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Health-Related Quality of Life among Palestinian Patients Suffering from Systemic Lupus Erythematosus at Al Makassed Hospital

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Thesis Approval

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Dedication

I would like to dedicate this work to my family and friends, who supported me in all phases of this thesis, particularly to my mother and brother, whom help will not be forgotten.

Special dedication to my father, for his support, care, and love**.**

DECLERATION

I certify that this thesis submitted for the degree of Master is the result of my own research, except where otherwise acknowledged and that this thesis (or any part of the same) has not been submitted for a higher degree to any other university or institution.

Name: Mahmoud Mohammad Hodrop

Signature

Date

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ABSTRACT

Systemic lupus Erythematosus (SLE) is a chronic multisystem autoimmune disease that is mostly affected women during their childbearing years. SLE is most prevalent among women, with usual disease onset between ages 15 and 40. Patients with the disease have a female to male ratio of 9:1. In SLE, the immune system attacks the body’s own cells, which can result in inflammation of multiple organ systems at the same time.

The study aim is to examine Health-related quality of life among Palestinian patients suffering of SLE and to assess the relationship between educational level and Health Related Quality of life in SLE patients.

Health Related Quality of Life (HRQoL) studies are an essential complement to medical evaluation. HRQoL is a multidimensional concept, which includes crucial areas such as physical health, psychological well being, social relationships, personal beliefs, so measurement of HRQoL, in addition to more clinical indicators of disease, allows comprehensive assessment to be a more effective on treatment and response.

The SF-36 is a generic HRQoL tool, which consists of 36-item self-report questionnaire. It was designed to be used in a variety of conditions, populations, and settings. The SF-36 has been shown to be a valid and reliable instrument in SLE and has been used in numerous studies in SLE.

A connivance sample size was 76 patients age 14 years and above from AL-Makassed Hospital and private clinic in Ramallah city diagnosed with SLE according to the standard of American Rheumatology College. Patients with other chronic diseases were excluded.

Results of the study showed that HRQoL was affected in all health domains, as patients responded that they have limitations due to their suffering of Systemic lupus Erythematosus (SLE); especially in physical functioning, bodily pain, social functioning, role physical, and in mental health. Educational level was tested and showed that HRQoL domains were the same and not affected by different qualification categories.

We conclude that the Health Related Quality of Life of SLE patients of the study sample was poor and the disease worsening their daily living.

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List of Abbreviation

ACR	American College of Rheumatology
ANAs	Antinuclear antibodies
CDC	Central disease control and prevention
DNA	Deoxyribonucleic acid
FM	Fibromyalgia
HRQoL	Health Related Quality of Life
SLE	Systemic Lupus Erythrematosus

Chapter one

Introduction

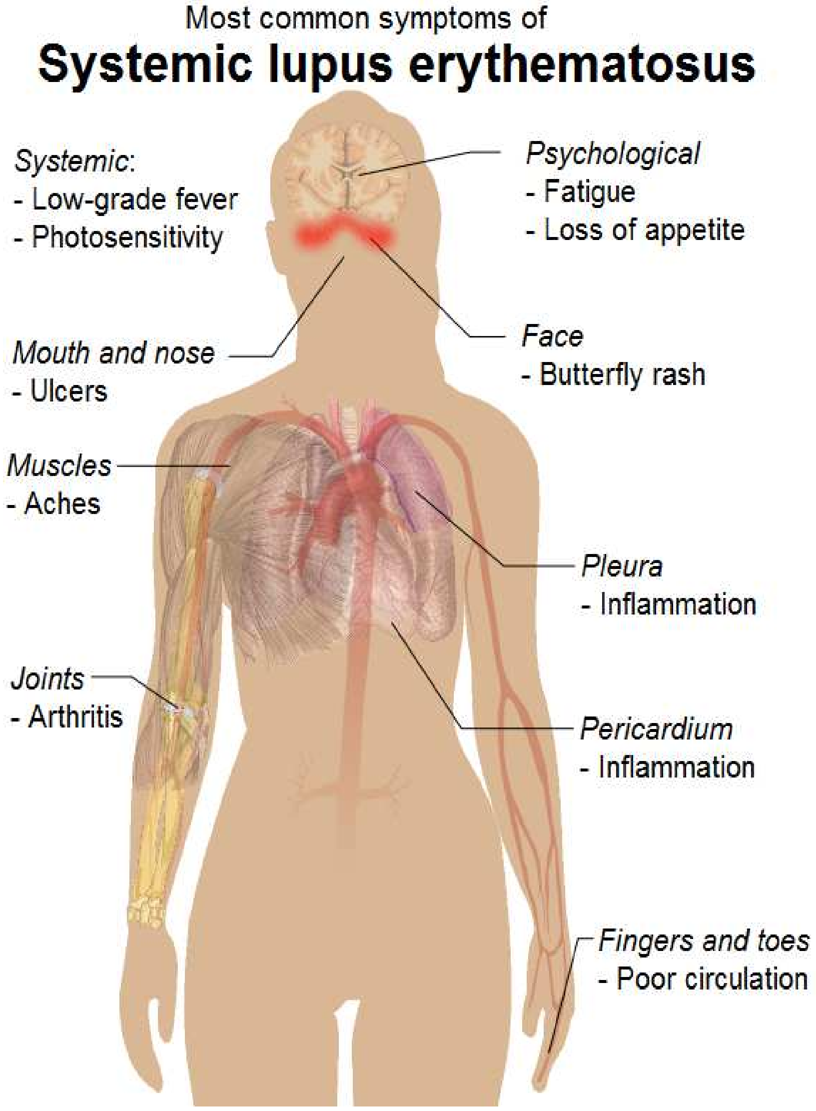
1.1 General background

Systemic Lupus Erythematosus (SLE) is a chronic autoimmune disease characterized by multisystem involvement, with a broad spectrum of clinical and laboratory manifestations. Etiopathogenetic factors, which can influence the development of SLE, mainly include, genetic background of the patient, external environmental agents (eg, superantigens, viruses, Ultra Violet radiation, drugs, chemicals), hormonal milieu, age, and probably other factors that are yet unknown. Consequently, the result would be the disturbance of the immunologic homeostasis, with resultant induction and production of autoantibodies contributing to tissue damage particularly renal failure (Tsokos, 2004).

In SLE, the immune system attacks the body's own cells, which can result in simultaneous inflammation of multiple organ systems (Figure.1). SLE is most prevalent among women in their reproductive years, with usual disease onset between ages 15 and 40 (Simard .,2007). The worldwide prevalence is estimated to be about one per 1000, and the female-to-male ratio is 10:1 (Manson & Rahman, 2006). Most patients manifest vague and varying symptoms, including marked malaise, extreme fatigue, and fever. Over-sensitivity to sun, painful joints, oral ulcers, and, on the psychosocial level, mild depression are also frequently reported. (Faurschou,et al., 2010).

Treatment of patients of SLE involves a balance between suppressing the signs and symptoms of the disease and minimizing the toxicities of the drugs used. With treatment, disease activity might improve but the patient might feel worse due to the side effects of the medication .(*K McElhone1,et a.,l 2006).*

Figure 1 . Most common symptom of Systemic Lupus Erythrematosus



MedicineNet.com. common symptom of Systemic Lupus Erythrematosus

Improvements in the survival of patients with SLE have been noted worldwide over the last 20 years. There is now a growing realization that physical attributes of health do not fully measure disease status in chronic conditions like SLE. Psychosocial factors such as pain, apprehension, difficulty in fulfilling personal and family responsibilities, and cognition dysfunction are equally important and must be assessed as (HRQoL).

(*Navarra SV, et al., 2006).*

The annual incidence of SLE averages five cases per 100,000 population. The Centers for Disease Control and Prevention (CDC) estimates a range between 1.8 and 7.6 per 100,000 persons per year in the continental United States. (CDC, 27, 2012.) .

The reported prevalence ranges from 52 cases per 100,000 population, which is consistent with the 2005 Central Disease Control Prevention estimates of 161,000 definite cases and 322,000 probable or definite SLE cases in the United States to estimates as high as 1:1000 (CDC, July 27. 2012.) . In addition, the incidence of SLE in black women is approximately 4 times higher than that in white women. SLE is also more frequent in Asian women than in white women. (Uramoto, et al., 1999). Worldwide, the prevalence of SLE varies. The highest rates of prevalence have been reported in Italy, Spain, Martinique, and the United Kingdom Afro-Caribbean population. (Danchenko N, et al., 2006).

Onset of SLE is usually after puberty, typically in the 20s and 30s, with 20% of all cases diagnosed during the first 2 decades of life. (Klein, et al., 2002). SLE does not have an age in males, although it should be noted that in older adults, the female-to-male ratio falls. This effect is likely due to loss of the estrogen effect in older females. (Boddaert, et al., 2004).

The frequency of SLE varies by race and ethnicity, with higher rates reported in blacks and Hispanics. The prevalence of SLE is approximately 40 per 100,000 whites in Rochester, Minnesota, and 100 per 100,000 Hispanics in Nogales, Arizona.(Balluz ,et al., 2001) .Also data about prevalence of SLE in Palestine are unavailable due to lack of database about many non-communicable diseases in both the ministry of health and in non-governmental organization focus in health issues .

Physicians may focus more on the aspects of SLE, which have the potential to cause organ damage or other major morbidity in the future, whereas patients may focus more on the symptoms that affect their everyday lives. (K Gallop, et al., 2012).

The survival of patients with SLE has significantly improved over the last 60 years. (Urowitz, et al., 2008) .There is evidence of the existence of a gap between the outcomes that are important to patients and those that are important to physicians. (Kirwan, et al, 2003), (Yen, et al., 1999).

1.2 Diagnosis of systemic lupus erythrematosus

The destructive lesions of the face and nose were first described as lupus by the British dermatologist Robert Willan (1757-1808), and the systemic manifestations of SLE (fever, weight loss, lymphadenopathy, anemia, and arthritis) were described in 1872 by Moriz Kaposi in Vienna(Kaposi also described a type of cancer, Kaposi sarcoma.) (Mallavarapu. 2007). Although Lupus nephritis, an inflammation of the kidneys, is the most prevalent manifestation in SLE that affects up to 60% of patients (Bihl. 2006).

Table (1.1-A) Diagnostic Criteria for Systemic Lupus Erythematosus according to American College of Rheumatology

If four or more these criteria are present and well documented at any time of the patient's medical history, the diagnosis is likely to be SLE.

Sign, Symptom or Lab result	**Definition**
Malar rash	Fixed erythema (redness), flat or raised, over the malar eminences (cheekbones)
Discoid rash	Erythematous (reddish) circular raised patches with adherent scaling of the skin
Photosensitivity	Exposure to ultraviolet light causes rash
Oral Ulcers	Includes oral and nasopharyngeal ulcers, observed by physician
Arthritis	Inflammation of two or more peripheral (limbs) joints, with tenderness, swelling, or effusion(fluid)

Table (1.1-B) Diagnostic Criteria for Systemic Lupus Erythematosus according to American College of Rheumatology

Sign, Symptom or Lab result	**Definition**
Serositis	Pleuritis or pericarditis documented by ECG or evidence of effusion (fluid)
Renal disorder	Proteinuria (protein in the urine)>0.5 g/d or 3+, or cellular casts (cells in the urine)
Neurological disorder	Seizures or psychosis without other causes
Hematological disorder	Hemolytic anemia, leukopenia or lymphopenia(low white blood cells), or thrombocytopenia (low platelets) in the absence of offending drugs
Immunological disorder	Anti-dsDNA (double stranded DNA), anti-Sm, and/or anti-phospholipid
Antinuclear antibodies	An abnormal titer of ANA (antinuclear antibodies) by immunofluorescence or an equivalent assay at any point in time in the absence of drugs known to induce ANAs

If four or more these criteria are present and well documented at any time of the patient's medical history, the diagnosis is likely to be SLE.
Updating the American College of Rheumatology revised criteria for the classification of systemic lupus erythematosus.(Hochberg MC,1997)

1.3 Health Related Quality of Life

Health Related Quality of Life has variously been defined as ‘a multi-domain concept that represents the patient’s overall perception of the impact of an illness and its treatment’ and the degree to which persons perceive themselves able to function physically, emotionally and socially’. (*Last JM. dictionary of epidemiology* 2001, *M Jolly*, et al 2009)

Health Related Quality of Life is significantly affected by SLE, particularly when the disease is active, when compared with the general population, there are significant decreasing in a wide variety of domains of HRQoL as measured by the SF-36 (a widely used none-disease-specific HRQoL instrument), where decrease in HRQoL are seen for both the physical and mental domains of health (Thumboo J., et al 2009).

The degree of reduction in HRQoL due to SLE when compared to that seen in severe medical illnesses, including Acquired Immune Defiance Syndrome AIDS, rheumatoid arthritis(RA),congestive heart failure and post-myocardial infarction.. Although Epidemiologic, socioeconomic, and psychosocial factors play an important role in health care and dealing with patients clinically of lupus erythematosus (SLE) (*Strand V., et al.*,2006).. The unpredictable and flares of disease, the need for long-term treatment, and the side effects and damage caused by the disease itself severely reduce quality of life. Problems appearing, involving family members, adherence to medical advice and therapy, communication and self-management. Stress factors that arise have a negative impact on the course of disease, increasing both fatigue illness. (*E Aberer, 2010*).

1.4 Problem statement and study justification

Many factors may affect quality of life among SLE patients including physical and psychological dysfunction that affect their daily life.

In this study we tried to measure Health-related quality of life among Palestinian patients suffering of Systemic Lupus Erythematosus due to lack of knowledge about quality of life in SLE patients in Palestine as well as in neighboring Arab countries . Therefore, this will be the first study of its kind to be carried out in Palestine about SLE patients. Also my work as A registered Nurse working in the medical department dealing with Palestinian patients suffering of Systemic Lupus Erythrematousus encourage me to see the impact of the disease and how patients live with the disease.

SLE may have a profound impact on the physical aspects of a person’s life but may also compromise mental, social, psychological, and. Also, poor quality of life for the mostly affected women in there reproductively age , even in improving life expectancy of SLE patients world wide and also in Palestine .

1.5 Goals of the study

General Objective

To examine eight domains of Health-related quality of life among Palestinian patients suffering of Systemic Lupus Erythematosus .

Specific Objectives

1. To assess the effect of educational level on Health Related Quality of life in SLE patients.
2. To identify sex ratio of the disease in our sample and compare it with the global trend.

1.6 Research questions

1. Is health related quality of life decreased by chronic disease of systemic lupus erythrematosus?
2. Is Health Related Quality of life affected by educational level in systemic lupus erythrematosus patients?

1.7. Al Makased Hospital

Makassed Islamic Charitable Society was officially established in 1956. It is a Palestinian none-profit, none-governmental organization that provides diversified humanitarian services in the Holy Land in accordance with its by-laws, without discrimination by color, religion, creed, or political belief.

Makassed Hospital today is the leading medical center in Palestine, providing secondary and tertiary health services to all citizens of Palestine. Now the Makassed Hospital has 250 beds and is staffed by 750 employees.

The hospital's mission is to offer its best and high level of medical services and to enhance the research scientific and medical programs among the doctors in their various specialties. The hospital also trains doctors who work within the specializing and training programs of the hospital in order to obtain both the Jordanian and Palestinian medical boards. It also trains the undergraduate medical students of the medical college of Al-Quds University. The significance of using AL-Makassed hospital as the setting of the study is that the hospital is considered as a referral one that receives patients from West Bank and Gaza Strip suffering of SLE patients.

(Al-Makassed society main website, http://www.almakassed.org/english.aspx)

Chapter 2

Literature review

SLE was first described by Hippocrates, who called it "Herpes Esthiomenos," which translates as "Gnawing Dermatosis." In the Middle Ages, the disfigurement brought on by SLE flares brought the myth of werewolves to the minds of people. These were feared to be human beings who had strange powers to transform themselves into animals. The name *lupus* may derive from the suggestion that the sufferer has been injured by a wolf, or resembles a wolf (Blotzer JW 1983).

SLE is a chronic multisystem autoimmune disease that is commonly diagnosed in women most, during their childbearing years. Patients with the disease have a female to male ratio of 9:1; disease onset is usually between the late teens and early forties and is more common among certain ethnic groups, such as people with Asian or African ancestry (D’Cruz DP., 2006).

SLE is a penetrative disease that results in variable and occasionally life-threatening manifestations. It afflicts young people, often at a crucial time in their lives when they are trying to establish relationships, start families and careers. As a result, persons with SLE may experience a wide range of physical, psychological and social problems that are not always fully clear by descriptions of the disease’s physiological consequences alone. In order to characterize the full spectrum of the effects of SLE, a comprehensive assessment should consider a variety of other outcomes, which may be of equal or even greater importance to the patient(Pantelis .,2006) .

In a study to investigate the role of clinical, immunological and psychological variables in influencing the health-related quality of life HRQoL of Italian patients with systemic lupus erythematosus, anxiety, depression and joint pain seem to be the major determinants of

HRQoL impairment in SLE patients. Damage seems to influence HRQoL mostly through depression (Doria, et al., 2004).

Hence, HRQoL studies are an essential complement to medical evaluation. HRQoL is a multi-dimensional concept, which consists of crucial areas such as physical health, psychological well being, social relationships, economic circumstances, personal beliefs and their relationship to salient features of the environment. Hence, measurement of HRQoL, in addition to more clinical indicators of disease, allows for a more comprehensive assessment and in some cases may prove to be more effective in treatment response (Strand et al., 2003).

The patient's health related quality of life (HRoL) is distinguished by its multidimensionality, and frequently defined as 'the patient's subjective perception of the impact of his disease and its treatment on his daily life, physical, psychological, and social functioning and wellbeing'(European Medicines Agency, 2006). Also Health-related quality of life (HRQoL) has been identified as a goal for all people across all life stages by leading health organizations(CDC,2000), HRQoL, that is, quality of life relative to one's health or disease status, is a concern of policymakers, researchers, and health care practitioners.(Till JE,1994) .

Due to of the multidimensional aspects of HRQoL, and the varied use of this term across many different health and disease conditions, researchers have used a variety of HRQoL models to guide their research.(Vallerand AH,2003) . There are many HRQoL models applied across different health and illness conditions, through the lifespan, and among individuals, their families, and communities. HRQoL is commonly considered as dynamic, subjective, and multidimensional, and the dimensions often include physical, social, psychological, and spiritual factors. (Haas BK, 1999). More specific dimensions such as emotions, cognitive function, economic status, and intelligence (Taylor. 2008).

Measuring of HRQoL provides patients with an opportunity to participate more fully in their treatment and ultimately facilitate better communication with the multi-disciplinary team of health professionals involved in their care (Seawell AH, 2004). The most commonly used measure of HRQoL is the short form (SF)-36. The SF-36 is a generic tool, which consists of a 36 items in self-report questionnaire. It was designed to be used in a variety of conditions, populations, and settings.

In order to evaluate HRQoL in rural and urban areas in Lebanone, the SF-36 health survey was adapted into Arabic (Sabbah I, 2003). In Arabic, reliability of an Arabic version of the SF 36-Item health survey and its equivalence to the US-English version was performed by Abdul-Mohsin et al 1998. The SF-36 a health survey measurement model, which was used in this study to assess HRQoL, is suitable for self-administration, computerized administration, or administration by a trained interviewer in person or by telephone, to persons aged 14 and older. The SF-36 consists of eight health status scales: Physical Functioning (PF), Role-Physical (RP), Bodily Pain (BP), General Health (GH), Vitality (VT), Social Functioning (SF), Role-Emotional (RE), Mental Health (MH), and Reported Health Transition (HT). Two summary measures aggregate these status scales, namely the Physical and Mental health summary scales.

To evaluate a cross-country comparison, (Panopalis et al., 2005) evaluated the Short Form-36 General Health Survey (SF-36) scores done e annually over 4 years in 231 patients from Canada, 269 from the United States, and 215 from the United Kingdom. They found that the physical and mental well-being components did not differ significantly between countries. Although, the SF-36 has proven useful in surveys of general and specific populations, comparing the relative diseases, and in differentiating the health benefits produced by a wide range of different treatments. In another study by Strand et al showed that, the impact of SLE was evident with decrease in HRQoL similar to those reported by patients with inflammatory arthritis, chronic congestive heart failure and post myocardial infarction (Lai-Shan., 2008).

A follow up study to assess whether the Lupus Quality of Life questionnaire contributed additional information not obtained using the Medical Outcomes Study Short-Form 36 questionnaire (SF-36) in a cohort of patients with systemic lupus erythematosus, the study showed that SF-36 is effective in assessing quality of life over time in this group of patients(Zahi Touma,2011). Although in musculoskeletal diseases that involve pain and reduced physical function, Health Related Quality of Life previous studies researchers used SF-36(H S J Picavet, 2004). A another study in neighboring country in Egypt, Pattern of SLE in Egyptian patients: The impact of disease activity on the quality of life was studied and showed that most of SLE studied patients were characterized predominantly by mucocutaneous and hematological manifestations. The QoL of SLE patients with renal involvement as measured by SF-36 was poorer than healthy control in all domains except emotional limitations and there are a significant negative correlations between general health, pain and social functions domains in QoL (Salim Hamdy,et al,2010) .

2.2 SLE in the Arab World

Kuwait

Khuffash et al (1990) conducted a hospital-based retrospective study over a period of 8-years on the epidemiology of arthritis and other connective tissue disorders among children in Kuwait. A total of 20 children under the age of 12-years with SLE were identified, giving an average annual incidence and prevalence of 0.53 and 3.37 per 100,000, respectively.

United Arab Emirates

In 1995, Al-Attia and George studied 28 SLE patients (Arabs and Asians) in the UAE. The F:M ratio was markedly high; 27:1 in the group as a whole and 21:1 among Arabs. Local patients (Emiratis) developed the disease at an earlier age compared to their expatriate Arab compatriots.

Arthropathy occurred in 86% and nephropathy in 43% of the cases. Next in frequency were leucopenia, mucocutaneous manifestations and serositis. Apart from lupus headache, the other neuro-psychiatric were uncommon or not encountered. Anti-cardiolipin syndrome, Sneddone 's syndrome, shrunken lung syndrome, sicca complex, thyrotoxicosis and myasthenia gravis were also present in this small group of patients.

One year later, Al-Attia (1996) conducted a clinical and laboratory survey of systemic lupus erythematosus in 33 Arab patients in the UAE. Arthropathy (91%) followed by renal involvement (54%) and hematological disorders (45.5%) were the major clinical manifestations. Discoid rash (3%) was the least common. Apart from headaches, other neuropsychiatric symptoms were uncommon or not encountered.

In 2006, Al Attia compared a subgroup of patients with borderline systemic lupus erythematosus (SLE) with those with classic lupus. A retrospective survey was undertaken of a database containing the clinical information of a total of 71 patients in an Abu Dhabi hospital setting over a 12-year period.

Fifty-six patients had SLE and 15 were considered to have borderline SLE as they satisfied less than four criteria of classification.

Age and female sex distribution were no different in the two subgroups, but the disease duration was shorter in patients with borderline lupus. The occurrence of arthropathy (none-erosive), serositis, thrombocytopenia, hemolytic anemia, and malar eruption was common to both subgroups. Patients with borderline SLE lacked other mucocutaneous manifestations of lupus and major organ disease involvement.

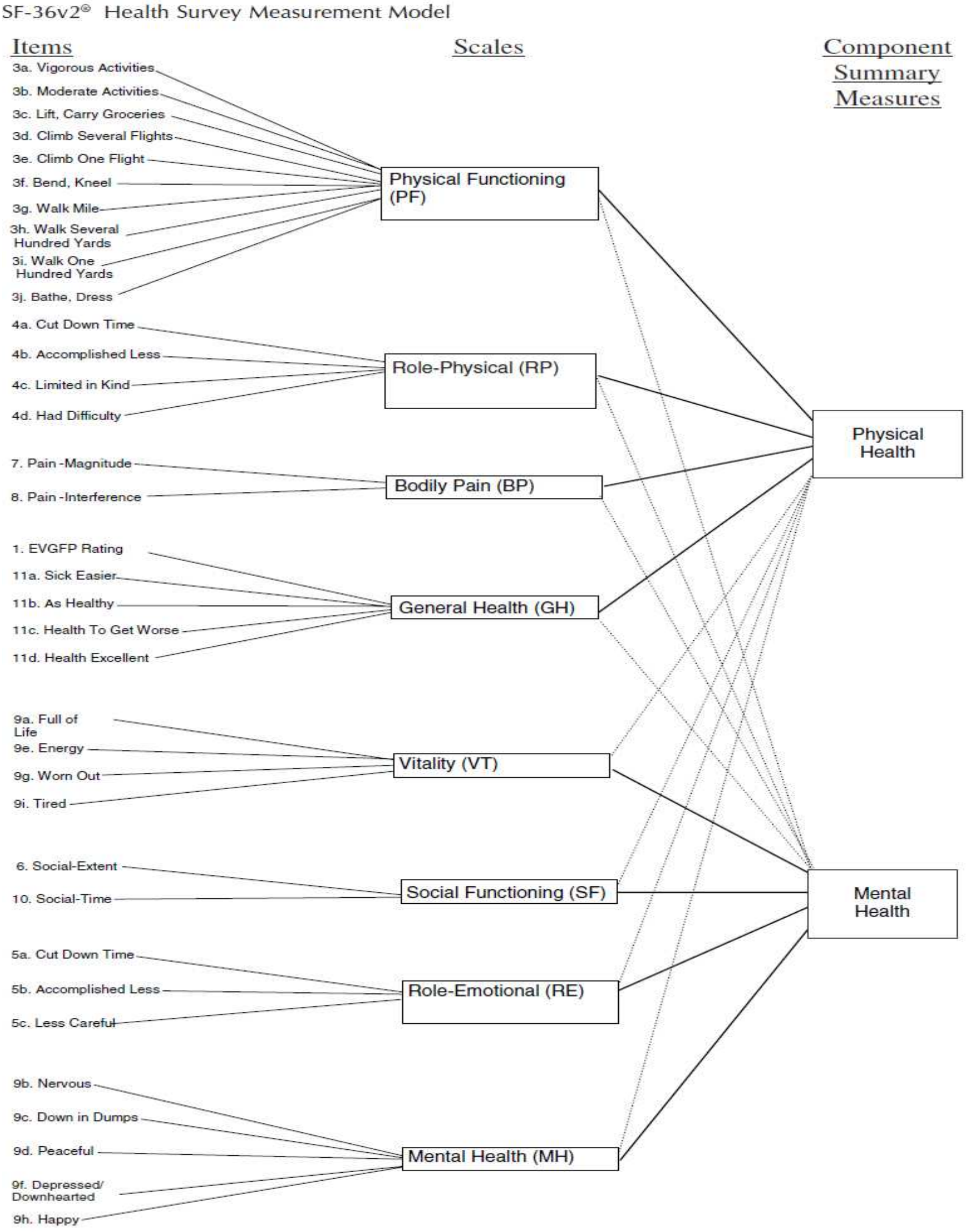
Bahrain

Ebrahim et al (2002) conducted the first study about SLE in Bahrain. The clinical and laboratory manifestations of 50 Bahraini patients were studied retrospectively over the ten-year period 1991- 2000 and the findings were compared with those of the SLE patients in the surrounding area and Caucasian patients. In addition, male to female ratio was 1:17, which was close to that of the UAE. The initial presenting symptoms were arthralgia/ arthritis (78%) and fever (66%). Renal involvement appeared in 25 patients (50%) in the form of proteinuria, hematuria, and/or biopsy changes.

Hematological findings showed the presence of anemia (84%), Coomb’s positive hemolytic anemia (4%), leucopenia (56%), and thrombocytopenia (16%) in Bahrain series. Ebrahim et al (2002) attributed the presence of low frequency of neuropsychiatric symptoms. Positive ANA test had the frequency of 100% and the antibodies were IgG type. Rheumatoid factor was tested in 29 patients and only three had positive result. Ten percent of the patients died from cerebral vasculitis, septicemia, renal failure and infection, and multiple organ failure.

Figure 3.1: Health Survey Measurement Model SF-36

SF-36.org



Chapter 3

Methodology

3.1 Study design

A cross sectional study design was adopted due to its simplicity, time saving; low cost on patient diagnosed with systemic lupus Erythrematosus whom age above 14 years.

3.2 Sampling and Data Collection

The target population of this study were Palestinians diagnosed with Systemic Lupus Erythramatosus. The significance of using ALMakassed hospital as the setting of the study is that the hospital is considered as a referral one that receives patients from West Bank and Gaza Strip suffering of SLE patients.

According to the aims and objectives of the cross sectional study a convenience sample was used to collect data from patients 14 years old and above who attended to rheumatology outpatient clinic or admitted to hospital departments and from a private rheumatology clinic in Ramallah city. The sample size was 76 patients diagnosed with SLE according to American Rheumatology College .Questionnaires of SF-36 health survey measurement model for health related quality of life were distributed and data collection was performed according to standard procedures.

Data was collected through a questionnaire SF-36 which is valid and translated in Arabic version by a nonprofit organization for research and developmental Corporation RAND (RAND.COM). It is (HRQoL) instrument measurement widely used with SLE patient. The researcher completed the questionnaire during the clinical interview and by two medical residents working in rheumatology clinic who were trained by the researcher on these instruments. The questionnaire contains a consent form for ethical consideration. The questionnaire of SF-36 Health Related Quality Of Life instrument contain 8 domains with 6 pages and take only 10 minutes to fill .

3.3 Patient inclusion and exclusion criteria

3.3.1 Inclusion Criteria

SLE patients who are diagnosed at AL-Makassed hospital by a rheumatologist according to (ACR).

Patients above the age of 14 years old.

3.3.2 Exclusion Criteria

Patients less 14 years old as they belong to pediatric section.

Patients with another chronic disease as co-morbid disease, 3 cases were excluded due to known to have hypertension.

3.4 The Study Setting

The study was carried out in East Jerusalem Central Hospital, Al-Makassed Islamic Charitable Society Hospital which is the main hospital for Arab residents in East Jerusalem and the main referral hospital for Palestinian Ministry of Health and from a private clinic runs by a rheumatologist in Ramallah city .The hospital was selected due to the fact that large referee from all Palestine usually visit it. Moreover, it is the only hospital in East Jerusalem and West Bank, which uses coding, and registration system for SLE patients and the only hospital that has rheumatology outpatient clinic with rheumatologist who adopt the standard of American College of Rheumatology in diagnosis and treatment of SLE.

3.5 Data analysis

SPSS was used to analyze the collected data. Diagrams and tables are included to describe the trends and frequencies in the variables. We also correlate variables and domains to understand the effects of this chronic disease on Quality Of Life of SLE patients.

3.6 Ethical consideration

Approval and permission for conducting the study at hospital setting were obtained from the hospital after formal written request for that from the university. Full disclosure about the study was given to patients who were informed about the purpose and objectives of the study. Patients were assured of anonymity and confidentiality. In addition, every patient was interviewed separately.

3.7 Instrumentation

The research instrument was a quantitative method, which includes assessments of age, gender, educational level, physical and mental health domains. The measurement tool was piloted and initially pre-tested by filling it out from first selected patients in outpatient clinic. In addition to that, consultants were consulted to catch the desired validity and trust of the measurement reliability before and after this pilot. Observations of the researcher were taken into consideration and the questionnaire was not modified and was valid and reliable to ensure validity and reliability of the study. Translating of the tool was depend on a previous study using SF- 36 validity, reliability and internal consistency in both English and Arabic languages and assess the health status of a sample of Saudi Arabian citizens using both the Arabic and English versions at Saudi ARAMCO company, Dhahran Saudi Arabia . The results of the study provided support for the reliability and equivalence of both versions. (Abdul-Mohsin. SA, et, al 1998).

3.8. Pilot testing

Pilot testing was done for 10% of total sample without modification on the instrument.

3.9. Constrains and limitations of the study

SLE is a chronic, episodic and unpredictable course, its extremely varied presentations within and between patients, associated psychosocial factors, and patient/family expectations complicate the measurement of quality of life patients.

Generic instruments developed for use within a general population or for patients with a variety of diseases may be limited to assessing the overall aspects of all diseases and may lack responsiveness to clinical changes.

Some female patient refused and did not show interest in this study due to fear of social stigma.

Lack of knowledge about quality of life in SLE patients in Palestine as well as in neighboring Arab countries, also prevalence of SLE is low in all countries as it is in Palestine and which is why this study sample included 76 patients.

Patients will be from one tertiary care hospital in Jerusalem and a private clinic in Ramallah, which might not reflect other patient populations.

3.10 Period of colleting data

Due to known of low prevalence of the disease, worldwide and our notice of low number of SLE cases come to the clinic and to fulfill requirements of master degree as a cross sectional study data collection were taken from February 2012 to July 2013.

Chapter 4

Results

Based on data collection, analysis of the 76 patient's health related quality of life was assessed by Questionnaire of SF-36 and using SPSS program for data entry and analysis to reach the following results:

4.1. Socio-demographic data and educational level

A total of 76 patients was the target group of this study , from two health centers , mostly from Al-Makassed Charitable Hospital in East Jerusalem and the rest from a private rheumatology clinic in Ramallah city. Sixty nine percent (69) of the patients were female (90.8 %); seven percent (7) (9.2%) were males as illustrated in table (4.1.a) and figure (4.1.b). Moreover, most of the female patients were of the age group 20-29, followed by the age group 30-39 which represents 19 patients, while the least group was 50-63 and was 5 patients as shown in table (5.1.c) and (figure 5.1.d). The majority had the educational level of a Bachelor's degree among study sample (28) patients most of them female in age 20-29 in a cross tabulation with age group. This was followed by secondary education, which included 27 patients, while two patients had no education, as clarified in table (5.1.e) and figure (5.1.f).

Table 4.1.a: Sample Distribution by sex

Sex	Frequency	Percent %	Valid Percent	Cumulative Percent %
male	7	9.2	9.2	9.2
female	69	90.8	90.8	100.0
Total	76	100.0	100.0	

Figure 4.1.b Distribution of the Sex

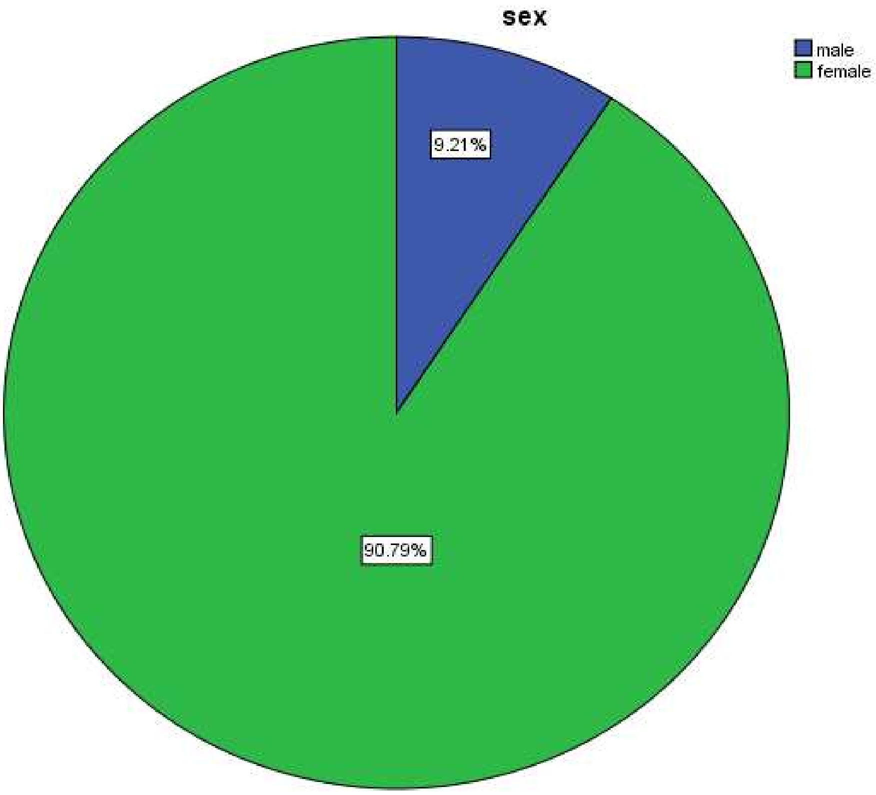


Table 4.1.c Sample distribution by age *sex Cross tabulation

Count			
Age categories	Sex		Total
	male	Female	
less than 20	5	3	8
20-29	2	31	33
30-39	0	19	19
40-49	0	11	11
50-63	0	5	5
Total	7	69	76

Figure 4.1.d: Distribution of the age Categories

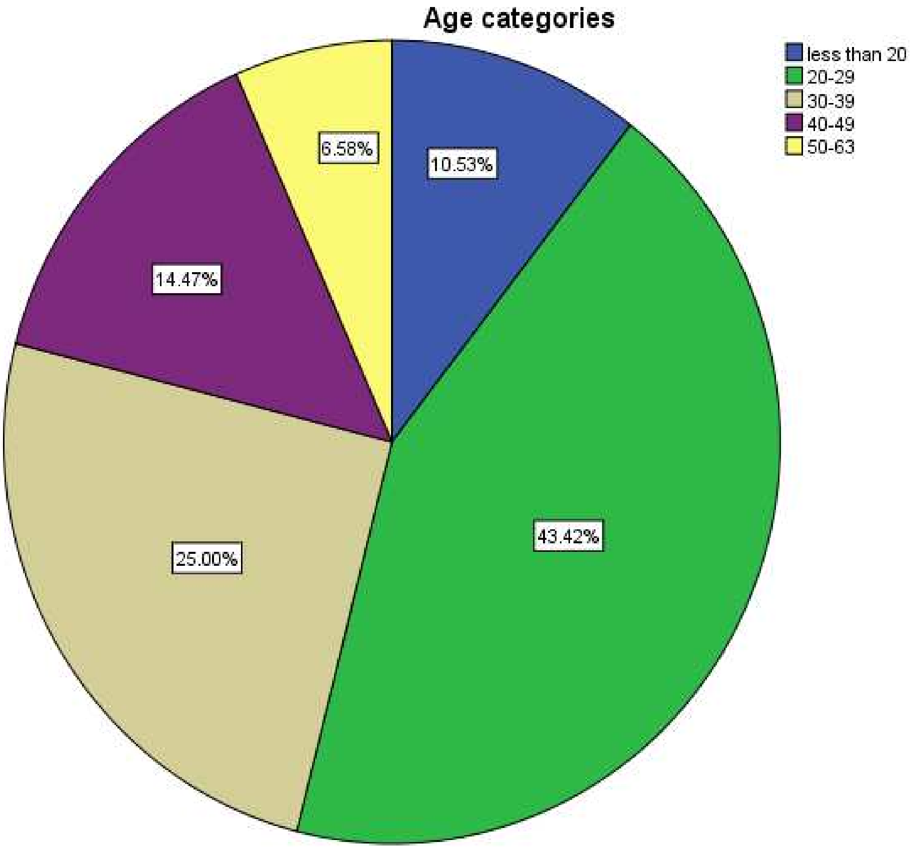
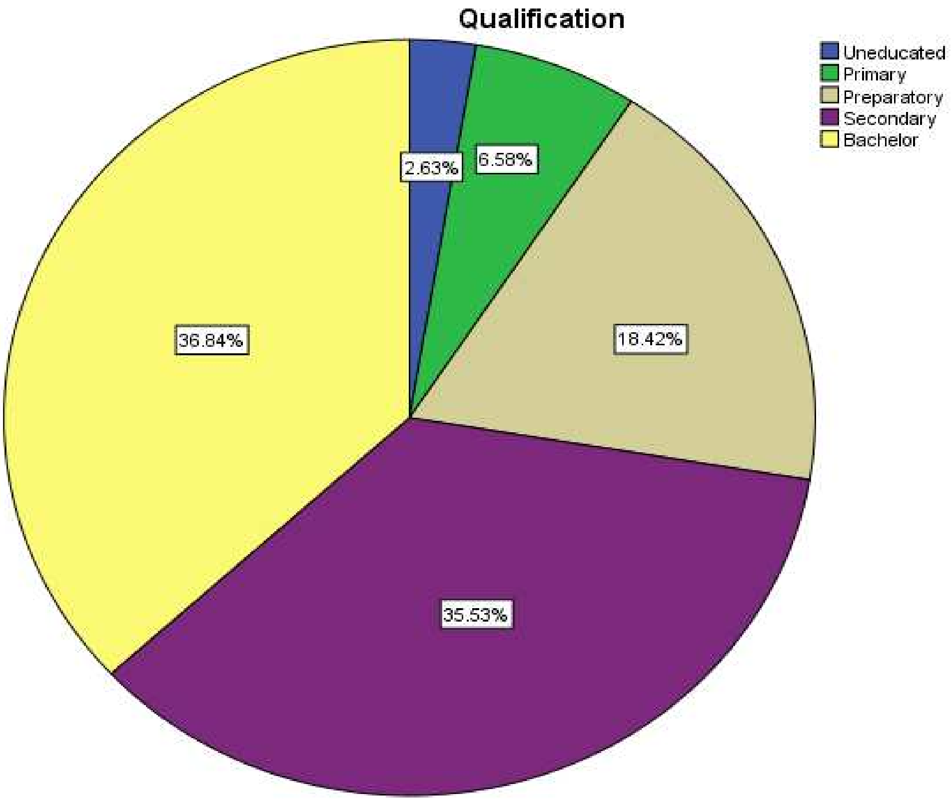


Table 4.1.e Sample Distribution According To Qualification Categories

Count

		Qualification					**Total**
		Uneducated	**Primary**	**Preparatory**	**Secondary**	**Bachelor**	
Age categories	less than 20	0	1	2	4	1	8
	20-29	0	0	3	12	18	33
	30-39	0	1	5	9	4	19
	40-49	0	2	4	1	4	11
	50-63	2	1	0	1	1	5
Total		2	5	14	27	28	76

Figure 4.1.f: Sample Distribution according to Qualification Categories



4.2: Physical and Mental Health Domains in Health Related Quality Of Life measurement after recoding and scoring of all items answers.

#	Scale	Items	Alpha	Mean	SD
1	Physical Functioning	10	.887	57.83	27.84
2	Role -Physical	4	.928	39.15	44.41
3	Role- Emotional	3	.899	47.37	45.63
4	Vitality	4	.680	44.80	20.86
5	Mental health	5	.725	49.37	20.81
6	Social Functioning	2	.545	57.73	27.15
7	Pain	2	.844	53.03	26.25
8	General Health	5	.589	43.36	18.56

4.2.1 Physical Functioning

Physical functioning focuses on patients daily activity that usually a healthy person can perform, from vigorous, moderate to slight activity such as such as running, lifting heavy objects, participating in strenuous sports as illustrated in table (5.2.1.a). Moderate activities include moving a table, pushing a vacuum cleaner, bowling, or playing golf as shown in table (5.2.1.b). Lifting or carrying groceries is illustrated in table(5.2.1.c), climbing several flights of stairs to one flight shown in tables(5.2.1.d,e), bending, kneeling or stooping as in table(5.2.1.f) , also walking more than one 1.5 Km to walking for one block as clarified in tables (5.2.1.g,h,i) and bathing or dressing one's self as in table(5.2.1.j).

Due to the course of the disease affecting body organs and severity of illness, patients have a kind of limitation from various activities, depending on the strength of activity as clarified in this study results as illustrated in climbing several flights of stairs in table (5.2.1.d, e), bending, or kneeling in table (5.2.1.f), walking more than 1.5Km in table (5.2.1.g) and lifting heavy object in item, In the first item in vigorous activity of physical functioning domain, most of the patients (44.7%) answered that they face a lot of limitation in doing such activities as running, lifting heavy objects, participating in strenuous sports as shown in table (5.2.1.a). Also in item "walking for more than one and half kilo meter", 36.8% of patients answered that they face a lot of limitation in doing it, as shown in table (5.2.1.g). Also after recoding and scoring of all items answers of the Physical Functioning domain which high score defines a more favorable health state , each item is scored on a 0 to 100 range, 57.83 was the score of patients answers about Physical Functioning in different activity as illustrated in table (4.2) .

Table (4.2.1.a) Vigorous activities

Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports

	Frequency	Percent
Yes, limited a lot	34	44.7
Yes, limited a little	29	38.2
No, not limited at all	13	17.1
Total	76	100.0

(4.2.1.b) Moderate activities

Moderate Activities, such as Moving a Table, Pushing a Vacuum Cleaner.

	Frequency	Percent
Yes, limited a lot	14	18.4
Yes, limited a little	28	36.8
No, not limited at all	34	44.7
Total	76	100.0

Table (4.2.1.c) Lifting or carrying groceries

	Frequency	Percent
Yes, limited a lot	20	26.3
Yes, limited a little	31	40.8
No, not limited at all	25	32.9
Total	76	100.0

Table (4.2.1.d) Climbing several flights of stairs.

	Frequency	Percent
Yes, limited a lot	36	47.4
Yes, limited a little	20	26.3
No, not limited at all	20	26.3
Total	76	100.0

Table (4.2.1.e) Climbing one flight of stairs

	Frequency	Percent
Yes, limited a lot	12	15.8
Yes, limited a little	24	31.6
No, not limited at all	40	52.6
Total	76	100.0

Table (4.2.1.f) Bending, kneeling or stooping.

	Frequency	Percent
Yes, limited a lot	25	32.9
Yes, limited a little	25	32.9
No, not limited at all	26	34.2
Total	76	100.0

Table (4.2.1.g) Walking more than 1.5 Km

	Frequency	Percent
Yes, limited a lot	28	36.8
Yes, limited a little	20	26.3
No, not limited at all	28	36.8
Total	76	100.0

Table (4.2.1.h) Walking several blocks

	Frequency	Percent
Yes, limited a lot	11	14.5
Yes, limited a little	19	25.0
No, not limited at all	46	60.5
Total	76	100.0

(4.2.1.i) Walking for one block

	Frequency	Percent
Yes, limited a lot	13	17.1
Yes, limited a little	18	23.7
No, not limited at all	45	59.2
Total	76	100.0

Table (4.2.1.j) Bathing or dressing yourself.

	Frequency	Percent
Yes, limited a lot	17	22.4
Yes, limited a little	7	9.2
No, not limited at all	52	68.4
Total	76	100.0

Table (4.2.1.k) Mean of all patients answers for previous ten items in physical function domain.

	Percent
Yes, limited a lot	27.63
Yes, limited a little	29.08
No, not limited at all	43.27
Total	100.0

4.2.2. Role-Physical (RP)

Role- Physical focuses on problems with one's work, or other regular daily activities, as a result of physical health such as cutting down the amount of time spent on work or other activities, who tend to accomplish less than they would like to do thus resulting in limitations in the nature of work or other activities in which they had difficulty in performing, indicating that it needed extra time. We found after recoding and scoring of all items of the Role-Physical domain that a high score defines a more favorable health state. As each item is scored on a 0 to 100 range, the mean score of patients answered was 39.15 those answered yes they have problems with work or other regular daily activities because of physical health in four items as illustrated in table (4.2.).

4.2.3. Bodily Pain (BP)

In the Bodily pain domain, which focuses on the severity of pain and how much pain interfered with normal work including both work outside the home and housework, during the past 4 weeks. Table (4.2) illustrated the scores after recoding answers of the (two-items) including pain magnitude and the pain interference with normal work found that the mean scores of patients answers was 53.03 These results may be due to the inflammation of the joints of hands wrist,, hip and knee pain, that cause tenderness and edema in addition to a vascular necrosis due to medication side effect such as glucocorticoids.

4.2.4 General Health (GH)

Several questions were asked concerning the general health of the patients and inconsistent results were noticed between different five questions assessing general health. Patients' answers seemed to depend on the severity of illness if kidneys and central nervous system were affected and the course of treatment effectiveness as shown in tables.

Table (5.2.4.a) illustrates answers of patients according to the following scale from Excellent to Poor, as "in general would you say your health is". 36.8% of patients answered that their health in general was good, while 21.1% of patients' answers were very good, but in contrast, when they asked if they get sick a little easier than other people as in table (5.2.4.b) 46.1% of patients answered definitely true and 25% answered mostly true, while only 2.6% of patients answered definitely false. Moreover, in table (5.2.4.c) if they are healthy as anybody they know, only 10.5% of patients answered definitely true, 22.4% of patients answered mostly false and 31.6% answered done ’t know . At the same time when patient asked if they expect their health to get worse as shown in table(5.2.4.d), 17.1% of patients answered definitely true ,22.4% answered mostly true while 46% of patients answered that they done ’t know, and only 5.3% of patients answered definitely false. More questions that are descriptive were directed to the patients to see whether their health is excellent. 42.1% of patients answered mostly true, also 14.5% answered definitely true but 21.1% of patients answered definitely false and 10.5%, they do not know. Although after recoding all answers in all items were scored on a 0 to 100 range so that a high score defines a more favorable health state. 43.36 of patients answered in somewhat that the have feel of poor general health as shown in table (4.2).

Table (4.2.4.a) General Health Rating Answers

In general, would you say your health is

	Frequency	Percent
Excellent	10	13.2
Very good	16	21.1
Good	28	36.8
Fair	12	15.8
Poor	10	13.2
Total	76	100.0

Table (4.2.4.b) Sick easier

I seem to get sick a little easier than other people

	Frequency	Percent
Definitely true	35	46.1
Mostly true	19	25.0
Done 't know	12	15.8
Mostly false	8	10.5
Definitely false	2	2.6
Total	76	100.0

Table (4.2.4.c) Patients as healthy

I am as healthy as anybody I know

	Frequency	Percent
Definitely true	8	10.5
Mostly true	14	18.4
Done 't know	24	31.6
Mostly false	17	22.4
Definitely false	13	17.1
Total	76	100.0

Table (4.2.4.d) Patients Health to Get Worse

I expect my health to get worse

	Frequency	Percent
Definitely true	13	17.1
Mostly true	17	22.4
Done 't know	35	46.1
Mostly false	7	9.2
Definitely false	4	5.3
Total	76	100.0

Table (4.2.4.e) Patients Health Excellency

My health is excellent

	Frequency	Percent
Definitely true	11	14.5
Mostly true	32	42.1
Done 't know	8	10.5
Mostly false	9	11.8
Definitely false	16	21.1
Total	76	100.0

4.2.5 Vitality (VT)

Vitality is the peculiarity distinguishing the living from the none living and power of enduring (Merriam-webster, 2013).

Four items were applied to assess the vitality in four questions, In one item if patients had feeling of full of life 42.2% of patients answered that they had felt all of the time to a good bit of the time, but also 57.9% of patients answers ranged from some of the time to none of the time, as shown in table (5.2.5.a). In another question that asked whether patients felt a lot of energy, to which 79% of patients answers ranged from some of the time to none of the time and only 21% of patients answers ranged from all of the time to a good bit of the time as shown in table(5.2.5.b). These results are normal in SLE, due to the course of the disease, as one sign of the disease is fatigue and pain of joints. Also, another question was asked if patient had felt worn out, to which 36.8% of patients answered yes, and the answers also varied from all of the time to a good bit of the time However, 63.2% of patients answered they had felt some of the time to none of the time as shown in table (5.2.5.c), results of this item may be a result to advance treatment in the last decade and the severity of illness of patient at the time of this study as a cross sectional study. Also in a question asked if the patient felt tired, 55.3% of patients answered yes they have some kind of tired and were varies from all of the time to a good bit of the time, and 44.7 % answered that they feel of tired some of the time to none of the time as shown in table (5.2.5.d) .After recoding and scoring question of patients answers in all items, 44.80 of patients answered in somewhat that the have feel of poor Vitality as shown in table (4.2).

Table (4.2.5.a) Feeling full of life

Did you feel full of pep (feeling full of life)?

	Frequency	Percent
All of the time	5	6.6
Most of the time	23	30.3
A good bit of the time	4	5.3
Some of the time	17	22.4
A little of the time	22	28.9
None of the time	5	6.6
Total	76	100.0

Table (4.2.5.b) Feeling of energy

Did you have a lot of energy?

	Frequency	Percent
All of the time	4	5.3
Most of the time	6	7.9
A good bit of the time	6	7.9
Some of the time	29	38.2
A little of the time	19	25.0
None of the time	12	15.8
Total	76	100.0

Table (4.2.5.c) Feeling worn out

Did you feel worn out?

	Frequency	Percent
All of the time	7	9.2
Most of the time	15	19.7
A good bit of the time	6	7.9
Some of the time	22	28.9
A little of the time	15	19.7
None of the time	11	14.5
Total	76	100.0

Table (4.2.5.d) Feeling tired

Did you feel tired?

	Frequency	Percent
All of the time	16	21.1
Most of the time	17	22.4
A good bit of the time	9	11.8
Some of the time	25	32.9
A little of the time	6	7.9
None of the time	3	3.9
Total	76	100.0

4.2.6 Social Functioning (SF)

Is defined as the ability of the individual to interact in the normal or usual way in society; can be used as a measure of quality of life (Mosby's 2008).

To assess social functioning, two questions were asked to the patients for social-extent and social time, after recoding and scoring of all items, patients score was 57.73 which means that patients have in somewhat problems in their social life as illustrated in table (4.2) , also when cut of points was done in the first question concerning on social-extent 36.8% of patients answered that there is no physical or emotional problem interfered with social life and 63.2% of patients answered yes and their answers were varied from slightly to extremely as illustrated in table (5.2.6.a). In the second question that focused on how much time interfered with social life due to emotional and physical health problems, to which 65.8% of patient answered yes and varied from all of the time to a good bit of the time as clarified in table (5.2.6.b). These results reflect how much patients social and daily life was affected due to the disease process.

Table (4.2.6.a) Social-Extent in social functioning.

During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups

	Frequency	Percent
Not at all	28	36.8
Slightly	13	17.1
Moderately	17	22.4
Quiet a bit	11	14.5
Extremely	7	9.2
Total	76	100.0

Table (4.2.6.b) Social-Time in social functioning.

During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting friends, relatives, etc.)?

	Frequency	Percent
All of the time	5	6.6
Most of the time	28	36.8
Some of the time	17	22.4
A little of the time	11	14.5
None of the time	15	19.7
Total	76	100.0

4.2.7 Role-Emotional (RE)

Role –emotional domain in health related quality of life measurement tool includes items that take problems with work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxiety). These include items such as "Cut down the amount of time spent on work or other activities, accomplished less than expected, didn't do work or other activities as carefully as usual". All items are scored so that a high score defines a more favorable health state. each item was recoded and scored on a 0 to 100 range so that the lowest and highest possible scores are 0 and 100 , table (4.2) showed that patient score in Role –Emotional was 47.37 which means that patients have problems with work or other regular daily activities as a result of any emotional problems .

4.2.8 Mental Health (MH)

Mental health domain in health related quality of life measurement focuses on evaluating patients' feeling and where in five items, if they have nervousness, down, feeling calm and peaceful, depressed/downhearted and happiness.

In general, mental health status was effected, as a high percentage of patient had some kind of nervousness and downhearted or blue and not happy due to the process of the disease as a chronic illness and neuropsychiatric involvement as results of this study showed.

In one of the questions that took nervousness as "have you been a very nervous person" in table (5.2.8.a), a 52.6% of patients answered yes varied from all of the time to a good bit of the time and the rest of patients answered some of the time to not at all. Also in a question "Have you felt so down that nothing could cheer you up" in table (5.2.8.b), 67.1% of patients answered no in different level from none of the time to some of the time , but 32.9 % of patients answered yes ranged from all of the time to a good bet of the time. In an item asked if patient feel of calm and peace which is shown in table (5.2.8.c), as "Have you felt calm and peaceful" 35.5% of patients answered yes they feel of calm and peaceful and 64.5% of patients answered no in different levels from some of the time to none of the time. Although in an item asked if patients have felt downhearted and blue, depressed , 47.3% of patients answered they have different level of downhearted and blue from all of the time to a good bit of the time, but also 52.7% of patient answered some of the time to none of the time as clarified in table (5.2.8.d). In an item asked if patients have been a happy person, 64.5% of patients answered were no varied from none of the time to some of the time illustrated in table (5.2.8.d).Also when recoded and scored patients answers from 0 to 100 in table (4.2) shows score of patients answers was 49.37 of 100 which means that patients have problems in their feeling.

Table (4.2.8.a) Patients feeling of nervousness.

Have you been a very nervous person?

	Frequency	Percent
All of the time	10	13.2
Most of the time	22	28.9
A good bit of the time	8	10.5
Some of the time	23	30.3
A little of the time	11	14.5
None of the time	2	2.6
Total	76	100.0

Table (4.2.8.b) Patients feeling of down.

Have you felt so downs nothing could cheer you up?

	Frequency	Percent
All of the time	6	7.9
Most of the time	17	22.4
A good bit of the time	2	2.6
Some of the time	25	32.9
A little of the time	14	18.4
None of the time	12	15.8
Total	76	100.0

Table (4.2.8.c) Patients feeling of calm and peaceful.

Have you felt calm and peaceful?

	Frequency	Percent
All of the time	1	1.3
Most of the time	23	30.3
A good bit of the time	3	3.9
Some of the time	19	25.0
A little of the time	26	34.2
None of the time	4	5.3
Total	76	100.0

Table (4.2.8.d) Patients feeling of downhearted and depressed.

Have you felt downhearted and blue?

	Frequency	Percent
All of the time	10	13.2
Most of the time	10	13.2
A good bit of the time	6	7.9
Some of the time	19	25.0
A little of the time	14	18.4
None of the time	17	22.4
Total	76	100.0

Table (4.2.8.e) Patients feeling as happy person.

Have you been a happy person?

	Frequency	Percent
All of the time	7	9.2
Most of the time	14	18.4
A good bit of the time	6	7.9
Some of the time	24	31.6
A little of the time	18	23.7
None of the time	7	9.2
Total	76	100.0

Table 4.3.1 Hypothesis Test Summary of Educational level and health related quality of life, Physical functioning domain

1	The distribution of Vigorous activities. Such as running. Lifting heavy objects, participating in strenuous sports is the same across categories of Qualification.	Independent samples kruskal- Wallis Test	.247	Retain the null hypothesis
2	The distribution of Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling or playing golf? Is the same across categories of Qualifications.	Independent samples Kruskal-Wallis Test	.118	Retain the null hypothesis
3	The distribution of Lifting or carrying groceries is the same across categories of Qualification.	Independent samples kruskal- Wallis Test	.191	Retain the null hypothesis
4	The distribution of climbing several flights of stairs is the same across categories of Qualification.	Independent samples Kruskal-Wallis Test	.297	Retain the null hypothesis
5	The distribution of Climbing one flight of stairs is the same across categories of Qualification.	Independent samples kruskal- Wallis Test	.287	Retain the null hypothesis
6	The distribution of Bending, kneeling or stooping, is the same across categories of Qualification.	Independent samples Kruskal-Wallis Test	.008	**Reject the null hypothesis**
7	The distribution of walking more than one mile is the same across categories of Qualification.	Independent samples kruskal- Wallis Test	.945	Retain the null hypothesis
8	The distribution of walking several blocks is the same across categories of Qualification.	Independent samples Kruskal-Wallis Test	.626	Retain the null hypothesis
9	The distribution of walking one block is the same across categories of Qualification	Independent samples kruskal- Wallis Test	.713	Retain the null hypothesis
10	The distribution of Bathing or dressing yourself, is the same across categories of Qualification	Independent samples kruskal- Wallis Test	.473	Retain the null hypothesis

Asymptotic significances are displayed. The significance level is.05.

Table 4.3.2 Hypothesis Test Summary of Educational level and health related quality of life, Role –physical domain

Null Hypothesis		Test	Sig	Decision
1	The distribution of cut down the amount of time you spent on work or other activities is the same across categories of Qualification.	Independent samples Kruskal-Wallis Test	.250	Retain the null hypothesis
2	The distribution of Accomplished less than you would like is the same across categories of Qualification.	Independent samples kruskal-Wallis Test	.178	Retain the null hypothesis
3	The distribution of Were limited in the kind of work or other activities is the same across categories of Qualification.	Independent samples Kruskal-Wallis Test	.169	Retain the null hypothesis
4	The distribution of Had difficulty performing the work or other activities (for example, it took extra time is the same across categories of Qualification.	Independent samples kruskal-Wallis Test	.086	Retain the null hypothesis

Table 4.3.3. Hypothesis Test Summary of Educational level and health related quality of life, Bodily pain domain

Null Hypothesis	Test	Sig	Decision
The distribution of How much bodily pain have you had during the past 4 weeks is the same across categories of Qualification.	Independent samples kruskal- Wallis Test	.086	Retain the null hypothesis
The distribution of During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework). Is the same across categories of Qualifications.	Independent samples Kruskal-Wallis Test	.326	Retain the null hypothesis

Asymptotic significances are displayed. The significance level is.05.

Table 4.3.4. Hypothesis Test Summary of Educational level and health related quality of life, General health domain.

Null Hypothesis		Test	Sig	Decision
1	The distribution of in general, you say your health is the same across categories of Qualification.	Independent samples kruskal-Wallis Test	.204	Retain the null hypothesis
2	The distribution of I seem to get sick a little easier than other people is the same across categories of Qualification.	Independent samples kruskal-Wallis Test	.547	Retain the null hypothesis
3	The distribution of I am as healthy as anybody I know is the same across categories of Qualification.	Independent samples Kruskal-Wallis Test	.139	Retain the null hypothesis
4	The distribution of I expect my health to get worse is the same across categories of Qualification.	Independent samples kruskal-Wallis Test	.807	Retain the null hypothesis
5	The distribution of My health is excellent is the same across categories of Qualification.	Independent samples Kruskal-Wallis Test	.400	Retain the null hypothesis

Asymptotic significances are displayed. The significance level is.05.

Table 4.3.5. Hypothesis Test Summary of Educational level and health related quality of life, Vitality domain

Null Hypothesis		Test	Sig	Decision
1	The distribution of did you feel full at pep? Is the same across categories of Qualification.	Independent samples kruskal- Wallis Test	.014	**Reject the null hypothesis**
2	The distribution of did you have a lot of energy? Is the same across categories of Qualification.	Independent samples kruskal- Wallis Test	.178	Retain the null hypothesis
3	The distribution of did you feel worn out? Is the same across categories of Qualification.	Independent samples kruskal- Wallis Test	.387	Retain the null hypothesis
4	The distribution of did you feel tired is the same across categories of Qualification.	Independent samples kruskal- Wallis Test	.140	Retain the null hypothesis

Table 4.3.6. Hypothesis Test Summary of Educational level and health related quality of life, Social functioning domain

Null Hypothesis		Test	Sig	Decision
1	The distribution of During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting friends, relatives, etc.)? is the same across categories of Qualification.	Independent samples Kruskal-Wallis Test	.114	Retain the null hypothesis
2	The distribution of During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups is the same across categories of Qualification.	Independent samples kruskal-Wallis Test	.289	Retain the null hypothesis

Table 4.3.7. Hypothesis Test Summary of Educational level and health related quality of life, Role emotional domain.

Null Hypothesis		Test	Sig	Decision
1	The distribution of Cut down the amount of time you spent on work or other activities is the same across categories of Qualification.	Independent samples Kruskal-Wallis Test	.252	Retain the null hypothesis
2	The distribution of Accomplished less than you would like is the same across categories of Qualification.	Independent samples kruskal-Wallis Test	.579	Retain the null hypothesis
3	The distribution of Did not do work or other activities as carefully as usual is the same across categories of Qualification.	Independent samples Kruskal-Wallis Test	.177	Retain the null hypothesis

Table 4.3.8. Hypothesis Test Summary of Educational level and health related quality of life, Mental Health domain

1	The distribution of have you been a very nervous person? Is the same across categories of Qualification?	Independent samples Kruskal-Wallis Test	.037	**Reject the null hypothesis**
2	The distribution of have you felt so down in the dumps nothing could cheer you up. Is the same across categories of Qualification?	Independent samples kruskal-Wallis Test	.266	Retain the null hypothesis
3	The distribution of have you felt calm and peaceful. Is the same across categories of Qualification?	Independent samples Kruskal-Wallis Test	.098	Retain the null hypothesis
4	The distribution of have you felt downhearted and blue. Is the same across categories of Qualification?	Independent samples Kruskal-Wallis Test	.232	Retain the null hypothesis
5	The distribution of have you been happy person? Is the same across categories of Qualification?	Independent samples Kruskal-Wallis Test	.169	Retain the null hypothesis

Chapter 5

Discussion

5.1 Introduction

The present study focuses on systemic lupus erythrematosus around world, and it is the first study that is concerned with this chronic autoimmune disease here in Palestine.

The purpose of this study is to examine health-related quality of life among Palestinian patients suffering of Systemic Lupus Erythematosus diagnosed and treated by rheumatologist at a major referral hospital (Al-Makassed Hospital).

To fulfill the purpose of the study, a cross sectional study was conducted of 76 patients as a target group, they were from two health centers, mostly from Al-Makassed Charitable Hospital in East Jerusalem and the rest from a private rheumatology clinic in Ramallah city. A convenience sample was used to collect the data from participants who come to the hospital for treatment and follow up patients from a private clinic in ages above 14 who were diagnosed with systemic lupus erythrematosus.

The sex ratio of the study sample was female 69 patients which represent (90.8 %); male 7 patients represent (9.2%) and our result is close to what is known world wide and in previous study(D’Cruz DP, 2006). The highest age group frequency among the study population was noticed among age group 20-29 who were 31 of 33 in this age group were female in a cross tabulation with sex as shown in table (5.2) which is near to previous study.(Blank M,2009) . Bachelor educational level were the largest among study sample 28 patients most of them female 20-29, next secondary level 27 patients. Health related quality of life measurement tool with eight domain was used to fulfill the goals of the study, while focusing on physical, mental health of patients and each domain includes several questions, which started with physical function and ended with mental health all are clarified by SF-36 model in Figure 3.1 Health Survey Measurement Model.

Because the course of the disease as an autoimmune disease that affects connective tissue of the patients organs so physical activity must be assessed. Physical Functioning domain that include 10 questions that assessing physical activity that ranged from vigorous to slight activities , patients answered that they have a kind of limitations fluctuating from a lot to a little of limitations depending on various activity that any healthy person can do in daily life. Data shows that 27.63 % of patients answered they have a lot of limitation in doing physical activity as shown in table (5.2.1.k). These results are closed to previous study shown that Pathophysiology of SLE can cause major organ damage. There are also many symptoms that may not directly lead to major morbidity, that can have a significant impact on the patient’s life; including fatigue, depression, pain, sleep disturbances, cognitive dysfunction, headaches and hair loss as shown in previous studies(K Gallop, et al., 2012) .

Also in Role-Physical domain that focuses on problems with patients' work or other regular daily activities as a result of physical health data shows that 60.85% of patient answered that they have limitations as shown in table (5.2.2.e), this result comes in partner with a Baseline data from randomized controlled trials study demonstrate that systemic lupus erythematosus impacts all domains of health-related quality of life including Role-Physical (Strand V, et al. 2006).

In another limitation was noticed in bodily pain domain, which focused on the severity of pain and how much pain interfered with normal work .Data shows that 87.4% of patients answered that they have pain and pain interference on work and daily life from slightly too extremely, as illustrated in tables (5.2.3). Patients' answers was due to the process of this chronic auto immune disease which cause inflammation of two or more peripheral joints of the limbs, swelling also hip and knee pain, that cause tenderness and edema, a vascular necrosis, fatigue, all these symptoms are consistent with prior studies concerning on symptoms of Systemic Lupus Erythrematosus with fatigue and pain (Taylor J, et al, 2000).

Although in general health domain five questions were asked and patients answers seemed to depend on the severity of illness ,patients answers in somewhat that they have poor general health which was illustrated in table (4.2) the data shows after recoding of all patients answered of score 43.36 from 100 ,which previously known that treatment of patients of SLE involves a balance between suppressing the signs and symptom of the disease and minimizing the toxicities of the drugs used , disease activity might improve but the patient feel worse due to the side effects of the medication . (K McElhone1, et al., 2006).

In another domain assessing the vitality ,several question were asked, and patients answered seemed in somewhat was poor in their feeling of full of life also answered feeling of tired, and feeling of worn out as the score of patients answers was 44.80 as shown in table (4.2) .These results are consistent with a partner study in course of the disease as one sign of SLE is fatigue ,pain of joints and feeling of tiredness (Zonana ,et a,2000) .

In Social Functioning domain two questions were asked to what extent and time has physical health or emotional problems interfered with normal social activities with family, friends, neighbors, or groups of patients and the data shows that patients who answered yes scored of 53.03 and their answers were varied from slightly to extremely as shown in table (4.2), this results reflects as previous study to how much patients socially affected and needs support due to the disease process (Zheng Y et al.,2009) . In another study which aimed to assess the QoL of SLE patients with renal involvement as measured by SF-36 was poorer than healthy control in all domains except emotional limitations and there are a significant negative correlations between general health, pain and social functions domains in QoL (Salim,et al,2010) .

Role- Emotional domain dialed with items like "Cut down the amount of time patients spent on work or other activities, or Accomplished less than patients would like, or didn't do work or other activities as carefully as usual as a result of any emotional problems such as feeling depressed or anxious, 47.37 was the mean score patients those answered of the three questions that yes they have emotional problems as illustrated in table (4.2) ,which was mostly as a result of emotional role in systemic lupus, which was the same in previous studies includes a negative aspects of life satisfaction in patients with systemic lupus erythematosus (kulczycka L,et al,2011) .

In mental Health domain which focuses on patients' feeling that includes nervousness, downhearted, happiness, feeling of peaceful , the mean score of patients who answers yes was 49.37 ,which explain that patients have some kind of nervousness and downhearted and not happy due to the process of the disease and neuropsychiatric involvement as shown in table (4.2) In one questions took nervousness as "have you been a very nervous person" in table (5.2.8.a), the data shows that a 52.6% of patients answered yes and varied from all of the time to a good bet of the time. These results are consistent with a previous study showed Stress factors that arise have a negative impact on the course of disease, increasing fatigue, and illness. (*E Aberer, 2010*). Our findings are consistent with other similar studies assessing depression in systemic lupus erythematosus (Iverson G, et al, 2001) .Although in a study to investigate the role of clinical, immunological and psychological variables in influencing the health-related quality of life HRQoL of Italian patients with systemic lupus erythematosus, Anxiety, depression and joint pain seem to be the major determinants of HRQOL impairment in SLE patients. Damage seems to influence HRQOL mostly through depression (Doria, et al, 2004).

5.2 Qualification level and health related quality of life

To explore the educational level with health related quality of life in SLE patients as the second goal of this study we analyze different eight domains of health related quality of life in a cross tabulation with qualification categories using Kruskal-wallis Test as a none-parametric method for testing whether samples originate from the same distribution, it usually used for comparing more than two samples that are independent, or not related. In our study we noticed that most of the domains items that summarize physical and mental health of patients, do not differ significantly between different qualification categories , except in three items, the first item in Physical function domain whether "the distribution of bending , kneeling or stooping is the same a cross categories of Qualification" Kruskal-wallis Test was rejecting the null hypothesis as significance level was .008 . Also in one vitality item in a question whether "the distribution of did you feel full of life? Is the same a cross categories of Qualification, "Kruskal-wallis Test rejecting the null hypothesis as significance level of .014. In addition, in one Mental health item in a question whether the distribution of "have you been very nervous person? Is the same a cross categories of qualification" Kruskal-wallis Test rejecting the null hypothesis as significance level was .037. In contrast, from one previous study, which focus on educational level and mortality in Systemic Lupus Erythematosus shows, that higher education levels are associated with lower mortality (Michaell M.2004).

5.3 Conclusion

International health related quality of life measurement tool such as SF-36 with eight domains Health Survey tool was used as questionnaire.

Results of the study demonstrate that Health Related Quality of Life of patients was affected nearly in all health related quality domains, patients responded that they limitations as results of their a chronic auto immune disease, especially in physical functioning, bodily pain, social functioning, role physical, and in mental health .Educational level was tested and showed that HRQoL domains were the same and not affected by different qualification categories.

5.4 Recommendations

Repeat similar studies with a large sample size on the same community (north, south, and middle of the west bank including Gaza strip.

Establish a database for the prevalence of SLE patients in Palestine for more access to the cases and more research.

Study of the Disease Severity of SLE Patients and Health-Related Quality of Life and in SLE

Creating assessment of quality of life in systemic lupus erythematosus patients in long-term disease in Palestine.

Improve knowledge and interest surrounding problems and limitations of health related quality of life in SLE patients in Palestine by doing more studies.

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Appendix

An official letter from Al-Quds University to Al-Makassed Hospital to coduct the study

Al Quds University
Faculty of Health Professions
Jerusalem –Abu Dies

جامعة القدس
كلية المهن الصحية
القدس- أبوديس

التاريخ:2012/3/24
الرقم:19/ج ق م ص/1794

حضرة الدكتور بسام أبو لبدة المحترم/
مدير عام مستشفى المقاصد الخيرية

الموضوع: الطالب محمود حدرب

تحيه طيبه وبعد،

أود إعلام حضرتكم أن الطالب المذكور أعلاه يقوم بإعداد رسالة ماجستير حول موضوع:

(Quality of life for Patients of Systemic Lupus Erytho matosus (SLE) in Palestine).

وعليه أرجو من حضرتكم الايعاز لمن يلزم بتسهيل مهمة الطالب في الحصول على معلومات عن المرض المذكور من خلال الرجوع إلى المعلومات المحفوظة على أجهزة الكمبيوتر وكذلك الملفات الخاصة بالمرضى وذلك لفترة عشر سنوات سابقة.

وتفضلوا بقبول فائق الاحترام والتقدير

أ.د. رسمي أبو حلو
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The study questionnaire (English copy)

SF-36(tm) Health Survey

Instructions for completing the questionnaire: Please answer every question. Some questions may look like others, but each one is different. Please take the time to read and answer each question carefully by filling in the bubble that best represents your response.

Patient Name: ____

SSN#: _________________________________

Date: _______________________________

Person heling to complete this form: ____

1. In general, would you say your health is:

☐Excellent ☐Very good ☐Good
☐Fair
☐Poor

2. Compared to one year ago, how would you rate your health in general now?
☐Much better now than a year ago
☐Somewhat better now than a year ago
☐About the same as one year ago
☐Somewhat worse now than one year ago
☐Much worse now than one year ago

3. The following items are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

a. Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports.

☐Yes, limited a lot.
☐Yes, limited a little.
☐No, not limited at all.

b. Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf?

☐Yes, limited a lot.
☐Yes, limited a little.
☐No, not limited at all.

c. Lifting or carrying groceries.

☐Yes, limited a lot.
☐Yes, limited a little.
☐No, not limited at all.

d. Climbing several flights of stairs.

☐Yes, limited a lot.
☐Yes, limited a little.
☐No, not limited at all.

e. Climbing one flight of stairs.

☐Yes, limited a lot.
☐Yes, limited a little.
☐No, not limited at all.

f. Bending, kneeling or stooping.

☐Yes, limited a lot.
☐Yes, limited a little.
☐No, not limited at all.

g. Walking more than one mile.

☐Yes, limited a lot.

☐Yes, limited a little.

☐No, not limited at all.

h. Walking several blocks.

☐Yes, limited a lot.

☐Yes, limited a little.

☐No, not limited at all.

i. Walking one block.

☐Yes, limited a lot.

☐Yes, limited a little.

☐No, not limited at all.

j. Bathing or dressing yourself.

☐Yes, limited a lot.

☐Yes, limited a little.

☐No, not limited at all.

4. During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

a. Cut down the amount of time you spent on work or other activities?

☐ Yes ☐ No

b. Accomplished less than you would like?

☐ Yes ☐ No

c. Were limited in the kind of work or other activities

☐ Yes ☐ No

d. Had difficulty performing the work or other activities (for example, it took extra time)

☐ Yes ☐ No

5. During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

a. Cut down the amount of time you spent on work or other activities?

☐ Yes ☐ No

b. Accomplished less than you would like

☐ Yes ☐ No

c. Didn't do work or other activities as carefully as usual

☐ Yes ☐ No

6. During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups?

☐Not at all
☐Slightly
☐Moderately
☐Quite a bit
☐Extremely

7. How much bodily pain have you had during the past 4 weeks?

☐Not at all
☐Slightly
☐Moderately
☐Quite a bit
☐Extremely

8. During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?

☐Not at all
☐Slightly
☐Moderately
☐Quite a bit
☐Extremely

9. These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks.

a. did you feel full of pep?

☐ All of the time

☐ Most of the time

☐ A good bit of the time

☐ Some of the time

☐ A little of the time

☐ None of the time

b. have you been a very nervous person?

☐ All of the time

☐ Most of the time

☐ A good bit of the time

☐ Some of the time

☐ A little of the time

☐None of the time

c. have you felt so down in the dumps nothing could cheer you up?

☐ All of the time

☐Most of the time

☐ A good bit of the time

☐ Some of the time

☐A little of the time

☐ None of the time

d. have you felt calm and peaceful?

☐All of the time

☐Most of the time

☐A good bit of the time

☐Some of the time

☐A little of the time

☐None of the time

e. did you have a lot of energy?

☐ All of the time
☐ Most of the time
☐ A good bit of the time
☐ Some of the time
☐ A little of the time
☐ None of the time

f. have you felt downhearted and blue?

☐ All of the time
☐ Most of the time
☐ A good bit of the time
☐ Some of the time
☐ A little of the time
☐ None of the time

g. did you feel worn out?

☐ All of the time
☐ Most of the time
☐ A good bit of the time
☐ Some of the time
☐ A little of the time
☐ None of the time

h. have you been a happy person?

☐ All of the time
☐ Most of the time
☐ A good bit of the time
☐ Some of the time
☐ A little of the time
☐ None of the time

i. did you feel tired?

☐ All of the time
☐ Most of the time
☐ A good bit of the time
☐ Some of the time
☐ A little of the time
☐ None of the time

10. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting friends, relatives, etc.)?

☐ All of the time
☐ Most of the time
☐ Some of the time
☐ A little of the time
☐ None of the time

11. How TRUE or FALSE is each of the following statements for you?

a. I seem to get sick a little easier than other people

☐ Definitely true
☐ Mostly true
☐ Don't know
☐ Mostly false
☐ Definitely false

b. I am as healthy as anybody I know

☐ Definitely true
☐ Mostly true
☐ Don't know
☐ Mostly false
☐ Definitely false

c. I expect my health to get worse

☐ Definitely true
☐ Mostly true ☐ Don't know ☐ Mostly false
☐ Definitely false

d. My health is excellent

☐Definitely true

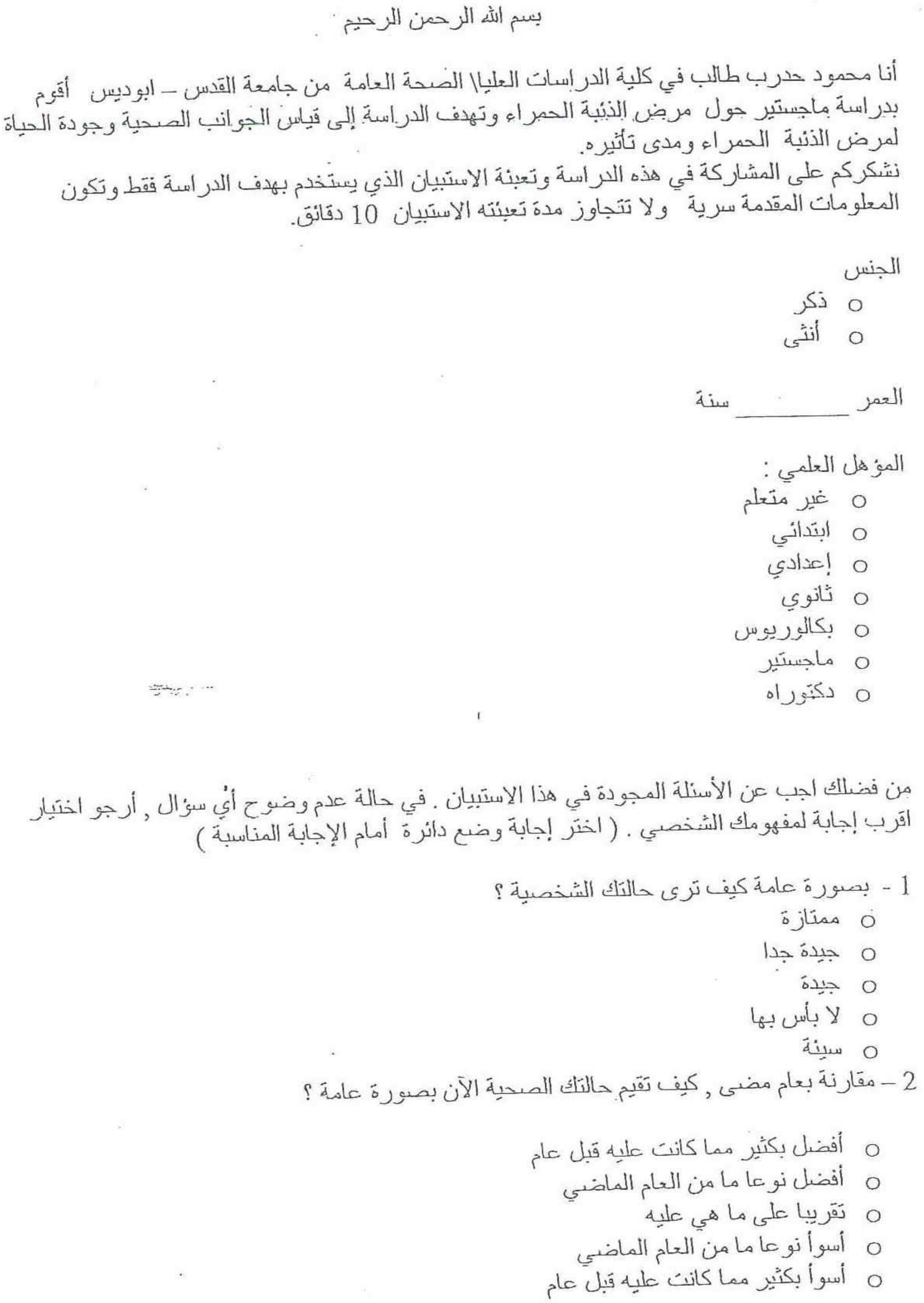
☐ Mostly true

☐ Don't know

☐ Mostly false

☐ Definitely false

The study questionnaire (Arabic copy



بسم الله الرحمن الرحيم

أنا محمود حدرب طالب في كلية الدراسات العليا\ الصحة العامة من جامعة القدس – ابوديس أقوم بدراسة ماجستير حول مرض الذئبة الحمراء وتهدف الدراسة إلى قياس الجوانب الصحية وجودة الحياة لمرض الذئبة الحمراء ومدى تأثيره.

نشكركم على المشاركة في هذه الدراسة وتعبئة الاستبيان الذي يستخدم بهدف الدراسة فقط وتكون المعلومات المقدمة سرية ولا تتجاوز مدة تعبئته الاستبيان 10 دقائق.

الجنس

- ○ ذكر
- ○ أنثى

العمر ________ سنة

المؤهل العلمي :

- ○ غير متعلم
- ○ ابتدائي
- ○ إعدادي
- ○ ثانوي
- ○ بكالوريوس
- ○ ماجستير
- ○ دكتوراه

من فضلك اجب عن الأسئلة المجودة في هذا الاستبيان . في حالة عدم وضوح أيِ سؤال , أرجو اختيار اقرب إجابة لمفهومك الشخصي . (اختر إجابة وضع دائرة أمام الإجابة المناسبة)

1 - بصورة عامة كيف ترى حالتك الشخصية ؟

- ○ ممتازة
- ○ جيدة جدا
- ○ جيدة
- ○ لا بأس بها
- ○ سيئة

2 – مقارنة بعام مضى , كيف تقيم حالتك الصحية الآن بصورة عامة ؟

- ○ أفضل بكثير مما كانت عليه قبل عام
- ○ أفضل نوعا ما من العام الماضي
- ○ تقريبا على ما هي عليه
- ○ أسوأ نوعا ما من العام الماضي
- ○ أسوأ بكثير مما كانت عليه قبل عام

3 – تتعلق البنود التالية بأنشطة يمكن ان تقوم بها خلال يومك العادي . في الوقت الحالي , إلى أي مدى تقيدك حالتك الصحية : (اختر الإجابة وضع علامة x تحت الإجابة المناسبة)

	نعم تقيدني كثيرا	نعم تقيدني قليلا	لا تقيدني إطلاقا
من ممارسة الأنشطة الشاقة مثل الجري , حمل الأشياء الثقيلة أو مزاولة الأنشطة الرياضية المجهدة جدا ؟			
من ممارسة الأنشطة متوسطة الجهد , كتحريك الطاولة أو التنظيف باستخدام المكنسة الكهربائية أو تنظيف حديقة المنزل والعناية بها ؟			
من حمل المشتريات من البقالة أو السوق المركزي (السوبر ماركت) ؟			
من صعود الدرج لعدة ادوار ؟			
من صعود الدرج لدور واحد فقط ؟			
من الانحناء أو الركوع أو السجود ؟			
من المشي لأكثر من كيلومتر ونصف ؟			
من المشي لمسافة نصف كيلو متر ؟			
لمسافة مئة متر ؟			
من الاستحمام أو ارتداء الملابس بنفسك؟			

الصحة الجسمية :

4 – تتعلق البنود التالية (ا ,ب ,ج , د) بالمشاكل التي يمكن أن تواجهك خلال تأديتك لعملك أو الأنشطة اليومية المعتادة نتيجة لحالتك الصحية الجسمية .
خلال الأسابيع الأربعة الماضية , هل تسببت حالتك الصحية الجسمية في :

	نعم	لا
التقليل من الوقت الذي تقضيه في العمل أو أي أنشطة أخرى ؟		
التقليل مما تود انجازه من العمل أو أي أنشطة أخرى ؟		
تقيدك في أداء نوع معين من الأعمال أو أي أنشطة أخرى ؟		
أن تجد صعوبة في تأدية العمل أو أي أنشطة أخرى ؟ (على سبيل المثال , احتجت إلى جهد إضافي لتأديتها)		

الصحة النفسية :

5 – تتعلق البنود التالية (أ, ب, ج, د) بالمشاكل التي يمكن أن تواجهك خلال تأديتك لعملك أو الأنشطة اليومية المعتادة كنتيجة لحالتك الصحية النفسية. (مثلا الشعور بالاكتئاب أو القلق)
خلال الأسابيع الأربعة الماضية, هل تسببت حالتك الصحية النفسية في:

	نعم	لا
التقليل من الوقت الذي تقضيه في العمل أو أي أنشطة أخرى ؟		
التقليل مما تود انجازه من العمل أو أي أنشطة أخرى ؟		
عدم انجاز العمل أو أي أنشطة أخرى بالحرص المعتاد ؟		

الصحة الجسمية أو النفسية

6 – خلال الأسابيع الأربعة الماضية, إلى أي مدى تعارضت صحتك الجسمية أو النفسية مع تأديتك لنشاطاتك الاجتماعية المعتادة مع عائلتك أو أصدقائك أو جيرانك أو أي من المناسبات الاجتماعية الأخرى ؟

- ○ لم يكن هناك أي تعارض إطلاقا
- ○ كان هناك تعارض قليل
- ○ كان هناك تعارض متوسط
- ○ كان هناك تعارض كبير
- ○ كان هناك تعارض كبير جدا

شدة الألم

7 – ما شدة الألم الجسمي الذي عانيت منه خلال الأسابيع الأربعة الماضية ؟

- ○ لم يكن هناك الم
- ○ كان هناك الم خفيف جدا
- ○ كان هناك ألم خفيف
- ○ كان هناك الم متوسط
- ○ كان هناك الم شديد
- ○ كان هناك الم شديد جدا

8 – خلال الأسابيع الأربعة الماضية , إلى أي مدى أدى الألم الجسمي إلى التعارض مع تأديتك لأعمالك المعتادة (سواء داخل المنزل أو خارجه) ؟

- ○ لم يكن هناك أي تعارض
- ○ كان هناك تعارض قليل جدا
- ○ كان هناك تعارض متوسط
- ○ كان هناك تعارض كبير
- ○ كان تعارض كبير جدا

9 – الأسئلة التالية تتعلق بكيفية شعورك وطبيعة سير الأمور معك خلال الأسابيع الأربعة الماضية, الرجاء إعطاء إجابة واحدة لكل سؤال بحيث تكون هذه الإجابة هي الأقرب إلى الحالة التي شعرت بها.

خلال الأسابيع الأربعة الماضية, كم من الوقت:

	في كل الأوقات	في معظم الأوقات	في كثير من الأوقات	في بعض الأوقات	في قليل من الأوقات	لم اشعر في أي وقت من الأوقات
شعرت بأنك مليء بالحيوية والنشاط ؟						
كنت شخصا عصبيا جدا ؟						
شعرت بأنك في حالة اكتئاب إلى درجة لم يمكن معها إدخال السرور إليك ؟						
شعرت بالهدوء والطمأنينة ؟						
كانت لديك طاقة كبيرة ؟						
شعرت بالإحباط واليأس ؟						
شعرت بأنك منهك (استنفذت قواك) ؟						
شعرت بأنك شخص سعيد ؟						
شعرت بأنك تعبان ؟						

10 – خلال الأسابيع الأربعة الماضية, ما مقدار الوقت الذي تعارضة فيه صحتك الجسمية أو مشاكلك النفسية مع نشاطاتك الاجتماعية (مثل زيارة الأصدقاء والأقارب وغير ذلك) ؟

○ كان التعارض في كل الأوقات
○ كان التعارض في معظم الأوقات
○ كان التعارض في بعض الأوقات
○ كان التعارض في قليل من الأوقات
○ لم يكن هناك أي تعارض في أي وقت من الأوقات

11 – ما مدى صحة أو خطأ كل من العبارات التالية بالنسبة إلى حالتك الصحية ؟

	صحيحة بلا شك	صحيحة غالبا	لا اعلم	خطأ غالبا	خطأ بلا شك
يبدو أنني أصاب بالمرض أسهل من الآخرين.					
حالتي الصحية مساوية لأي شخص .					
أتوقع إن تسوء حالتي الصحية .					
حالتي الصحية ممتازة .					

جودة الحياة الصحية للمرضى الفلسطينيين الذين يعانون من مرض الذئيبة الحمراء في مستشفى المقاصد

اعداد الطالب: محمود محمد حدرب

اشراف الدكتور: رسمي ابو حلو

الملخص

مرض الذئبية الحمراء هو داء مناعي ذاتي يشتمل في أكثر من جهاز في جسم الإنسان وفي معظم حالات المرض يكون لدى النساء في عمر الإنجاب وتكون نسبة المرض بين الذكور والإناث هي9:1، ويكون حدوث المرض في المعظم ما بين عمر 15-40، وفي هذا المرض يهاجم الجهاز المناعي خلايا الجسم نفسه لدى المريض وتكون النتيجة التهابات في عدة أعضاء في الجسم .

هدفت هذه الدراسة إلى قياس جودة الحياة المتعلقة في الصحة لدى مرضى الذئبية الحمراء الفلسطينيين في مستشفى المقاصد ومعرفة تأثير مستوى التعليم مع جودة الحياة لديهم .

إن الدراسات المتعلقة في جودة الحياة المتعلقة في الصحة هي مهمة للتقييم الطبي، وهي تركز على عدة جوانب مهمة مثل الصحة الجسمية، الحياة الجيدة النفسية، والعلاقات الاجتماعية والمعتقدات الشخصية، لذلك إن قياس جودة الحياة الصحية إضافة إلى العلامات والمؤشرات السريرية للمرض تسمح لتقييم شامل ليكون ذو فعالية في العلاج والاستجابة .

إن SF-36 هي أداة علمية لقياس جودة الحياة المتعلقة بالصحة وتتكون من 36 عنصر في استبيان وصممت لتستخدم في عدة ظروف واختلافات سكانية وأماكن، حيث أظهرت بأنها ذات مصداقية وموثوقة في دراسة جودة الحياة لدى مرضى الذئبية الحمراء في العديد من الدراسات.

اشتملت العينة على 76 مريض فوق سن 14 و مشخص في المرض حسب نظام الكلية الأمريكية لأمراض الروماتيزم، حيث تم استثناء المرضى في أمراض مزمنة أخرى، كانت العينة ترتيبية حسب حضور المريض إلى مستشفى المقاصد في القدس وعيادة خاصة في أمراض الروماتزم في مدينة رام الله .

لقد أشارت الدراسة في نتائجها إلى أن جودة الحياة الصحية لدى مرضى الذئبية الحمراء تأثرت بشكل سلبي في كل الحقول حيث استجاب المرضى أن لديهم مشاكل نتيجة مرضهم المناعي المزمن خاصة في حقل الصحة الجسمية، وفي حقل الألم الجسمي، وحقل الوظيفة الاجتماعية وفي الصحة العقلية .

أيضا تم فحص المستوى التعليمي لدى المرضى حيث اظهر بأن جودة الحياة الصحية لدى المرضى بالذئبية الحمراء في معظم الحقول لا تتغير مع المستوى التعليمي .