

The Effect of Implementing A protocol of Nursing Care on SLE Patients' Knowledge and Health Related Quality of Life

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Abstract: Lupus is a chronic disease that requires an interdisciplinary treatment management approach to facilitate optimal outcomes. One key component believed critical to overall treatment management is the inclusion of educational programs to improve patient knowledge. It is unclear which educational programs are most effective in improving patient knowledge of lupus and, ultimately, long-term outcomes. The purpose of this review is to examine the current literature Design: the study followed a quasi-experimental design. Setting: the study was carried out in the Main University Hospital Alexandria University. Subjects: Convenience sample of two hundred patients who agreed to participate in the study. Interviews were conducted with patients who met the study criteria to fulfill the study's tools. Tools: Two tools were used to collect the necessary data Tool I: socio-demographic and clinical data structured interview schedule Tool II: Patients' knowledge assessment schedule to obtain base line data about SLE patients' knowledge. Tool III Systemic lupus erythematosus-specific quality-of-life questionnaire (SLEQoL). Method: A total of 100 Systemic lupus erythematosus patients aged 20- 60 years or over, admitted at the Main University Hospital and exposed to training by the researcher for period of three months pre and post assessment was performed for each patients using tool II and III. Results: there was a statistical significant difference between patients' knowledge and quality of life before and after receiving training. Conclusion patients who were exposed to training show better improvement to their level of knowledge and health related quality of life.

Keywords: Assessment, Systemic, Lupus, Erythematosus, Quality of Life.

I. INTRODUCTION

Assessment of quality of life (QOL) of women with systemic lupus erythematosus (SLE) can be as important as measurements of morbidity and mortality. The effect of changes caused by the disease process and therapy in the clinical course of disease demands actions that improve the QOL as an essential tool of satisfaction for patients and health professionals. In periods of intense inflammatory activity, the widespread deposition of immune complexes in sites like blood vessel walls produces inflammation and functional changes in various organs, which gives the disease its systemic character. These periods are marked by severe signs and symptoms and clinical and laboratory changes, requiring the use of high dose steroids and, quite often, immune suppressants(1).

Several signs and symptoms may interfere with QOL during periods of SLE activity, such as vacuities causing skin rash; painful lesions and hyperemia in palms and soles, palate or limb regions; fever without infection; weight loss; headache; alopecia; asthenia; mialgia; eye problems; hepatomegaly; splenomegaly; and adenopathy. Although the etiology remains unclear, the disease is strongly influenced by genetic, hormonal (estrogen), environmental (ultraviolet radiation, drugs), infectious (viral), and psychological stress factors, which participate in its pathogenesis. SLE is one of the most common autoimmune diseases in young women, with the highest incidence in the age group of 15-40 years, at a ratio of six women for each man. Therefore, the odds of developing this predominantly female disease differ between genders(2).

The QOL issue incorporated into the health practice of professionals has been designated as health-related quality of life and used in clinical setting to express the physical and psychosocial impact caused by physical and biological changes produced by disease and therapies that interfere with daily life conditions.⁸⁰⁻¹⁰ The attempt to achieve QOL, as well as seeking to define it, has followed the historical and cultural development of mankind. The QOL construct is very comprehensive, reflecting the historical moment, social class, and culture of the individual, since it comes from experience, knowledge, and values both individual and collective. One definition of QOL has been proposed by a study group on QOL of the World Health Organization (WHO), World Health Organization Quality of Life Group (WHOQOL): "An individual's perception of his/her position in life in the context of the culture and value systems in which he/she lives, and in relation to his/her goals, expectations, standards and concerns." The WHOQOL-100 is a generic QOL instrument developed by the WHO in 1998 from a multicenter study. It contains 100 questions divided into 24 groups of four questions whose answers are punctuated by scores that range from 0 to 1.0 for each domain. Systemic lupus erythematosus-specific quality-of-life questionnaire (SLEQoL) it was used in this study to assess quality-of-life in individuals with SLE. The original development and validation study of the

English language survey took place in Singapore by Leong et al. (3).

It contains six domains including physical functioning, activities, symptoms, treatment, mood and self-image. Also, subdivided into 40 items, including physical functioning (6 items), activities (9 items), symptoms (8 items), treatment (4 items), mood (4 items) and self-image (9 items). Response options/scale by using 7-point response scale (subsections have different anchors, including "not difficult at all" to "extremely difficult", "not at all" to "extremely troubled", and "not at all" to "extremely often"). (4).

Patient education is a typical part of standard care; however, the content, format, frequency and method of dissemination vary. For patients with lupus, limited research has been conducted on patient education. As a critical component of patient management, the development of model lupus-specific patient education studies will facilitate future studies and lupus outcomes. (5).

The complex manifestation of lupus and its comorbid consequences may contribute to both the limited and mixed results of current lupus patient education. Thus, additional investigations of multifaceted, nonpharmacological lupus patient education are needed to manage lupus effectively and improve patients' quality of life. Patient education is a component of disease management plans and ranges from general information to treatment strategies and decision-making resources to benefit an individual's quality of life. Approaches to patient education for patients with lupus vary in terms of intervention type, mode of administration, number of educational sessions and duration of intervention, facilitator type and outcome measures. Patient educational programs designed to improve disease-related risk factor control and a disease-specific therapy (steroid pulse therapy), specific cholesterol lowering diet program for patients with lupus to reduce cardiovascular risk, disease management strategies to achieve better physical and psychosocial health. Lupus is an oftentimes devastating and debilitating condition. If the goal of lupus interventions is to promote effective and meaningful therapeutic clinical interactions between patients with lupus, healthcare providers and the healthcare system, then the development of comprehensive disease management programs is warranted to improve patient quality of life as the current findings suggest opportunities and challenges. Patient education interventions are a key component of patient management programs(6).

II. MATERIALS

This was a quasi-experimental study developed in the Department of Rheumatology of Main University Hospital included 100 women, with data collected for a period of three months Inclusion criteria were , female, age 20-60 years, meeting at least four criteria for SLE diagnosis (according to the American College of Rheumatology-ACR-1982), ability to communicate verbally or in writing on interview and data collection instrument, agree to participate in the study, and sign informed consent(7).

Exclusion criteria were presence of other chronic infectious diseases non-associated with SLE activity and chronicity, and suspected or confirmed pregnancy. The instruments used for data collection were: form for collecting demographic and clinical data and Systemic lupus erythematosus-specific quality-of-life questionnaire (SLEQoL). The Systemic Lupus Erythematosus Disease Activity Index (SLEDAI) was used to classify groups of participants based on disease activity index. (8).

III. METHOD

1. An official letter was obtained from the administrative office of the Faculty of Nursing.
2. A written approval was obtained from the hospital administrators and head Department of Rheumatology of Main University Hospital , after explanation of the study aim.
3. The study tool I part I,II were developed by the researcher after a
4. thorough review of relevant literature.
5. hundred adult patients were assigned in the study
6. Completion of Systemic lupus erythematosus-specific quality-of-life questionnaire (SLEQoL).was performed preferentially by the participant herself, respecting the privacy requirements of the clinical setting. When indicated, due to clinical status or education level, the filling was carried out with assistance and support directly from the researcher .In these situations, the questions were read by the researcher and the participant indicated her response options. The question was repeated as often as was needed, without adding explanations that would direct the response.

The protocol of care consisted of six weekly 2 hour sessions for two month for the study group the control group did not receive an intervention. The protocol of care consisted of

- Need knowledge instructions about the disease course
- Diet counseling
- Physical activity exercises program

After completion of training reassessment of patient using Systemic lupus erythematosus-specific quality-of-life questionnaire (SLEQoL) tool

For statistical analysis were applied the Student’s t-test and analysis of variance (ANOVA) for the domains addressed in Systemic lupus erythematosus-specific quality-of-life questionnaire (SLEQoL), and Pearson’s correlation for continuous demographic variables. Through statistical analysis

IV. RESULTS

Table (1) shows distribution of the studied group regarding their demographic data. More than one third of the patients were in the age group of 50 > 60 . Females were 61(61%).Regarding occupation, Not-working cases was higher with 50(50%) and widows were higher 35(35%) .As for education level, primary & prep school was higher 34(34%). BMI was 39(39%) was obese patients

Table (2) shows the clinical data of the studied group 25 % of the patients have bone pain , quarter of them have diabetes mellitus and 14% have previous hospitalization. Table (3) illustrated comparison between Levels of knowledge of the studied group there was highly statistical differences between patients’ knowledge level before and after implementation of the educational program (p=0.0001*)

Table (4)shows comparison between quality of life score in the studied group there was highly statistical differences between patients’ knowledge level before and after implementation of the educational program (p=0.0001*)

B. Table, Figures, Headings and Equations

Table (1): Distribution of the studied group regarding their demographic data

	Number	Percent
Age in year		
21>30	19	19.0
30>40	30	30.0
40>50	17	17.0
50>60	34	34.0

Gender		
Male	39	39.0
Female	61	61.0
Occupation		
Manual worker	26	26.0
Employee	24	24.0
Notworking	50	50.
Marital status		
Single	21	21.0
Married	18	18.0
Divorced	26	26.0
Widow	35	35.0
Education level		
Illiterate or read & write	33	33
Primary & prep school	34	34
Secondary	17	17.0
University	16	16.0
BMI		
Normal weight	25	25.0
Over weight	36	36.0
Obese	39	39.0

Table (2): Clinical data of the studied group.

	Number	Percent
Chief complains:		
Bone pain	25	25.0
Respiratory infection	10	10.0
Blurral vision	14	14.0
Headache	10	10.0
Immobility	11	11.0
Urinary incontinence	15	15.0
Rash on skin	15	15.0
Associated diseases		
Diabetes	21	21.0
Renal	12	12.0
Hypertension	13	13.0
Bleeding	13	13.0
Rheumatic	27	27.0
Past history		
Previous hospitalization	14	14.0

Table (3): comparison between Levels of knowledge of the studied group

Level of knowledge	Before program		After program	
	No.	%	No.	%
Excellent	0	0.0	21	21.0
Good	15	15.0	45	45.0
Faire	40	40.0	22	22.0
Poor	45	45	12	12.0
Total	100	100.0	100	100.0
P	0.0001*			

Table (4): comparison between quality of life score in the studied group

Q o l score	Before program		After program	
	No.	%	No.	%
Excellent(40-100)	0	0.0	20	20
Good(-160)	15	15.0	45	45
Faire (-220)	35	35	20	20
Poor(-280)	50	50	15	15
Total	100	100.0	100	100.0
P	0.0001*			

V. DISCUSSION

The quality of life is defined by WHO as ‘the experience of living conditions related to their goals, expected values, standard and attention point for people in different cultural and value systems’ (11). Targeted nursing requires nursing workers to show human concern and integrate nursing concept for the patients. The frame of nursing process which emphasizes human orientation, focuses on the health of nursing subjects, osmosis of human concern and care in a nursing evaluation to intervention and assessment, and shows the three-in-one service concept of body-psychology-society (12). It is widely believed that good clinical nursing adds strength to health, especially psychological health (13).

The efficacy of nursing intervention with SLE patients. The results showed that, disease activity and injury index score and incidence of complications were significantly decreased in the targeted nursing group compared to that of the regular nursing group. Furthermore, targeted nursing significantly improved therapeutic compliance, quality of life and nursing content satisfaction compared to regular special nursing. Nursing management is needed for clinical work and nursing operation, in addition to important interventions to improve nursing quality and achieve a harmonious physician-patient relationship. Targeted nursing emphasizes specialization and individuation of nursing, and fully utilizes nursing resources, carrying out specific nursing services to different patients, which yields a positive effect in the treatment of SLE (8).

The compliance of hormone therapy is the key to stabilization of SLE pathogenic condition and to control recurrence. The lack of relevant knowledge and supervision of medication, psychological fear, obvious adverse reaction, chronic pathogenesis, lack of economic resources and social support are all important factors affecting treatment compliance (9). Due to lack of supervision from health care workers following discharge of patients from the hospital, unwillingness to continue medication after disappearance of symptoms, not turning up for reassessment, reduced consumption of prescribed drugs or number of times, and changing drugs or administering dosage other than that prescribed by the medical staff lead to poor prognosis and even disease recurrence. Targeted nursing is patient-oriented and aimed at improving the quality of life of the patients during hospitalization and after discharge (10). It improves the nursing by combining oral and written propagation, in the form of lectures, bulletin boards, informal discussions between nurses and patients, and other individuation methods through nursing intervention for patients with complications according to their actual conditions.

VI. CONCLUSION

In conclusion, nursing intervention can significantly improve therapeutic compliance and clinical outcome of SLE patients and also reduce the incidence of complications and ameliorate quality of life. We also suggest that future studies should focus on targeted nursing for different complications that arise during SLE treatment and to evaluate the efficacy of targeted nursing and its clinical application

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