematosus is classified into four main types: Lupus induced by drugs, an autoimmune response brought on by exposure to specific drugs, Neonatal lupus erythematosus is a rare form of lupus that affects infants. Systemic lupus erythematosus is the most common type which affects the internal organs. Discoid or cutaneous lupus erythematosus affects only the skin **(Maidhof, & Hilas, 2012)**.

Systemic lupus erythematosus is rare disease, with an incidence about 1-10 / 100000 persons- years and a prevalence of 20-200 / 100000 persons-years, affecting females more often than males with the incidence ratio varying between 8:1 and 15:1 and the greater incidence in African

American populations ,followed by Hispanic and Asian populations **(Ali et al., 2018)**, **(Christou et al., 2019)**. The incidence and prevalence of SLE vary throughout the world depending on factors such as age, sex, ethnicity, and time.

In Iraq, the incidence was approximately one case per 1,867 or 53.6 per 100,000 general population, one case per 1,127 or 88.7 per 100,000 total female population, and one case per 616 women aged 10 to 49 **(AlBidri, Zghayer Mayouf, 2008)**.

Sex hormones, mainly estrogen are the major factor that associated with higher incidence of SLE in women as well as failures in X chromosome inactivation and changes in microRNA function **(Nusbaum et al., 2020)**.The influence of sex hormones on disease activity is evident in exacerbations during puberty, pregnancy, and post-partum periods. Oral contraceptives and hormonal replacement therapy (HRT) that contain estrogen and progesterone, have been considered unsafe and not often prescribed for women with SLE **(Benagiano et al., 2019)**.

Exposure to toxic components from cigarette smoke (e.g., nicotine, polycyclic aromatic hydrocarbons, carbon monoxide, and free radicals) can induce oxidative stress and directly damage endogenous proteins and DNA, leading to genetic mutations that potentially induce autoimmunity **(Monteiro and Pizarro, 2022)**.

The disease has very broad and diverse clinical symptoms, ranging from mild mucocutaneous symptoms to severe multiorgan and severe central nervous system involvement, leading to disability and mortality. Other autoimmune diseases are more common in SLE patients, such as Sjogren's syndrome and antiphospholipid syndrome that require additional treatments **(www.cdc.gov, 2018)**.

Non-erosive arthritis, malar rash, and nephritis are the most common clinical signs seen at the time of diagnosis of SLE **(El Hadidi, KT et al. 2018)**. In addition to arthritis, SLE can involve internal organs including the nervous system, liver, kidneys, blood vessels, heart, and lungs and take a chronic or relapsing and remitting disease course **(Yen and Singh, 2018)**

The diagnosis of SLE is difficult and can be challenging. American College of Rheumatology (ACR) classification criteria, originally established in 1982, updated in 1997, and 2012 publication of the Systemic Lupus International Collaborating Clinics (SLICC) criteria, can be applied for the diagnosis of SLE **(Petri et al., 2012)**. Four of the 11 criteria (at least one of them clinical and at least immunological) have to be fulfilled for the diagnosis of SLE or lupus nephritis has to be diagnosed histologically in the presence of ANA or anti-dsDNA antibodies **(Kuhn et al. 2015)**. Clinical criteria of SLICC includes: cutaneous lupus, oral/nasal ulcers, alopecia, synovitis, serositis, renal, neurological, hemolytic anemia, leuko/lymphopenia, thrombocytopenia and immunological criteria: ANA, Anti- dsDNA Ab, Anti-Smith Ab, Antiphospholipid Ab, low complements (C3, C4, CH50), direct Coomb's test.

As soon as the diagnosis is confirmed, antimalarial medication should be administered to every patient. Specifically, hydroxychloroquine, which even in cases of lupus nephritis is associated with a high remission rate, low numbers of relapses, and decreased disease- related damage. According to EULAR guidelines, immunosuppressive drugs such mycophenolate mofetil, methotrexate, or azathioprine may be administered to reduce glucocorticoids. High-dose glucocorticoids should only be administered when acutely indicated. Recently, belimumab was authorized as an adjuvant medication for autoantibody-positive SLE patients who were not responding to standard treatment and had significant disease activity **(Kuhn et al., 2015)**.

There are numerous non-pharmacologic strategies for managing SLE symptoms and preserving remission. They could be carried out by educating patients on lifestyle changes and avoiding recognized triggers. According to **(Lewis et al., 2011)**, these precautions include getting enough rest, adequate exercise, avoidance of smoking, limiting exposure to excessive ultraviolet sunlight, adequate nutrition and healthy coping with stress.

The mortality rate is still two to three times higher than in the general population, and the most common causes of death in SLE patients are infections, cardiovascular disease, and SLE itself **(Barber et al., 2021)**; **(MorenoTorres et al., 2021)**. Due to earlier diagnosis and better treatment, the survival rate of SLE patients have attained 95.3, 92.9, 88.5, and 84.5% at 5, 10, 15, and 20 years, respectively **(Mok et al., 2020)**.

Patients with SLE experience events related to disease activity, irreversible damage, and medication's sides effects which may negatively impact on their HRQOL and eventually may result in disability **(Schmeding and Schneider, 2013)**. SLE patients have major physical, psychological, and social challenges when their disease worsens. According to **(Tran et al., 2014)**, patients face additional difficulties when dealing with the adverse effects of their medications and adjusting their daily schedules to comply with their treatment plans. Many SLE

patients have burdens associated with their medications, according to a study conducted on a sample of individuals with SLE in Iraq **(Abbas et al., 2022)**.

There is no doubt that SLE patients' life expectancy and quality of life are significantly affected by their signs and symptoms, as well as treatment-related adverse events. These effects include a significant decline in job performance, career development, and social relationships, which may result in social isolation and frustration from the inability to perform daily activities as before. Furthermore, anxiety, fear and mood disorders in these patients will ultimately lead to poor sleep that negatively affects their quality of life (**Almehed et al., 2010**). The fatigue and pain were the most reported symptoms affecting QOL of SLE patients, therefore poor sleepers had worse HRQOL in all domains of LupusQoL than good sleepers **(Chalhoub & Luggen, 2022)**.

Studies showed that depression and anxiety prevalence rates in SLE patients ranged widely, from 8.7% to 78% and 1.1% to 71% respectively **(Moustafa et al., 2020)**. Depression and anxiety account for a major morbidity among SLE patients. Anxiety is associated with fibromyalgia, whereas depression is associated with smoking, single marital status, organ damage, and increased severity of SLE **(LeónSuárez et al., 2023)**.

Health-related quality of life (HRQoL) is defined by the World Health Organization (WHO) as an individual's perception of their position in life with respect to the community and value systems they live in, as well as their expectations, standards, goals, and concerns. It’s a broad term that includes a wide range of factors such as an individual's physical and psychological well-being, level of independence, relationships with others, personal beliefs, and relationship to the key aspects of their environment **(WHOQOL, 1997)**.

The three components of evaluating the impact of SLE on a patient's life are the quality of life, organ damage along the course of the disease, and the assessment of disease activity. The degree of organ damage is evaluated using the SLICC ACR Damage Index, while the disease activity is evaluated using a variety of scores, such as SELENA-SLE and BILAG index.

Numerous rheumatic disorders, including juvenile rheumatoid arthritis **(Tsipoura et al., 2018)**, osteoarthritis (OA), rheumatoid arthritis (RA), and fibromyalgia syndrome have been associated with a worse quality of life **(Ataoğlu et al., 2018)**.

According to a study, the quality of life was significantly poorer in Egyptian SLE patients, especially among those who were obese **(Rizk et al., 2012)**.

In a Swedish SLE population, obesity and ongoing tobacco smoking have been independently associated with worse outcomes - compared with normal weight and individuals who never smoked, respectively - regarding HRQoL, fatigue, pain and functional disability **(Gomez, Parodis and Sjowall, 2022)**.

A physician can assess a patient holistically by evaluating their quality of life, taking into account not just their clinical condition but also their emotional and mental well-being and socioeconomic status. Determining the quality of life is an important part of diagnosing and treating chronic illnesses. It also maintains the appropriate physician-patient relationship and facilitates in the organization and planning of patient care.

Two approaches have been used in the measurement of quality of life: generic questionnaires and questionnaires specific to a particular condition. While disease-specific questionnaires are used to measure quality of life in a single disease or condition, generic questionnaires can be used in a variety of conditions and populations. The most widely used generic measure of quality of life is the medical Outcome Study Form 36 (SF-36), that could be used in a variety of conditions, including SLE. Recently, SLE-specific measures may prove to be more sensitive than generic assessments **(Mikdashi, 2018)**.

Objectives of the study

1. to assess the health-related quality of life of patients with SLE

2. to evaluate the association between the health related quality of life of SLE patients and different sociodemographic and clinical characteristics of SLE patients in karbala Governorate.

Justification of the study

Systemic lupus erythematosus is associated with a significant worldwide burden and causes a variety of problems affecting multiple body organs, making diagnosis and treatment difficult and challenging. Despite the advancements in treatment and investigations and the survival of SLE patients, and because of the complexity and the chronicity of the disease, health related quality of life of the patients is highly compromised. In Iraq, the disease is rare, and many studies have been conducted on the clinical outcome of SLE, but limited information is available regarding the impact of the disease on health-related quality of life among SLE patients. This study, therefore, will assess HRQOL and the association between HRQOL with various sociodemographic and clinical factors to decrease disease development, and implement guidelines that improve QOL.

CHAPTER TWO

PATIENTS AND METHODS

Patients and methods

Study design

This is an observational cross sectional study on patients with systemic lupus erythematosus.

Study setting and timing

The study was carried out in Karbala Governorate, Iraq; according to the Ministry of Health's annual data report for Environment 2023 (Iraqi Ministry of Health, 2023), the governorate has a population of around 1350757 and it is situated 100 kilometers southeast of Baghdad, on patients diagnosed with systemic lupus erythematosus who attended the Rheumatology outpatients clinics in the general public teaching hospital with a capacity of 492-beds, Imam Al-Hassan Al-Mujtaba, to follow up during a flare or relapses. This study was conducted during the period from January 2023, to March 2024.

Study participants

Patients with SLE were involved in the study , who fulfilled the Systemic Lupus International Collaborating Clinics (SLICC) criteria **(Petri et al., 2012)**, (Appendix 1), and they met the inclusion criteria. The diagnostic sensitivity and specificity of 2012 SLICC criteria were confirmed in a recent Scandinavian study **(Dahlström and Sjöwall, 2019)**.

Inclusion criteria:

Eligible patients 18 years or older, with disease duration equal or more than six months, diagnosed by a rheumatologist based on their recognition of distinctive symptoms and signs in the context of serological investigations using the 2012 SLICC criteria, after ruling out other possible diagnoses.

Exclusion criteria:

Patients with SLE overlap with other rheumatic diseases such as Rheumatoid arthritis or mixed connective tissue disease or with other existing comorbidities not related to SLE that may impact on their quality of life such as diabetes, hypertension, cancer, dementia or psychosis, were excluded from the study to avoid confounder factors.

Sampling Type:

A convenience sample of 75 adult patients diagnosed with SLE were included in the study.

Data collection

During the period of 1st March 2023 to 30th June 2023, data was collected by means of direct interviews conducted with patients, taking into account their privacy. Each interview took approximately 20-30 minutes. Four hours are needed for data collecting every day, two or three days a week, from 8:00 AM to 12:00 PM. The missing information was took over phone calls with the participants. Clinical information was obtained from the patients through history taking and physical examination. All of the patients' medical records were reviewed.

Questionnaire form

A structured questionnaire was prepared for the study and evaluated by the experts specialists in the community medicine and internal medicine. The questionnaire consisted of the following data:

1. Sociodemographic data : age, sex, residence, marital status, education and occupation.

2. Clinical characteristics: disease duration from the date of the diagnosis, erythrocytes sedimentation rate (ESR) results, an inflammatory marker, that it's use was taken into account due to its convenience and cost and the normal values as follows: Male < 50 years old: < 15 mm/hr. Female < 50 years old: < 20mm/hr. Systemic Lupus Erythematosus Disease Activity Index (SLEDAI-2K) which is one of the most commonly used measure for the global disease activity of SLE, that introduced in 2002 **(Gladman, Ibañez and Urowitz, 2002)** consists of 24 items covering nine organ systems. The recall period for disease activity is the previous 10 days. The score ranges from 0 to 105 points with the higher values signifying higher disease activity as follows: no activity (SLEDAI = 0), mild activity (SLEDAI =1 to 5) moderate activity (SLEDAI = 6 to 10), high activity (SLEDAI =11 to 19), and very high activity (SLEDAI > 20)

(Appendix 3), and medications including steroids, Hydroxychloroquine, Immunosuppressants, and biological therapy) were assessed for all patients.

3. Lupus Quality of life (LupusQoL) questionnaire was used to assess disease specific health related quality of life in adult SLE patients and was validated for use in the general population **(McElhone et al., 2010)**, (Appendix 2), and there is a validated linguistically translated Arabic version of Lupus QoL that was used in this study. An e- mail was sent to an Egyptian author by **Amanda.Rosett@rws.com** and then Arabic version of LupusQoL questionnaire was received. LupusQoL consists of eight domains with 34 items. These domains are physical health (8 items), pain (3 items), planning (3 items), intimate relationship (2 items), burden to other (3 items), emotional health (6 items), body image (5 items), fatigue (4 items). Every LQoL question has 5 –point Likert scale response format (0 = all the time, 1 = most of the time, 2 = a good bit of the time, 3 = occasionally, and 4 = never). The item response scores are totaled for each domain and the mean raw domain score is calculated by dividing the total score by the number of items in that domain. The mean raw domain score is converted to scores ranging from 0 (worst HRQoL) to 100 (best HRQoL) by dividing by 4 (the 5 Likert response minus 1) and then multiplying by 100 : (mean raw domain score divided by 4) * 100=transformed score for domain.

Scoring System for LupusQoL questionnaire

From 0 to < 50 ---poor QoL

From 50 to < 65 ---- average QoL and > 65---- good QoL

Patient consent and ethical approval

The scientific and ethical committee of Family and Community Medicine Department examined and gave its approval to the study proposal that was submitted to the College of Medicine, University of Kerbala (No. 8, date: 4/2/2023). A facilitated letter was sent from Karbala University's College of Medicine to Imam Al- Hassan Al- Mujtaba Hospital. Verbal consent was provided by the patients after explaining the objectives of the study. Direct interview with each patient in a private room to ensure privacy. The patients were informed that the data will be treated with complete confidentiality and privacy protection, and it is anonymous.

Statistical analysis:

The data of the present study were entered and analyzed throughout the Statistical Package for the Social sciences (SPSS 23). Descriptive statistics presented as frequency and percentage and mean ± Standard deviation (mean±SD) in appropriate tables and graphs. Possible association for abnormally distributed variables (by using Kolmogorov–Smirnov test) was determined through the use of the Mann-Whitney test to compare the means between two groups, or Kruskal-Wallis test to compare the means among three or more groups. Significance level was considered when $p < 0.05$. Multiple regression analysis was used to detect association between demographic or clinical variables and QOL. The Total mean QOL Score was obtained by average the 8 QOL scale.

Significance level was considered if $p \leq 0.05$.

CHAPTER THREE

RESULTS

The mean age of the study participants was 38.12 ± 11.70 years. The study participants were predominantly of (97.3%) females. More than two thirds of the patients were of an urban residence as shown in table1.

Table-1: Sociodemographic characteristics of the study participants.

Characteristics		**Number (%) N=75**
Age (years)	Below 30	18 (24)
	30-49	46 (61.3)
	50 and above	11 (14.7)
Sex	Male	2 (2.7)
	Female	73 (97.3)
Residence	Urban	52 (69.3)
	Rural	23 (30.7)
Academic qualification	Does not read & write	7 (9.3)
	Read & write	10 (13.3)
	Primary school	29 (38.7)
	Secondary school	15 (20)
	Bachelor's/ university	14 (18.7
Occupation	Housewife	62 (82.6)
	Employee/free work	13 (17.3)
Marital status	Single	14 (18.7)
	Married	61 (81.3)

Thirty-two percent of the study participants had kidney/neurological involvement with disease duration (months) was of 71.29±65.65, disease activity index was equal to 19.96±11, and ESR of 36.84±26.09 as shown in table-2.

Table- 2: Clinical characteristics and some clinical parameters of study participants.

Clinical characteristics		Number (%) N=75
Kidney and/ or neurological involvement	Present	24 (32.1)
	Absent	51 (67.9)
Disease duration (months)	Mean±SD	71.29±65.65
SLEDAI	Mean±SD)	19.96±11
ESR(mm/hr)	Mean±SD	36.84±26.09

SLEDAI= Systemic Lupus Erythematosus Disease Activity Index, ESR= Erythrocytes sedimentation rate

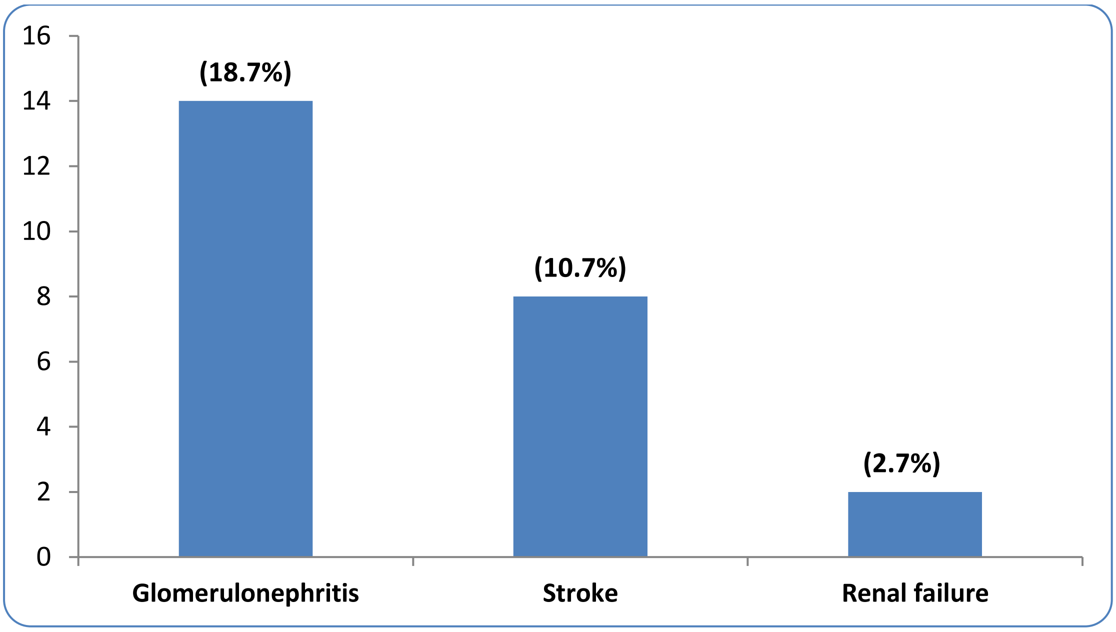

Figure-1. Frequencies of the Kidney and neurological involvement of the study patients (n= 75)

The results of the present study revealed that the most frequent medications used included steroids (used by 92% of the study patients), followed by Immunosuppressant (74.7%), Hydroxychloroquine (65.3%) and biological therapy (5.3%) as shown in figure-2.

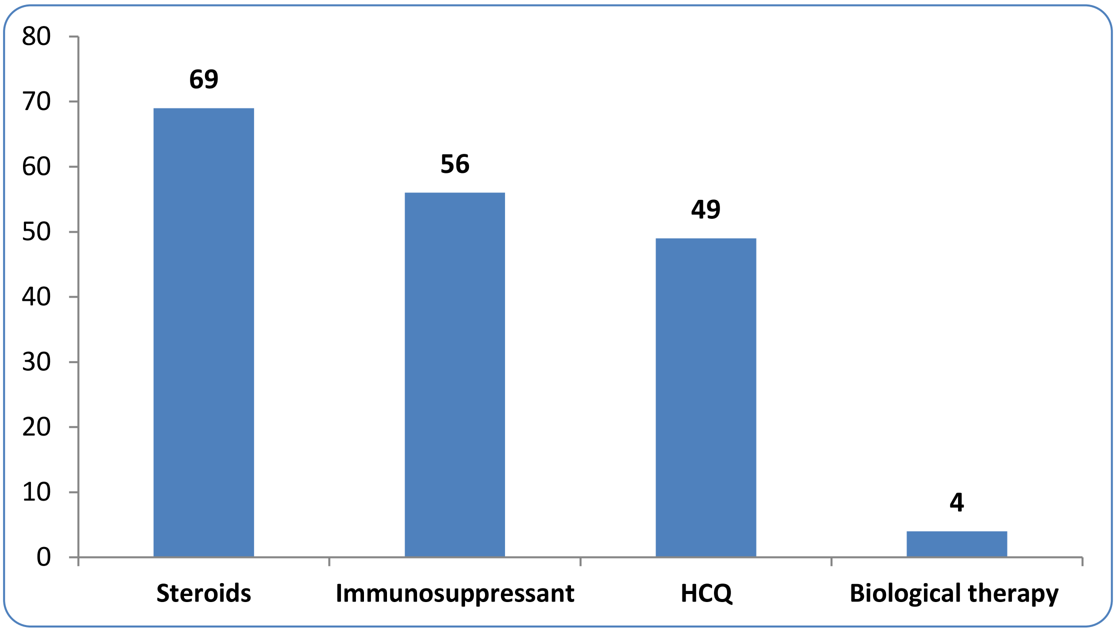

Figure-2. Frequencies of the drug history of the study participants (n= 75) HCQ= Hydroxychloroquine

The total mean Score of QOL was 43.44±22.75 .The highest score of SLE patients' QOL is related to relationship (55.05±38.45) and the lowest score of QOL was related to fatigue (35.51±29.61) as shown in table-3.

Table-3. Total mean score and subscales of the QOL of the study patients.

Scale	Mean	SD	Range
Physical Health	46.62	28.20	6.2-100
Pain	43.52	29.22	0-100
Planning	43.64	29.84	0-100
Intimate Relationship	55.05	38.45	0-100
Burden to other	50.36	34.18	0-100
Emotional	51.68	23.92	4.16-100
Body Image	38.68	23.73	5-90
Fatigue	35.51	29.61	0-100
Total Score	43.44	22.75	7.5-94.49

The analysis of data revealed that there was no significant statistical associations of Total mean score of QOL and the demographic characteristics of the study patients (table-4).

Table-4. Comparison of Total Mean Score of QOL based on demographic and clinical characteristics of study patients

Characteristics		The total mean score of QOL	P value
Age (years)	Below 30	49.79±19.87	0.138
	30-49	41.63±22.80	
	50 and above	40.59±26.87	
Residence	Urban	46.26±23.19	0.077
	Rural	37.07±20.81	
Academic qualification	Illiterate	37.87±26.40	0.853
	Primary / Read & write	41.25±22.44	
	Secondary school	46.55±21.17	
	College and higher	48.98±24.37	
Occupation	Housewife	41.33±21.98	0.502
	Employee/free work	51.71±26.23	
Marital status	Single	42.24±19.82	0.924
	Married	43.71±23.51	
Kidney/ Neuropsychiatric involvement	Present	43.37±25.54	0.737
	Absent	43.47±21.90	

The analysis of data revealed that younger age groups significantly scored higher than older age groups in the domains of Physical Health, Planning, Relationship and Fatigue. In regard to occupation, the employee significantly scored higher than housewife in Physical Health domain. Regarding residence, urban residence patients significantly scored higher than rural residence in Physical Health domain. The analysis of data revealed that the patients with Kidney/ Neuropsychiatric involvement significantly scored higher than the patients with no Kidney/ Neuropsychiatric involvement as illustrated in table-5 below.

Table-5. QOL scores (mean and standard deviation) according to demographic and some clinical characteristics of study patients

	Physical Health	Pain	Planning	Relationship	Burden to other	Emotional	Body Image	Fatigue	Total Score
Age (years)									
Below 30	63.84± 25.55	53.67± 25.74	55.07± 26.37	57.50± 37.36	59.41± 30.37	52.72± 23.39	39.87± 17.66	41.78± 30.25	49.79± 19.87
30-49	43.97± 26.39	42.54± 29.97	43.26± 29.88	54.04± 37.65	44.72± 33.40	50.59± 23.35	38.86± 24.64	29.19± 27.79	41.63± 22.80
50 and above	29.51± 27.48	31.05± 28.15	26.50± 28.80	56.25± 47.72	59.98± 34.18	54.52± 28.88	36.02± 23.73	51.69± 30.24	40.59± 26.87
P value	**0.003**	0.120	**0.041**	**0.034**	0.193	0.870	0.913	**0.043**	0.399
Academic qualification									
Illiterate	30.31± 26.13	38.07± 29.59	30.93± 29.91	56.25± 51.54	47.59± 34.93	52.34± 23.54	29.64± 18.17	41.96± 29.48	37.87± 26.40
Primary/ Read & write	43.71± 27.45	38.43± 26.92	41.21± 28.58	54.58± 39.73	46.77± 31.33	50.40± 25.15	36.34± 24.74	32.35± 31.05	41.25± 22.44
Secondary	49.74± 30.86	43.31± 30.56	46.09± 32.25	50± 37.50	68.87± 33.41	52.71± 25.71	42.81± 21.48	38.89± 30.12	46.55± 21.17
College and higher	59.56± 24.98	60.69± 30.38	54.14± 30.26	61.11± 35.05	41.63± 38.51	53.79± 20.71	45.29± 25.28	37.46± 26.93	48.98± 24.37
P value	0.115	0.097	0.344	0.946	0.121	0.970	0.408	0.801	0.604
Occupation									
Housewife	43.20± 28.22	40.56± 27.20	41.50± 29.76	53.87± 39.86	49.21± 32.97	49.90± 23.88	37.21± 22.82	33.39± 29.38	41.33± 21.98
Employee	63.04± 23.21	59.6± 35.44	55.28± 30.34	65.63± 34.56	49.20± 40.53	55.96± 22.64	43.10± 28.01	40.30± 29.19	51.71± 26.24
P value	**0.031**	0.051	0.163	0.440	0.999	0.437	0.448	0.474	0.165
Marital status									
Single	51.74± 24.75	47.00± 27.06	46.99± 28.59	-	53.79± 37.02	53.21± 19.20	40.56± 21.38	37.47± 29.62	42.24± 19.82
Married	45.45± 29.00	42.73± 29.86	42.87± 30.29	-	49.56± 33.77	51.32± 25.00	38.25± 24.38	35.06± 29.84	43.71± 23.51
P value	0.455	0.625	0.644	-	0.679	0.792	0.746	0.786	0.829
Residence									
Urban	51.64± 29.40	47.24± 31.33	47.24± 31.54	56.91± 37.18	52.49± 33.24	53.07± 24.49	40.08± 24.24	37.71± 29.98	46.26± 23.19
Rural	35.29±	35.13±	35.49±	50.00±	45.62±	48.53±	35.52±	30.54±	37.7±

	21.87	22.18	24.24	42.74	36.50	22.80	22.73	28.78	20.81
P value	**0.020**	0.098	0.116	0.571	0.427	0.452	0.446	0.337	0.107
Kidney/ Neuropsychiatric involvement									
Present	46.04± 27.24	41.48± 27.18	42.39± 28.41	57.43± 38.47	55.90± 32.78	50.64± 24.03	38.74± 23.33	34.91± 28.69	43.37 ±25.54
Absent	48.22± 31.38	49.14± 34.38	47.07± 34.01	49.17± 39.09	35.40± 34.19	54.52± 23.99	38.54± 25.42	37.17± 32.72	43.47 ±21.90
P value	0.770	0.319	0.552	0.488	**0.021**	0.539	0.975	0.772	0.987

In order to identify predictors for the Physical Health, Pain, Planning, Relation, Burden to other, Emotional, Body image and Fatigue QOL, separate multiple linear regression analysis was performed. Result of multiple regression analysis revealed that age was the strongest predictor in the Physical Health domain of QOL (β = -0.8). This means that younger age patient showed better General Health than older one (Table.6).

Table-6. Association between QOL of SLE patients and predictor variables

Variables	Physical Health		Pain		Planning		Relation		Burden to other		Emotion		Body image		Fatigue	
	β	p	β	p	β	p	β	p	β	p	β	p	β	p	β	p
Age (years)	-0.8	**0.03**	-0.5	0.21	-0.7	0.07	-0.8	0.22	-0.1	0.96	0.2	0.61	0.2	0.57	0.5	0.22
Residence	-11.2	0.18	-6.6	0.44	-8	0.38	-9.2	0.56	-2.9	0.78	-9.3	0.19	-5.5	0.47	-12.8	0.18
Education	-2.5	0.64	-0.8	0.89	-0.7	0.91	-16.4	0.25	-4	0.55	-4.6	0.33	4.1	0.39	-2.8	0.64
Occupation	9.2	0.47	-1.4	0.92	2.2	0.88	-3.7	0.92	-2.9	0.86	2.5	0.83	-8.1	0.49	1.9	0.89
Marital status	-0.9	0.92	3.4	0.73	2.8	0.79	-21.3	0.65	-3.2	0.79	-3.6	0.66	0.2	0.98	-9	0.4
Kidney/neurological involvement	-2.30	0.76	3.1	0.69	-1.6	0.85	-13	0.34	-16.4	0.09	0.8	0.91	-3.9	0.57	1.9	0.83
SLEDAI	0.15	0.62	-0.2	0.67	0.3	0.39	-0.3	0.59	-0.8	0.07	-0.3	0.24	-0.1	0.88	-0.1	0.81
Disease duration	0.1	0.21	-0.1	0.29	0.1	0.17	-0.1	0.61	0.1	0.89	0.7	0.27	0.1	0.13	0.1	0.43

CHAPTER FOUR

DISCUSSION

Discussion

Systemic lupus erythematous (SLE) is a chronic multisystemic autoimmune disorder that may have different serious complications on all body organs. SLE patients' quality of life has been negatively affected as a result of these effects. Therefore, assessing the quality of life facilitates in determining patients' needs and creating a complete treatment plan for them **(Olesińska & Saletra, 2018)**. This study is the first in the Karbala Governorate to evaluate HRQoL in SLE patients since getting an updated picture of HRQoL is essential to understanding of the disease burden.

The current study found that the vast majority of the studied patients were women. These findings corroborated those of **(Elmetwaly, Ahmed, and Mohamed, 2021)**, who found in their study on "Effect of nurse-led lifestyle intervention protocol on associated symptoms and self-efficacy of patients with systemic lupus erythematosus" that all of the patients were females. A study conducted by **(Ferreira et al., 2023)**, found that women are more susceptible to stress and that female hormones like estrogen increase the risk of developing SLE.

Regarding marital status, more than half of the studied patients were married, and this result was in accordance with **(Zienab Abd- Lateef Mohamad, Elbadry Ibrahim AboElNoor, et al., 2020)**; this could be because marriage adds more responsibilities, which raises stress levels and is regarded as one of the SLE risk factors. In contrast, a study about "depression-, pain-, and health related quality of life in patients with systemic lupus erythematosus" by **(Chalhoub & Luggen, 2022)** revealed that half of the studied patients were single.

According to the results of the present study, the mean age of the participants was 38.12±11.70 years, in accordance with the results obtained by **(YilmazOner et al., 2016)**, who reported that the mean age of all participants was 40.6±11.9 years old on average. Also, according to **(Mohammedy et al, 2022)**, more than half of the patients in their study were over 30 years old. One explanation might be because the highest quantities of estrogen are found in women in reproductive age, which increases the risk of SLE.

In the current study the total mean QoL score in patients with SLE was 43.44±22.75, and the overall scores range from 1 to 100, with higher scores indicating better HRQoL. It was consistent with the finding of **(YilmazOner et al., 2016)** by which the total mean QoL score was 41.2±9.0 using SF-36 , 60.9±23.3 using Lupus QoL-TR . The mean score of Lupus QoL –TR was > 60 in five domains (physical health, emotional health, pain, planning, body image) and < 60 in three domains (fatigue, intimate relationship, and burden to others). Moreover, **(Yazdany, 2011)** evaluated the subjects from the United Kingdom with total mean score of LupusQOL (71.07±7.64) and the United States of (47.30±5.68).

All domains of LupusQOL were low and consistent with impaired quality of life, and the most impaired domains were fatigue and body image, consistent with other studies by **(McElhone et al., 2010)** that revealed that all lupusQOl domain was impaired, with fatigue, being most significantly impacted. Since we did not screen our patients for fibromyalgia, fatigue may have a role in fibromyalgia. Using SF- 36 questionnaire to assess QoL , an Egyptian study conducted at Tanta University Hospital, found that all domains were lower in SLE patients, with impairment of physical and emotional domains of QoL with disease activity was also observed **(Shahba and Kabbash, Ibrahim Ali, 2015)**.

Skin involvement is common in systemic lupus erythematosus. Classic facial erythema, discoid rash, lesions that have a tendency to scar, skin atrophy, and hair loss are all considered unattractive and can have a negative impact on a patient's self-esteem. Patients with SLE frequently experience appearance-related embarrassment as a result of these symptoms. Additionally, patients report increased photosensitivity and susceptibility to bruises. They also worry that using glucocorticosteroids may cause them to gain weight. Also, in agreement with **(Gorden, 2013)**, who found the lowest score observed in the domain of body image and the highest observed in intimate relationship.

Intimate relationship was the least affected side. The sensitive nature of the question, however, can make the letter observation unclear. It is possible that patients are uncomfortable sharing this information, and studies on intimacy often contain incomplete or inaccurate data.

Concerning the association between LupusQol domain scores and sociodemographic characteristics, such as patients' age, the present study revealed that the younger age groups significantly scored higher than older age groups in the domains of Physical Health, Planning, Relationship and Fatigue. In terms of physical health, the result agreed with **(Darvish et al., 2017)** in their study about health-related quality of life in patients with SLE and rheumatoid arthritis compared to the healthy population, who found that the quality of life decreased with advancing age in SLE patients. A possible explanation could be that older patients naturally have lower HRQOL because of longer disease duration and a higher incidence of organ damage from disease, such as more degenerative joint disease, which impairs physical health, and the existence of comorbidities associated with increased disability led the patients to have lower quality of life.

A lot of studies demonstrate that older age has a negative impact on HRQOL **(Barnado et al., 2012); (Alarcón et al., 2004).** The contrast of that in the others **(Ali et al., 2018) and (Faiq, Kadhim and Gorial, 2019)** found no significant association between the mean scores of lupus quality of life questionnaire and age. This dissimilarity may be due to variable sample size, variable patients' ages, different disease durations, and regional, seasonal, or racial variations.

Regarding the gender effect on HRQOL, it has been found that there was no statistical difference in the current study. According to **(Mok et al., 2009)**, disease activity, depression, and anxiety both directly and indirectly impacted HRQOL, but socioeconomic characteristics such as age, sex, education, income/family, and work status did not directly affect HRQOL. Unlike **(Jolly et al., 2019)**, who examined the sex differences in HRQOL in SLE patients and discovered that women had significantly worse symptoms, cognition, and procreation domains with trends for worse physical health and pain, while men experienced more damage and worse social support.

Regarding marital status effect on LupusQoL, the present study revealed no significant difference , in contrast to a study that reported those who lived alone reported higher HRQOLs than those who did not **(Alarcón et al., 2004)**.

Moreover, sociodemographic factors such as level of education had no significant association with HRQOL. According to **(Mok et al., 2009)** in their study about " the effect of disease activity and damage on quality of life in patients with systemic lupus erythematosus", mentioned that there was no significant relationship between age, level of education, disease duration, and lupus quality of life. In contrast to a study done by **(McElhone et al., 2006)** who reported that age, disease duration, low education, and low socioeconomic status have been reported as the main barriers to improve lupus prognosis.

Regarding residence, the present study revealed that patients of an urban residency significantly scored higher than rural residency in Physical Health domain. According to an Egyptian study by **(Abdul-Sattar and El, 2017)**, whose findings indicate that poor socioeconomic status, rural residency are associated with depression and lower SF-36 physical functioning. Compared with rural, urban residence was associated with earlier (by almost seven years) disease diagnosis – despite comparable diagnostic delay – and lower female predominance (6.8:1 versus 15:1). Rural patients had fewer years of education and lower employment rates. pesticide use was increased among rural patients. A pattern of malar rash, photosensitivity, oral ulcers and arthritis was more prevalent in rural patients **(Gergianaki et al., 2019)**.

In regard to occupation, the majority of SLE patients were unemployed and the employee significantly scored higher than housewife in Physical Health domain, other studies found similar results to the current study **(Barnado et al., 2012), (Shaymaa, 2018)** and a higher prevalence of unemployment (59%) was found in SLE patients and associated with higher age at disease onset, neuropsychiatric organ damage, diabetes mellitus, and lower quality of life than employed patients **(Bultink et al., 2008)**. Pain and fatigue is experienced by up to 90% of SLE patients and are considered their most disabling disease symptoms by 50% of patients **(Arnaud et al., 2019)**. Lower education, disease duration, disease activity,organ damage, depressive symptoms, comorbidities and cognitive dysfunction have been correlated with limiting work in all patients **(Yelin et al., 2009).** Patients have often problem with being concentrated on the work and memory loss **(Holloway et al., 2014)**.

According to the current study the length of time that the patients suffered from the disease had no a significant difference with their quality of life, this finding was similar to that of **(Ali et al., 2018)** and **(Faiq, Kadhim and Gorial, 2019)** who found no association between the duration of a patient's illness and their quality of life. The LQoL was not related to age, disease duration and level of education as demonstrated by **(Gaballah, Nahla M and ElNajjar, Amany R, 2019)**. The results contrasted with of **(Ibrahim et al., 2023)** and **(Hassan et al., 2017)**, who found a statistically significant association between the duration of the disease and patients' quality of life. For newly diagnosed patients, educational programs covering all aspects of disease are offered with the goal of enhancing quality of life.

LupusQOL was not related to disease activity in SLE patients in the current study, in agreement with certain studies **(Schmeding and Schneider, 2013)** and **(YilmazOner et al., 2016)** who found that there was no correlation between HRQOL and SLEDAI scores in Turkish SLE patients. This finding revealed that factors other than disease activity could affect QOL, particularly in patients who are clinically inactive or mildly active. In contrast to other studies **(Gaballah, Nahla M and ElNajjar, Amany R, 2019), (McElhone et al., 2010)** and **(Román Ivorra, J. A et al., 2019)**, which showed a significant negative correlation with the domains of LQOL. According to **(Mok et al., 2009)**, the correlation between disease activity and HRQOL in SLE is still debatable. This could be caused by a number of variables, including various study designs, the disease's heterogeneity, the various measures to evaluate disease activity, and the disease's fluctuating states.

In regard to the association between taking prednisolone, antimalarial agents, immunosuppressants, and biological therapy, there was no significant correlation with HRQOL, unlike **(Golder et al., 2017)**, who found a significant negative association with physical component score and prednisolone dose, but not with other types of medications.

Regarding association with renal involvement, the present study revealed that the patients with renal involvement significantly scored higher than the patients with no Kidney/ Neuropsychiatric involvement in burden to others domain of LQoL. **(Jolly et al., 2018)** who demonstrated that patients with active lupus nephritis have worse domains of HRQoL. However the most impacted domains were excluded in the generic QoL tools used in SLE as lupus symptoms, lupus drugs, procreation, and desires-goals domains. A longitudinal study with multiple QOL evaluations of the patients would have been ideal. In contrast to **(Golder et al, 2017)** who reported that the presence or absence of renal disease did not significantly impact on SF-36 domain scores.

Regarding predictive factors of quality of life, the results of multiple regression analysis revealed that age was the strongest predictor in physical health domain, similar to the results of **(Plantinga et al., 2016)** on " association of age with health related quality of life in a cohort of patients with systemic lupus erythematosus: the Georgians Organized Against Lupus study" revealed that older age was associated with lower physical HRQOL among patients with SLE.

Strengths and Limitations

There are important points that should be mentioned about the strengths and limitations of this study. Due to the rare nature of the condition, the small sample size, time limitations, and challenges associated with data collecting from a single study center. Also, because the study was cross-sectional in nature, longitudinal follow up study is recommended. Additionally, a number of significant variables that could have an impact on how the results are estimated were not examined in this study, including income level, anxiety, stress, and depression. Furthermore, we did not test for fibromyalgia, a condition that can alter a patient's HRQoL. More accurate estimation of the impacts can be achieved through the design of case-control studies. The study's key strengths were its use of a validated, disease-specific questionnaire and its examination of the variables affecting quality of life (QoL) in various sub-dimensions in an appropriate sample size of Iraqi SLE patients.

CHAPTER FIVE

CONCLUSIONS AND RECOMMENDATIONS

Conclusions

Systemic lupus erythematosus has a major impact on the quality of life of patients. Younger age groups, employee and patients of an urban residence significantly scored higher than older age groups and housewives in Physical Health domain. The patients with Kidney/ Neuropsychiatric involvement significantly scored higher than the patients with no Kidney/ Neuropsychiatric involvement. Result of multiple regression analysis revealed that age was the strongest predictor in the Physical Health domain of QOL.

Recommendations

1. Regular assessment of the quality of life of SLE patients and conducting this study again with a larger sample size drawn from various regions of the country are recommended to confirm the results and precisely identify potential risk factors.
2. Provide patients and their families with simple definition of SLE, risk factors, and clinical manifestations to improve quality of life through videos, printed materials, and mass media health education programs.
3. Improvement of health information system at the level of the general hospital, health directorate, and ministry of health.
4. Analytical and Interventional studies are strongly requested to address the psychosocial aspects of the patients with this chronic disease.
5. Improvement of public and health care providers awareness about the importance of HRQOL of SLE patients by using mass media and religious leaders.

6. Establishing an association of SLE patients for psychosocial support.
7. Perform training courses for newly graduated health care providers at PHC level and engagement of family medicine and EB practice.

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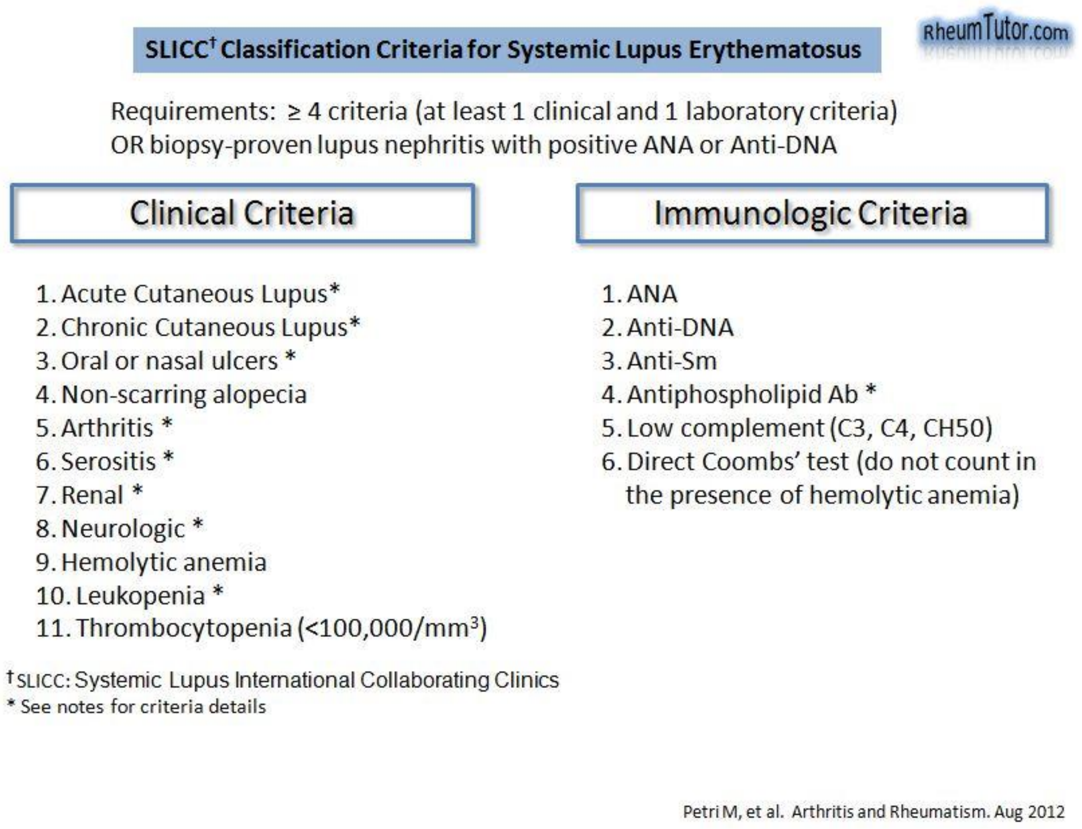
APPENDIX

Appendix 1



SLICC[†] Classification Criteria for Systemic Lupus Erythematosus

RheumTutor.com

Requirements: ≥ 4 criteria (at least 1 clinical and 1 laboratory criteria)
OR biopsy-proven lupus nephritis with positive ANA or Anti-DNA

Clinical Criteria

1. Acute Cutaneous Lupus*
2. Chronic Cutaneous Lupus*
3. Oral or nasal ulcers *
4. Non-scarring alopecia
5. Arthritis *
6. Serositis *
7. Renal *
8. Neurologic *
9. Hemolytic anemia
10. Leukopenia *
11. Thrombocytopenia (<100,000/mm^3)

Immunologic Criteria

1. ANA
2. Anti-DNA
3. Anti-Sm
4. Antiphospholipid Ab *
5. Low complement (C3, C4, CH50)
6. Direct Coombs' test (do not count in the presence of hemolytic anemia)

[†] SLICC: Systemic Lupus International Collaborating Clinics
* See notes for criteria details

Petri M, et al. Arthritis and Rheumatism. Aug 2012

Appendix2

Age in years-----------------

Sex ☐ male ☐ female

Place of residence ☐ urban ☐ rural

Educational level ☐ does not read and write
☐ read and write
☐ primary
☐ secondary
☐ bachelor's / university

Occupation ☐ housewife
☐ employee
☐ retired
☐ gainer (free business)

Impact of illness on work or education level ☐ number of sick leave
☐ duration of sick leave
☐ early retirement

Marital status ☐single
☐ married
☐ divorced
☐ widow

Disease duration from the date of diagnosis---------------

ESR--------------

Medications ☐HCQ
☐Steroids
☐ DMARDs
☐ Biology (Rituximab)

Do you have complications of the disease ? what are they:-----------------

Appendix 2

Appendix A. LupusQoL Questionnaire

The following questionnaire is designed to find out how SLE affects your life. **Read** each statement and then circle theresponse, which is **closest to how you feel**. Please try to answer all the questions as honestly as you can.

How often over the last 4 weeks

1. **Because of my Lupus I need help to do heavy physical jobs such as digging the garden, painting and/or decorating, movingfurniture**

All of the time most of the time a good bit of the time occasionally never

2. **Because of my Lupus I need help to do moderate physical jobs such as vacuuming, ironing, shopping, cleaning thebathroom**

All of the time most of the time a good bit of the time occasionally never

3. **Because of my Lupus I need help to do light physical jobs such as cooking/preparing meals, opening jars, dusting, combingmy hair or attending to personal hygiene**

All of the time most of the time a good bit of the time occasionally never

4. **Because of my Lupus I am unable to perform everyday tasks such as my job, childcare, housework as well asI would like to**

All of the time most of the time a good bit of the time occasionally never

5. **Because of my Lupus I have difficulty climbing stairs**

All of the time most of the time a good bit of the time occasionally never

6. **Because of my Lupus I have lost some independence and am reliant on others**

All of the time most of the time a good bit of the time occasionally never

7. **I have to do things at a slower pace because of my Lupus**

All of the time most of the time a good bit of the time occasionally never

8. **Because of my Lupus my sleep pattern is disturbed**

All of the time most of the time a good bit of the time occasionally never

How often over the last 4 weeks

9. **I am prevented from performing activities the way I would like to because of pain due to Lupus**

All of the time most of the time a good bit of the time occasionally never

10. **Because of my Lupus, the pain I experience interferes with the quality of my sleep**

All of the time most of the time a good bit of the time occasionally never

11. **The pain due to my Lupus is so severe that it limits my mobility**

All of the time most of the time a good bit of the time occasionally never

12. **Because of my Lupus I avoid planning to attend events in the future**

All of the time most of the time a good bit of the time occasionally never

13. **Because of the unpredictability of my Lupus I am unable to organise my life efficiently**

All of the time most of the time a good bit of the time occasionally never

14. **My Lupus varies from day to day which makes it difficult for me to commit myself to social arrangements**

All of the time most of the time a good bit of the time occasionally never

15. **Because of the pain I experience due to Lupus I am less interested in a sexual relationship**

All of the time most of the time a good bit of the time occasionally never
not applicale

16. **Because of my Lupus I am not interested in sex**

All of the time most of the time a good bit of the time occasionally never
not applicable

17. **I am concerned that my Lupus is stressful for those who are close to me**

All of the time most of the time a good bit of the time occasionally never

18. **Because of my Lupus I am concerned that I cause worry to those who are close to me**

All of the time most of the time a good bit of the time occasionally never

19. **Because of my Lupus I feel that I am a burden to my friends and/or family**

All of the time most of the time a good bit of the time occasionally never

contined

Over the past 4 weeks I have found my Lupus makes me

20.Resentful

All of the time most of the time a good bit of the time occasionally never

21.So fed up nothing can cheer me up

All of the time most of the time a good bit of the time occasionally never

22.Sad

All of the time most of the time a good bit of the time occasionally never

23.Anxious

All of the time most of the time a good bit of the time occasionally never

24.Worried

All of the time most of the time a good bit of the time occasionally never

25.Lacking in self-confidence

All of the time most of the time a good bit of the time occasionally never

How often over the past 4 weeks

26.My physical appearance due to Lupus interferes with my enjoyment of life

All of the time most of the time a good bit of the time occasionally never

27.Because of my Lupus, my appearance (e.g. rash, weight gain/loss) makes me avoid social situations

All of the time most of the time a good bit of the time occasionally never
not applicable

28.Lupus related skin rashes make me feel less attractive

All of the time most of the time a good bit of the time occasion not applicable

How often over the past 4 weeks

29.The hair loss I have experienced because of my Lupus makes me feel less attractive

All of the time most of the time a good bit of the time occasion not applicable

30.The weight gain I have experienced because of my Lupus treatment makes me feel less attractive

All of the time most of the time a good bit of the time occasionally never
not applicable

31.Because of my Lupus I cannot concentrate for long periods of time

All of the time most of the time a good bit of the time occasionally never

32.Because of my Lupus I feel worn out and sluggish

All of the time most of the time a good bit of the time occasionally never

33.Because of my Lupus I need to have early nights

All of the time most of the time a good bit of the time occasionally never

34.Because of my Lupus I am often exhausted in the morning

All of the time most of the time a good bit of the time occasionally never

Please feel free to make any additional comments.

Appendix 3

العمر بالسنوات -----------

الجنس ☐ ذكر ☐ انثى

محل الاقامة ☐ ريف ☐ مدينة

مستوى التعليم ☐ لا يقرا ولا يكتب

☐ يقرا ويكتب

☐ ابتدائي

☐ ثانوي

☐بكالوريوس \ جامعي

المهنة ☐ ربة بيت

☐ موظف\ة

☐ متقاعد\ة

☐ كاسب

تأثير المرض على العمل او مستوى التعليم ☐ اجازات مرضية عددها----- مدتها ------

☐ تقاعد مبكر

الحالة الاجتماعية ☐ غير متزوج\ة

☐ متزوج\ة

☐ منفصل\ة

☐ ارملة

فترة المرض من تاريخ التشخيص ---------------

ESR ----------------

الادوية ☐ HCQ

Steroids ☐

DMARDs ☐

Biology (Rituximab) ☐

هل لديك مضاعفات المرض ماهي :--------------------

Appendix3

Systemic lupus erythematosus Disease Activity Index (SLEDAI -2K)

Seizure (recent onset) No^0 Yes^{+8}

Psychosis No^0 Yes^{+8}

Organic brain damage No^0 Yes^{+8}

Visual disturbance No^0 Yes^{+8}

New onset sensory or motor neuropathy

Involving cranial nerve syndrome No^0 Yes^{+8}

New onset stroke No^0 Yes^{+8}

Vasculitis No^0 Yes^{+8}

Arthritis No^0 Yes^{+4}

Myositis No^0 Yes^{+4}

Urinary casts No^0 Yes^{+4}

Hematuria No^0 Yes^{+4}

Proteinuria No^0 Yes^{+4}

Pyuria No^0 Yes^{+4}

New rash No^0 Yes^{+2}

Alopecia No^0 Yes^{+2}

Mucosal ulcers No^0 Yes^{+2}

Pleurisy No^0 Yes $^{+2}$

Pericarditis No^0 Yes^{+2}

Low complement No^0 Yes^{+2}

High binding DNA No^0 Yes^{+2}

Fever No^0 Yes^{+1}

Platelets $< 100*10^{9/}$ No^0 Yes^{+1}

WBC $< 3*10^{9/L}$ No^0 Yes^{+1}

Appendix 3

استبيان عن نوعية الحياة للمصابين بمرض الذئبة

يهدف الاستبيان التالي إلى معرفة كيفية تأثير مرض الذئبة الحمراء المجموعية على حياتك. **اقرأ** كلّ جملة ثم اختر الإجابة **الأقرب إلى ما تشعر به**. يُرجى محاولة الإجابة على جميع الأسئلة بأقصى ما تستطيع من الأمانة.

ما هو معدل تكرار حدوث ما يلي خلال الأسابيع الأربعة الماضية

1. بسبب مرض الذئبة الذى أعاني منه، أحتاج للمساعدة في القيام بالأعمال البدنية الشاقة	☐ في كل الأوقات ☐ في أكثر الأوقات ☐ في نسبة غير قليلة من الوقت ☐ أحياناً ☐ لم يحدث قط
2. بسبب مرض الذئبة الذى أعاني منه، أحتاج للمساعدة للقيام بالأعمال البدنية متوسطة المجهود، كاستخدام المكنسة الكهربائية والكيّ، والتسوّق وتنظيف الحمام	☐ في كل الأوقات ☐ في أكثر الأوقات ☐ في نسبة غير قليلة من الوقت ☐ أحياناً ☐ لم يحدث قط
3. بسبب مرض الذئبة الذى أعاني منه، أنا بحاجة للمساعدة للقيام بالأعمال البدنية الخفيفة، كالطبخ/إعداد الوجبات، أو فتح البرطمانات أو نفض الغبار أو تمشيط شعري، أو المحافظة على نظافتي الشخصية.	☐ في كل الأوقات ☐ في أكثر الأوقات ☐ في نسبة غير قليلة من الوقت ☐ أحياناً ☐ لم يحدث قط
4. بسبب مرض الذئبة الذى أعاني منه، لا أستطيع القيام بمهامي اليومية، كمهمات وظيفتي، والعناية بالأطفال، والأعمال المنزلية، كما أريد.	☐ في كل الأوقات ☐ في أكثر الأوقات ☐ في نسبة غير قليلة من الوقت ☐ أحياناً ☐ لم يحدث قط
5. بسبب مرض الذئبة الذى أعاني منه، أجد صعوبة في صعود الدرج.	☐ في كل الأوقات ☐ في أكثر الأوقات ☐ في نسبة غير قليلة من الوقت ☐ أحياناً ☐ لم يحدث قط
6. بسبب مرض الذئبة الذى أعاني منه، فقدت قدراً من اعتمادى على نفسي وأصبحت معتمداً على غيرى	☐ في كل الأوقات ☐ في أكثر الأوقات ☐ في نسبة غير قليلة من الوقت ☐ أحياناً ☐ لم يحدث قط
7. أنا مضطر لأداء أمورى على نحو أبطأ بسبب مرض الذئبة الذى أعاني منه	☐ في كل الأوقات ☐ في أكثر الأوقات ☐ في نسبة غير قليلة من الوقت ☐ أحياناً ☐ لم يحدث قط
8. بسبب مرض الذئبة الذى أعاني منه، فإن نمط نومي مضطرب	☐ في كل الأوقات ☐ في أكثر الأوقات ☐ في نسبة غير قليلة من الوقت ☐ أحياناً ☐ لم يحدث قط
9. يمنعني الألم الذى يسببه مرض الذئبة من القيام بأنشطتي كما أحبُّ.	☐ في كل الأوقات ☐ في أكثر الأوقات ☐ في نسبة غير قليلة من الوقت ☐ أحياناً ☐ لم يحدث قط

استبيان عن نوعية الحياة للمصابين بمرض الذئبة (تابع)

ما هو معدل تكرار حدوث ما يلي خلال الأسابيع الأربعة الماضية

10. بسبب مرض الذئبة الذي أعاني منه، يؤثر الألم على جودة نومي.	☐ في كل الأوقات ☐ في أكثر الأوقات ☐ في نسبة غير قليلة من الوقت ☐ أحياناً ☐ لم يحدث قط
11. شدة الآلام التي يسببها مرض الذئبة لي شديدة جداً لدرجة أنها تحد من قدرتي على التنقل.	☐ في كل الأوقات ☐ في أكثر الأوقات ☐ في نسبة غير قليلة من الوقت ☐ أحياناً ☐ لم يحدث قط
12. بسبب مرض الذئبة الذي أعاني منه، أتجنَّب التخطيط لحضور ما يُقام من مناسبات في المستقبل.	☐ في كل الأوقات ☐ في أكثر الأوقات ☐ في نسبة غير قليلة من الوقت ☐ أحياناً ☐ لم يحدث قط
13. نظراً لصعوبة التنبؤ بتطورات مرض الذئبة الذي أعاني منه، أنا غير قادر على تنظيم حياتي تنظيماً فعَّالًا.	☐ في كل الأوقات ☐ في أكثر الأوقات ☐ في نسبة غير قليلة من الوقت ☐ أحياناً ☐ لم يحدث قط
14. تتغير أحوال مرض الذئبة الذي أعاني منه من يوم لآخر، ولهذا يصعب عليّ القيام بما علي من واجبات اجتماعية.	☐ في كل الأوقات ☐ في أكثر الأوقات ☐ في نسبة غير قليلة من الوقت ☐ أحياناً ☐ لم يحدث قط
15. بسبب الألم الذي أعاني منه من مرض الذئبة، أنا أقل رغبة في علاقة جنسية.	☐ في كل الأوقات ☐ في أكثر الأوقات ☐ في نسبة غير قليلة من الوقت ☐ أحياناً ☐ لم يحدث قط ☐ لا ينطبق على الحال
16. بسبب مرض الذئبة الذي أعاني منه، لا أرغب في الجنس.	☐ في كل الأوقات ☐ في أكثر الأوقات ☐ في نسبة غير قليلة من الوقت ☐ أحياناً ☐ لم يحدث قط ☐ لا ينطبق على الحال
17. أشعر بالقلق حيال ما يسببه مرض الذئبة الذي أعاني منه من إجهاد للقريبين مني.	☐ في كل الأوقات ☐ في أكثر الأوقات ☐ في نسبة غير قليلة من الوقت ☐ أحياناً ☐ لم يحدث قط
18. بسبب مرض الذئبة الذي أعاني منه، أتضايق من أنني أسبب القلق لهؤلاء القريبين مني.	☐ في كل الأوقات ☐ في أكثر الأوقات ☐ في نسبة غير قليلة من الوقت ☐ أحياناً ☐ لم يحدث قط

استبيان عن نوعية الحياة للمصابين بمرض الذئبة (تابع)

ما هو معدل تكرار حدوث ما يلي خلال الأسابيع الأربعة الماضية

19. بسبب مرض الذئبة الذي أعاني منه، أشعر بأنني عبء على أهلي و/أو أصدقائي.

☐ في كل الأوقات
☐ في أكثر الأوقات
☐ في نسبة غير قليلة من الوقت
☐ أحياناً
☐ لم يحدث قط

على مدى الأسابيع الأربعة الماضية، وجدت أن مرض الذئبة الذي أعاني منه يجعلني

20. ناقماً

☐ في كل الأوقات
☐ في أكثر الأوقات
☐ في نسبة غير قليلة من الوقت
☐ أحياناً
☐ لم يحدث قط

21. في حالة غم بالغة بحيث لا أجد شيئًا مسليًا.

☐ في كل الأوقات
☐ في أكثر الأوقات
☐ في نسبة غير قليلة من الوقت
☐ أحياناً
☐ لم يحدث قط

22. حزيناً

☐ في كل الأوقات
☐ في أكثر الأوقات
☐ في نسبة غير قليلة من الوقت
☐ أحياناً
☐ لم يحدث قط

23. متوتراً

☐ في كل الأوقات
☐ في أكثر الأوقات
☐ في نسبة غير قليلة من الوقت
☐ أحياناً
☐ لم يحدث قط

24. قلقاً

☐ في كل الأوقات
☐ في أكثر الأوقات
☐ في نسبة غير قليلة من الوقت
☐ أحياناً
☐ لم يحدث قط

25. مفتقرا إلى الثقة بالنفس

☐ في كل الأوقات
☐ في أكثر الأوقات
☐ في نسبة غير قليلة من الوقت
☐ أحياناً
☐ لم يحدث قط

ما هو معدل تكرار حدوث ما يلي خلال الأسابيع الأربعة الماضية

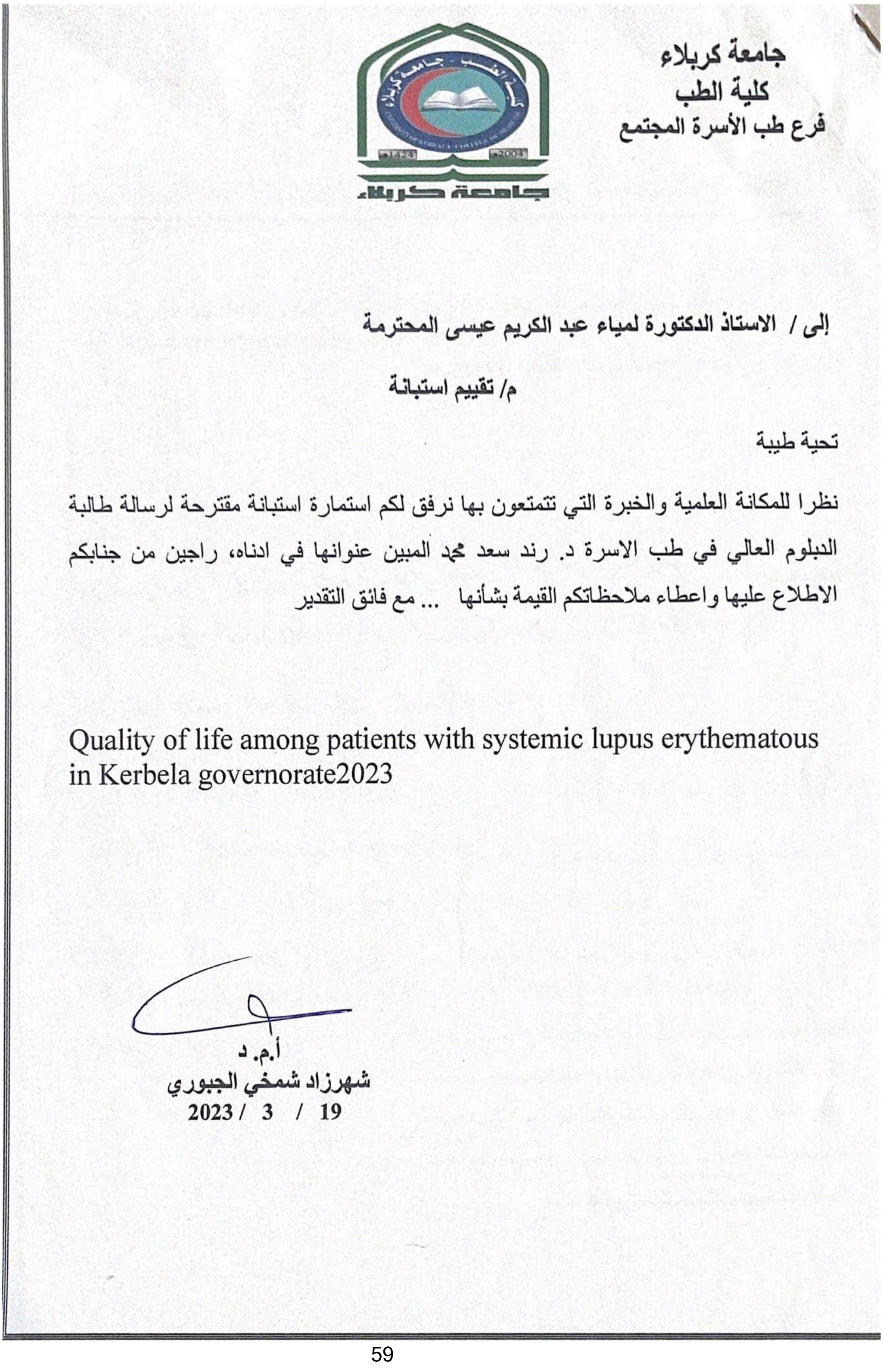
26. مظهري الجسدي الناتج عن مرض الذئبة يتعارض مع استمتاعي بالحياة.

☐ في كل الأوقات
☐ في أكثر الأوقات
☐ في نسبة غير قليلة من الوقت
☐ أحياناً
☐ لم يحدث قط

استبيان عن نوعية الحياة للمصابين بمرض الذئبة *(تابع)*

ما هو معدل تكرار حدوث ما يلي خلال الأسابيع الأربعة الماضية

27. بسبب مرض الذئبة الذى أعاني منه، يجعلني مظهرى (مثلا: كالطفح الجلدى، أو زيادة الوزن أو نقصانه) أتجنب المناسبات الاجتماعية.	☐ في كل الأوقات ☐ في أكثر الأوقات ☐ في نسبة غير قليلة من الوقت ☐ أحياناً ☐ لم يحدث قط ☐ لا ينطبق على الحال
28. الطفح الجلدى الذى بسببه مرض الذئبة يجعلني أشعر بأني أقلّ جاذبية.	☐ في كل الأوقات ☐ في أكثر الأوقات ☐ في نسبة غير قليلة من الوقت ☐ أحياناً ☐ لم يحدث قط ☐ لا ينطبق على الحال
29. تساقط الشعر الذى أصابني بسبب مرض الذئبة الذى أعاني منه يجعلني أشعر بأني أقلّ جاذبية.	☐ في كل الأوقات ☐ في أكثر الأوقات ☐ في نسبة غير قليلة من الوقت ☐ أحياناً ☐ لم يحدث قط ☐ لا ينطبق على الحال
30. زيادة الوزن التي عانيت منها بسبب العلاج الذى أتلقاه لمرض الذئبة يجعلني أشعر بأني أقلّ جاذبية.	☐ في كل الأوقات ☐ في أكثر الأوقات ☐ في نسبة غير قليلة من الوقت ☐ أحياناً ☐ لم يحدث قط ☐ لا ينطبق على الحال
31. بسبب مرض الذئبة الذى أعاني منه لا أستطيع التركيز لفترات طويلة من الزمن.	☐ في كل الأوقات ☐ في أكثر الأوقات ☐ في نسبة غير قليلة من الوقت ☐ أحياناً ☐ لم يحدث قط
32. بسبب مرض الذئبة الذى أعاني منه، أشعر بالإرهاق والخمول.	☐ في كل الأوقات ☐ في أكثر الأوقات ☐ في نسبة غير قليلة من الوقت ☐ أحياناً ☐ لم يحدث قط
33. بسبب مرض الذئبة الذى أعاني منه، أحتاج إلى النوم مبكراً.	☐ في كل الأوقات ☐ في أكثر الأوقات ☐ في نسبة غير قليلة من الوقت ☐ أحياناً ☐ لم يحدث قط
34. بسبب مرض الذئبة الذى أعاني منه، كثيراً ما أشعر بالإرهاق في الصباح.	☐ في كل الأوقات ☐ في أكثر الأوقات ☐ في نسبة غير قليلة من الوقت ☐ أحياناً ☐ لم يحدث قط



جامعة كربلاء
كلية الطب
فرع طب الأسرة المجتمع

إلى / الاستاذ الدكتورة لمياء عبد الكريم عيسى المحترمة

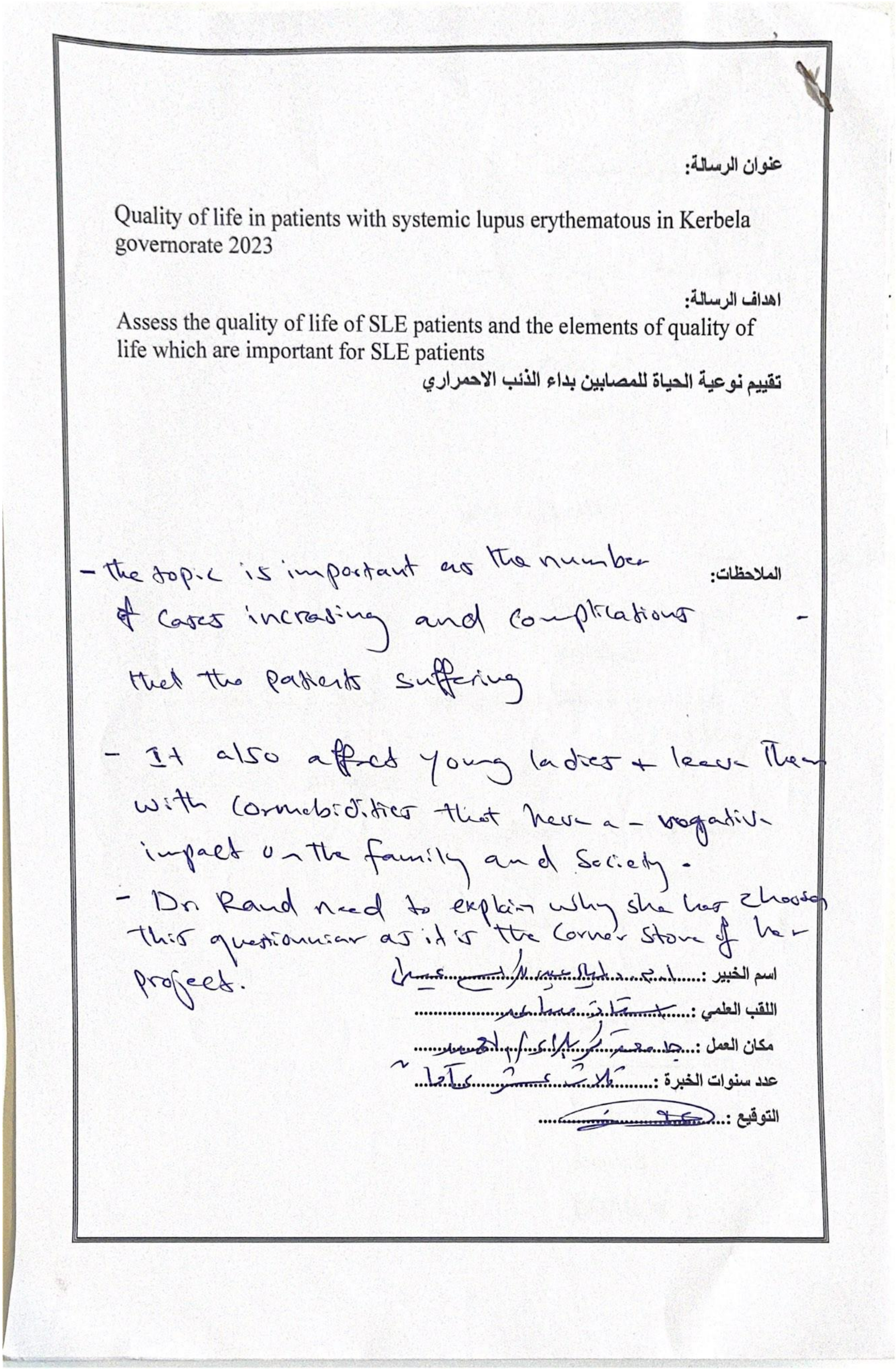
م/ تقييم استبانة

تحية طيبة

نظرا للمكانة العلمية والخبرة التي تتمتعون بها نرفق لكم استمارة استبانة مقترحة لرسالة طالبة الدبلوم العالي في طب الاسرة د. رند سعد محمد المبين عنوانها في ادناه، راجين من جنابكم الاطلاع عليها واعطاء ملاحظاتكم القيمة بشأنها ... مع فائق التقدير

Quality of life among patients with systemic lupus erythematous in Kerbela governorate2023

أ.م. د
شهرزاد شمخي الجبوري
2023 / 3 / 19



عنوان الرسالة:

Quality of life in patients with systemic lupus erythematous in Kerbela governorate 2023

اهداف الرسالة:

Assess the quality of life of SLE patients and the elements of quality of life which are important for SLE patients

تقييم نوعية الحياة للمصابين بداء الذئب الاحمراري

الملاحظات:

- the topic is important as the number of cases increasing and complications that the patients suffering
- It also affect young ladies + leave them with cormobidities that have a - negative impact on the family and Society.
- Dr Rand need to explain why she has choosen this questionniar as it is the corner stone of her project.

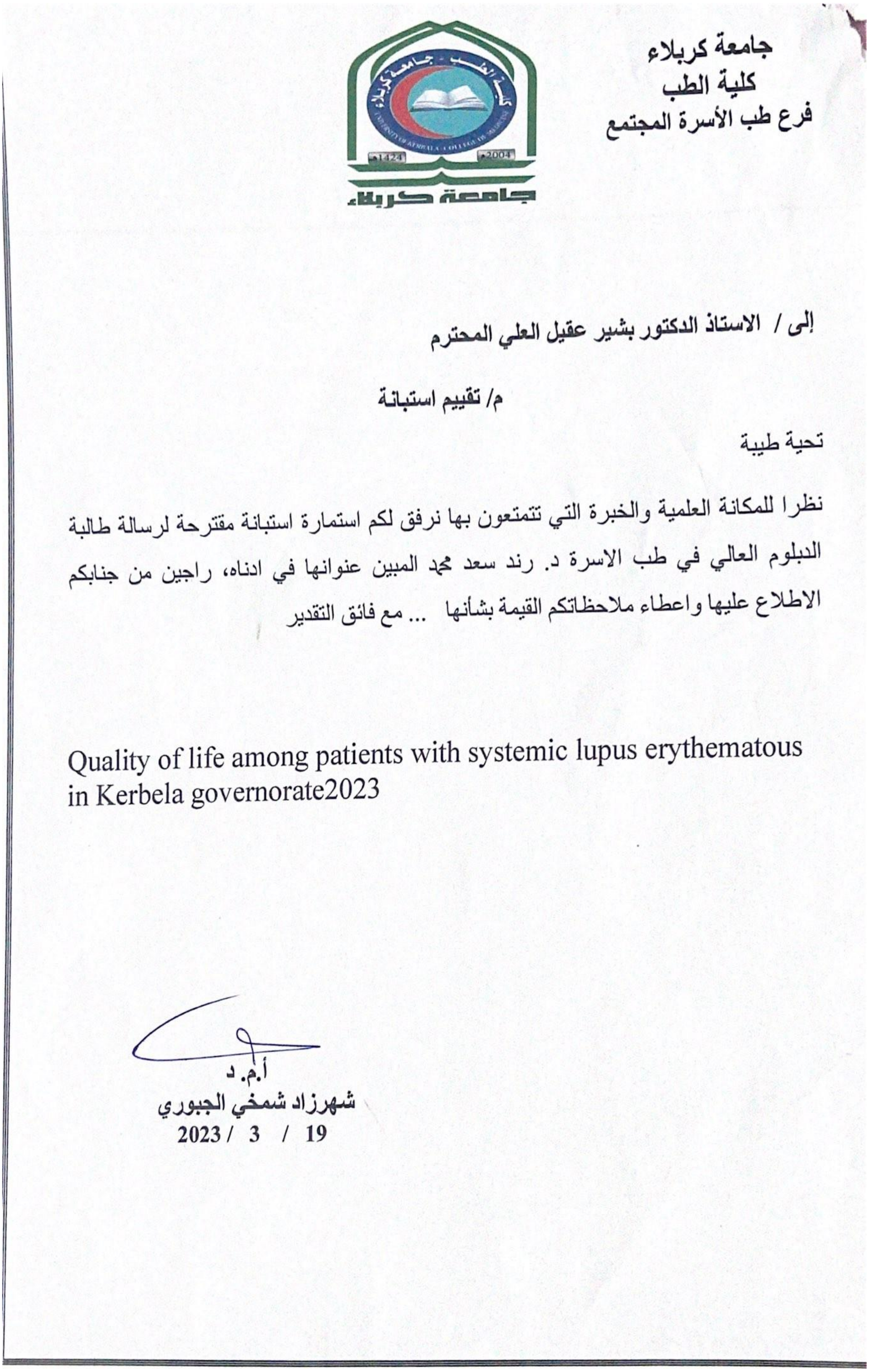
اسم الخبير : أ.م.د. [illegible]

اللقب العلمي : استاذ مساعد

مكان العمل : جامعة كربلاء / الطب

عدد سنوات الخبرة : ثلاثة عشر عاماً

التوقيع :



جامعة كربلاء
كلية الطب
فرع طب الأسرة المجتمع

إلى / الاستاذ الدكتور بشير عقيل العلي المحترم

م/ تقييم استبانة

تحية طيبة

نظرا للمكانة العلمية والخبرة التي تتمتعون بها نرفق لكم استمارة استبانة مقترحة لرسالة طالبة الدبلوم العالي في طب الاسرة د. رند سعد محمد المبين عنوانها في ادناه، راجين من جنابكم الاطلاع عليها واعطاء ملاحظاتكم القيمة بشأنها ... مع فائق التقدير

Quality of life among patients with systemic lupus erythematous in Kerbela governorate2023

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عنوان الرسالة:

Quality of life in patients with systemic lupus erythematous in Kerbela governorate 2023

اهداف الرسالة:

Assess the quality of life of SLE patients and the elements of quality of life which are important for SLE patients

تقييم نوعية الحياة للمصابين بداء الذئب الاحمراري

الملاحظات:

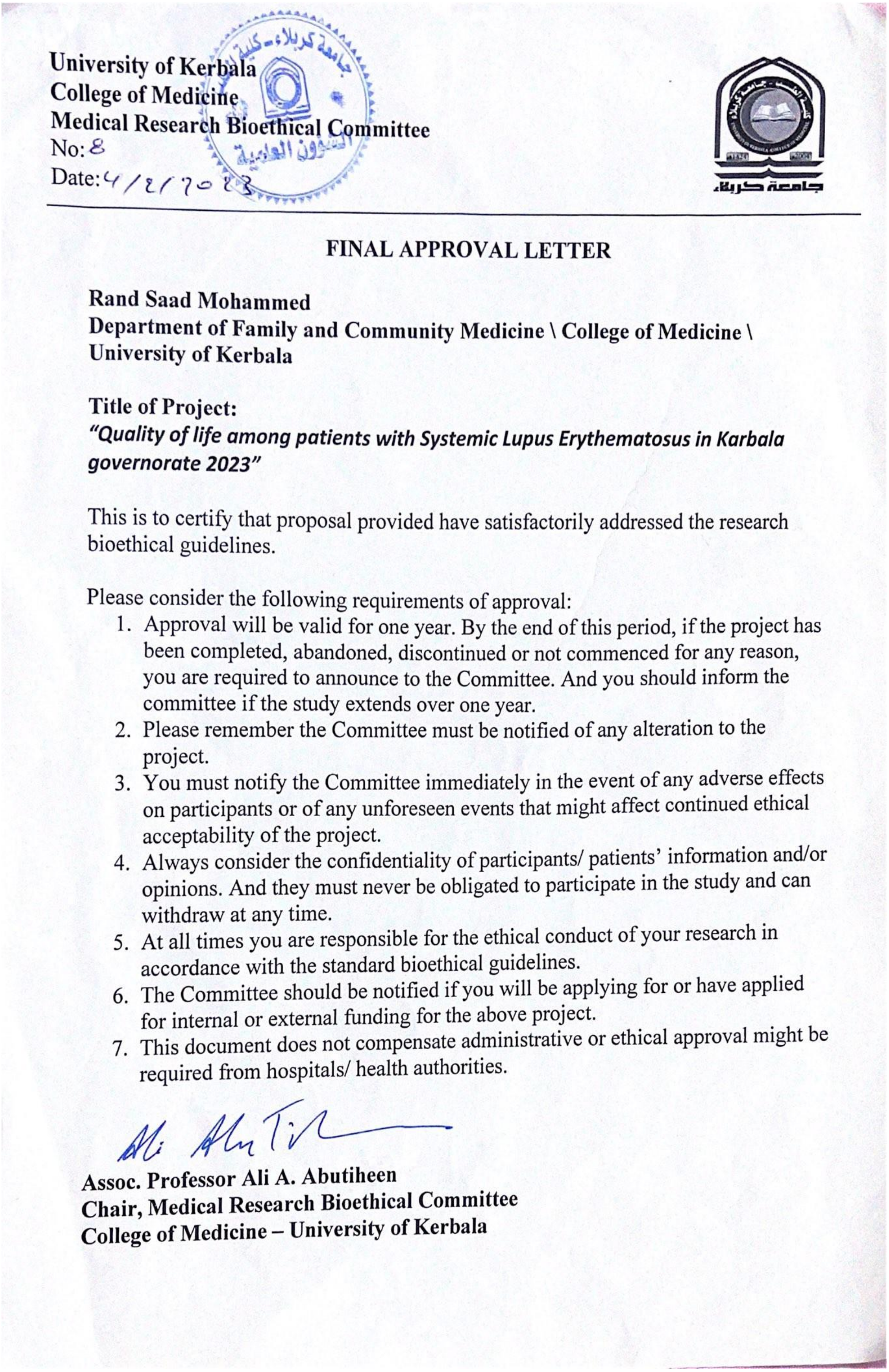
اسم الخبير : بشير كفيل مسلم العلي

اللقب العلمي : استاذ مساعد

مكان العمل : كلية الطب / جامعة كربلاء

عدد سنوات الخبرة : ٤٢ سنة

التوقيع :



University of Kerbala
College of Medicine
Medical Research Bioethical Committee
No: 8
Date: ٤/٢/٢٠٢٣

FINAL APPROVAL LETTER

Rand Saad Mohammed
Department of Family and Community Medicine \ College of Medicine \ University of Kerbala

Title of Project:
"Quality of life among patients with Systemic Lupus Erythematosus in Karbala governorate 2023"

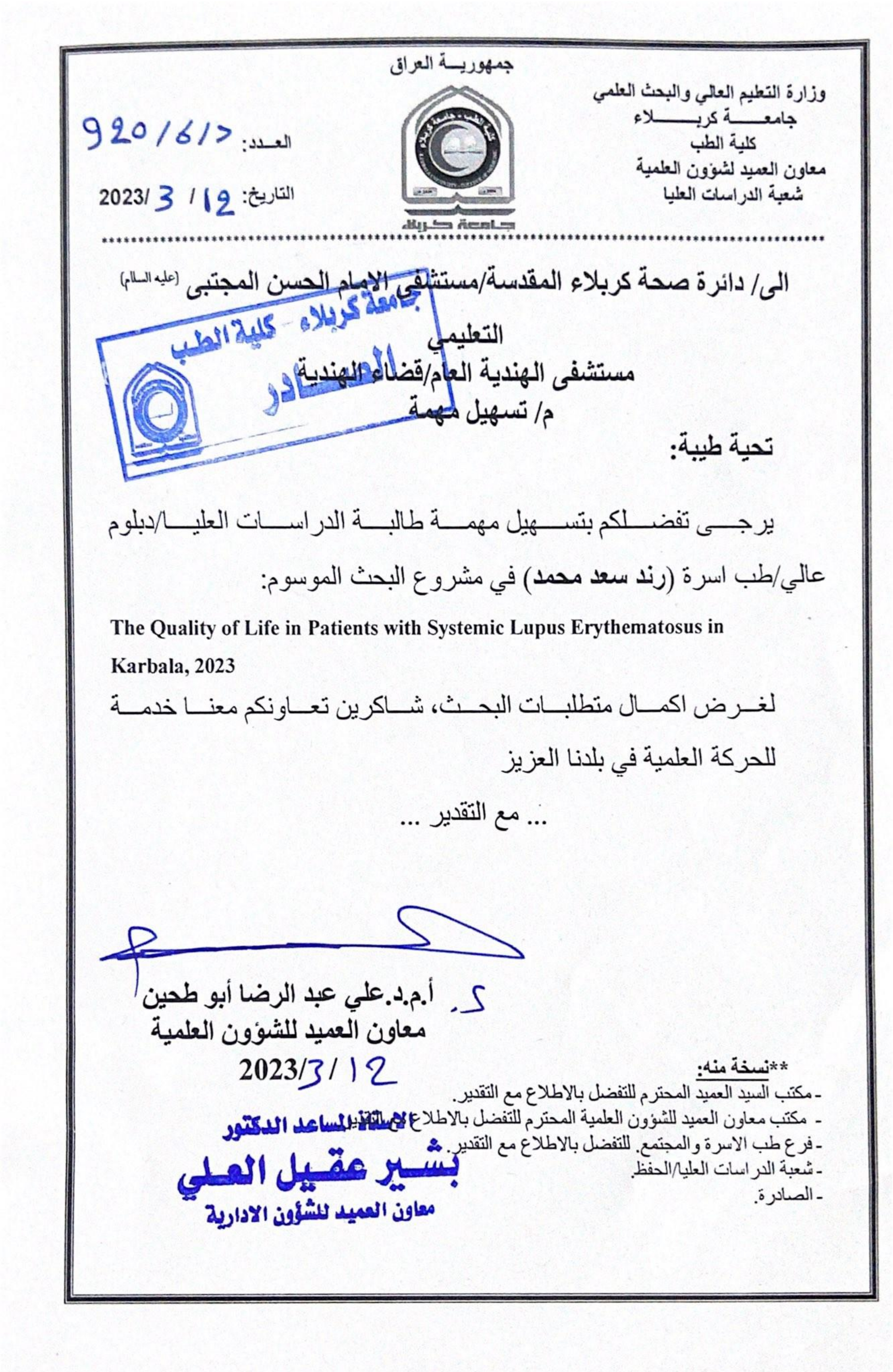
This is to certify that proposal provided have satisfactorily addressed the research bioethical guidelines.

Please consider the following requirements of approval:

1. Approval will be valid for one year. By the end of this period, if the project has been completed, abandoned, discontinued or not commenced for any reason, you are required to announce to the Committee. And you should inform the committee if the study extends over one year.
2. Please remember the Committee must be notified of any alteration to the project.
3. You must notify the Committee immediately in the event of any adverse effects on participants or of any unforeseen events that might affect continued ethical acceptability of the project.
4. Always consider the confidentiality of participants/ patients' information and/or opinions. And they must never be obligated to participate in the study and can withdraw at any time.
5. At all times you are responsible for the ethical conduct of your research in accordance with the standard bioethical guidelines.
6. The Committee should be notified if you will be applying for or have applied for internal or external funding for the above project.
7. This document does not compensate administrative or ethical approval might be required from hospitals/ health authorities.

Ali AbuTi

Assoc. Professor Ali A. Abutiheen
Chair, Medical Research Bioethical Committee
College of Medicine – University of Kerbala



جمهوريـــة العراق

وزارة التعليم العالي والبحث العلمي
جامعـــــة كربـــــلاء
كلية الطب
معاون العميد لشؤون العلمية
شعبة الدراسات العليا

العـــدد: 920/6/7

التاريخ: 2023/3/12

جامعة كربلاء - كلية الطب
الصادر

الى/ دائرة صحة كربلاء المقدسة/مستشفى الامام الحسن المجتبى (عليه السلام) التعليمي
مستشفى الهندية العام/قضاء الهندية
م/ تسهيل مهمة

تحية طيبة:

يرجـــى تفضـــلكم بتســـهيل مهمـــة طالبـــة الدراســـات العليـــا/دبلوم عالي/طب اسرة (**رند سعد محمد**) في مشروع البحث الموسوم:

The Quality of Life in Patients with Systemic Lupus Erythematosus in Karbala, 2023

لغـــرض اكمـــال متطلبـــات البحـــث، شـــاكرين تعـــاونكم معنـــا خدمـــة للحركة العلمية في بلدنا العزيز

... مع التقدير ...

أ.م.د.علي عبد الرضا أبو طحين
معاون العميد للشؤون العلمية
2023/3/12

****نسخة منه:**
- مكتب السيد العميد المحترم للتفضل بالاطلاع مع التقدير.
- مكتب معاون العميد للشؤون العلمية المحترم للتفضل بالاطلاع مع التقدير.
- فرع طب الاسرة والمجتمع. للتفضل بالاطلاع مع التقدير.
- شعبة الدراسات العليا/الحفظ.
- الصادرة.

الاستاذ المساعد الدكتور
بشير عقيل العلي
معاون العميد للشؤون الادارية

الخلاصة

الخلفية:

الذئبة الحمامية الجهازية هو مرض مناعي ذاتي مزمن وغير متجانس مع مجموعة متنوعة من الأعراض السريرية التي تؤثر في المقام الأول على النساء في سن الإنجاب. يرتبط الذئبة الحمامية الجهازية بعبء كبير على المريض.

الأهداف: تقييم جودة الحياة المتعلقة بالصحة (HRQOL) بين مرضى الذئبة الحمامية الجهازية وتقييم ارتباطها بالخصائص الاجتماعية والديموغرافية والسريرية المختلفة لمرضى الذئبة الحمامية الجهازية.

الطرق: شارك خمسة وسبعون مريضًا مصابًا بالذئبة الحمامية الجهازية والذين حضروا العيادة الخارجية لأمراض الروماتيزم وإعادة التأهيل في مستشفى الإمام الحسن المجتبى التعليمي في كربلاء بالعراق في دراسة مقطعية وصفية. كانت الفترة الزمنية لهذه الدراسة كانون الاول 2022- اذار 2024. تم جمع البيانات من خلال المقابلات المباشرة ومن خلال استخدام الاستبيانات المنظمة. تم استخدام استبيان جودة حياة الذئبة (lupusQoL) لتقييم جودة الحياة المتعلقة بالصحة الخاصة بالمرض. وسجل مؤشر نشاط مرض الذئبة الحمامية الجهازية (SLEDAI-2K).

النتائج: شملت هذه الدراسة 75 مريضًا بمرض الذئبة الحمامية الجهازية بمتوسط عمر 38.12 ± 11.70 عامًا، وكانوا في الغالب من الإناث بنسبة 97.3٪، وكانت مدة المرض (71.29 ± 65.65 شهرًا). جميع مجالات جودة حياة الذئبة كانت منخفضة. كان متوسط الدرجة الإجمالية لجودة الحياة 43.44 ± 22.75. 38.45). لم تكن هناك فروق إحصائية كبيرة في متوسط الدرجة الإجمالية لجودة الحياة والخصائص الديموغرافية لمرضى الدراسة. سجلت الفئات العمرية الأصغر والموظفون والمرضى المقيمون في المناطق الحضرية درجات أعلى بشكل ملحوظ من الفئات العمرية الأكبر سنًا وربات البيوت في مجال الصحة البدنية. سجل المرضى الذين يعانون من امراض في الكلى / الأمراض العصبية والنفسية درجات أعلى بشكل ملحوظ من المرضى الذين لا يعانون من امراض في الكلى / الأمراض العصبية والنفسية. أظهرت نتيجة تحليل الانحدار المتعدد أن العمر كان أقوى مؤشر في مجال الصحة البدنية لجودة الحياة ($\beta = -0.8$) .

الاستنتاجات: كان لدى مرضى الذئبة الحمامية الجهازية درجات منخفضة في جميع مجالات جودة الحياة. يجب على الأطباء التركيز على جودة الحياة وكيفية تحسينها من خلال المراقبة المنتظمة لجودة حياة مرضى الذئبة الحمامية الجهازية ، ويجب أن تركز إدارة المرض على المرضى، وليس فقط على المرض، مع العمل التعاوني بين أطباء الباطنية وأطباء الروماتيزم

وزارة التعليم العالي والبحث العلمي
جامعة كربلاء كلية الطب
فرع طب الاسرة والمجتمع

جودة الحياة بين مرضى الذئبة الحمامية الجهازية في محافظة كربلاء 2023

رسالة

مقدمة من مجلس كلية الطب- جامعة كربلاء كجزء من متطلبات نيل شهادة الدبلوم العالي (سنتان تقويميتان) في اختصاص طب الاسرة

من قبل

رند سعد محمد

بكالوريوس طب وجراحة عامة

باشراف

أ.م. د. شهرزاد شمخي الجبوري **م. د. زهراء حسين غليص**
بورد طب المجتمع بورد طب المفاصل
2024 1445