Journal of Taibah University Medical Sciences (2018) ■(■), 1–7

Taibah University

Journal of Taibah University Medical Sciences

www.sciencedirect.com

Original Article

Self-care model application to improve self-care agency, self-care activities, and quality of life in people with systemic lupus erythematosus

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Received 14 February 2018; revised 9 July 2018; accepted 13 July 2018; Available online ■ ■ ■

الملخص

أهداف البحث: تهدف هذه الدراسة لفحص تأثير تطبيق نموذج الرعاية الذاتية لتحسين قوة الرعاية الذاتية، وعملية الرعاية الذاتية، وجودة الحياة للمرضى الذين يعانون من الذئبة الحمامية الجهازية.

طرق البحث: استخدمت هذه الدراسة تصميما تجريبيا مسبقا مع مجموعة واحدة قبل الاختبار- وبعد الاختبار. تم اختيار ستة وثلاثين مستجيبا باستخدام أسلوب أخذ العينات الكلي. كما تم إجراء تدريب إدارة الرعاية الذاتية على المجموعة التجريبية التي تمت متابعتها كزيارة منزلية أربع مرات أسبوعيا. وتم قياس قوة الرعاية الذاتية باستخدام مقياس تدريب قوة الرعاية الذاتية. وقياس المتغيرات الأخرى بواسطة قدرات ذاتية التقييم لمقياس الممارسات الصحية وجودة مخزون الذئبة. وتم تحليل البيانات بواسطة اختبار ت — المزدوج مع الفا أقل من ٠.٠٥.

النتائج: معظم من يعانون من الذئبة الحمامية الجهازية سيدات عاملات نشطات متزوجات في عمر الإنجاب. معظمهن لديهن الذئبة الحمامية الجهازية منذ ١-٢ عاما (٣٣.٣٪)، تم تسجيل التهاب المفاصل من الأعراض الأكثر شيوعا لدى ٦١.١٪. وكان العامل المحفز للظهور عند الغالبية هو الإجهاد البدني (٦٦.٧٪) الذي أدى إلى التعب. في المتوسط، تطبيق نموذج الرعاية الذاتية ممكن أن يحسن قوة الرعاية الذاتية ١٩.٩٣٪، وعملية الرعاية الذاتية ٥٣.١٧٪ وجودة الحياة ١٢.١٩٪. كانت فعالة بشكل كبير في تعزيز قوة الرعاية الذاتية، وعملية الرعاية الذاتية، وجودة الحياة عند مرضى الذئبة الحمامية الجهازية.

الاستنتاجات: تطبيق نموذج الرعاية الذاتية ل"أوريم" فعال في تحسين قوة الرعاية الذاتية، والرعاية الذاتية، وجودة الحياة، ويقدم الدليل على ذلك استخدامه في الرعاية التمريضية لمرضى الذئبة الحمامية الجهازية في المجتمع. يجب على مقدمي الرعاية الصحية دمج نموذج الرعاية الذاتية لإوريم في الرعاية التمريضية لتعزيز قوة الرعاية الذاتية، الرعاية الذاتية وجودة الحياة عند مرضى الذئبة الحمامية الجهازية.

الكلمات المفتاحية: الذئبة الحمامية الجهازية؛ نموذج الرعاية الذاتية؛ قوة الرعاية الذاتية؛ الرعاية الذاتية؛ جودة الحياة

Abstract

Objectives: This study aimed to examine the effect of the application of a self-care model to improve self-care agency (SCA), self-care operation, and quality of life (QoL) in patients with systemic lupus erythematosus (SLE).

Methods: This study employed a pre-experimental design with one pretest-posttest group. Thirty-six respondents were selected through total sampling. The experimental group was provided self-care management training, followed by four weekly home visits. Self-care agency was measured with the self-care agency scale, the other variables through self-rated abilities on the health practices scale and Lupus quality inventory. Data were analysed using paired *t*-tests with $\alpha < 0.05$.

Results: SLE was common in actively working married women of childbearing age, most of whom had had SLE for 1–2 years (33.3%), with arthritis being the most common symptom (reported by 61.1%). The major flare trigger factor was physical stress (66.7%), resulting in fatigue. On average, the self-care model was able to

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Peer review under responsibility of Taibah University.

ELSEVIER Production and hosting by Elsevier

 https://doi.org/10.1016/j.jtumed.2018.07.002

Please cite this article in press as: Kusnanto K, et al., Self-care model application to improve self-care agency, self-care activities, and quality of life in people with systemic lupus erythematosus, Journal of Taibah University Medical Sciences (2018), https://doi.org/10.1016/j.jtumed.2018.07.002

improve SCA by 19.93%, self-care operation by 17.53%, and QoL by 12.19%. It was significantly effective in enhancing SCA, self-care operation, and QoL in patients with SLE ($p < 0.001$).

Conclusions: The application of Orem's self-care model is effective in improving SCA, self-care, and QoL, and this study provides evidence of the benefits of its use in the nursing care of patients with SLE in a community setting. Health care providers should incorporate Orem's self-care model in nursing care to enhance SCA, self-care, and QoL in patients with SLE.

Keywords: Self-care; Self-care agency; Self-care model; Systemic lupus erythematosus; Quality of life

Introduction

Systemic lupus erythematosus (SLE), a chronic autoimmune disease with varying degrees of systemic involvement and courses of illness, is a complex pathogenic pathway that culminates in the formation of auto-antibodies.[1] There are 5 million people with SLE worldwide, 90% of whom are women between 15 and 44 years.[2] SLE is often more severe in people of African, Hispanic, Chinese, and Asian descent.[1] The estimated number of SLE patients in Indonesia is between 200,000 and 300,000, with a male-female ratio of 1:9.[3] The incidence of SLE is in the range of 0.001−0.01% and has a prevalence of 0.02−0.2% per 100,000 per year. SLE identification continues to rise since health workers and the public have greater awareness of SLE. Patients with SLE have had a 5-year survival rate of over 90% and 87.4% for 10 years.[4,5] The increased life expectancy of patients with SLE is related to improvements in meeting the needs of long-term care, and the independence of people with SLE has become an important element in SLE management, especially in the community context.

SLE is a source of disability that can create a burden of poor quality of life.[6–10] The quality of life of SLE patients is always worse than that of healthy people and remains poor even in patients with SLE without complications and organ damage.[6,11] The low quality of life of people with SLE seems to limit daily life activities, especially due to joint pain resulting from SLE relapses, depression and withdrawal from the environment, changes in interpersonal relationships, discrimination, difficulties in finding employment, obstacles to performing social roles, and a high risk of infertility.[10,12–18] Low quality of life because of SLE flares cannot be predicted due to the increased intensity of exposure factors.[1,19] SLE flares affecting the quality of life can impact aspects of a patient's emotional and social life, family relationships, daily activities, cognition, appearance, occupation, and independence.[8]

Models that focus on improving client independence through self-care activities include a model of self-care proposed by Orem.[20] Orem states that nurses can implement a supportive educational system by providing nursing agency in the form of health promotion activities to address the self-care deficit. The model of self-care is often used in nursing research in the case of chronic diseases, such as stroke, diabetes, arthritis, and others, and has shown good results against measured parameters.[21–23] The self-care model can also be applied in cases of SLE to improve self-care agency (SCA) and self-care activities in order to allow patients with SLE to improve their quality of life independently. Studies have indicated that health behaviour can affect individuals' health status and later their quality of life, so the approach recommended was to modify health behaviour through self-care activities to increase the quality of life for people with SLE.[22] This study aimed to demonstrate and analyse the effectiveness of a self-care model for improving SCA, self-care activities, and quality of life in SLE patients.

Materials and Methods

This was a pre-experimental study with a one group pretest-posttest design. The population comprised patients with Systemic Lupus Erythematosus (SLE) (without any organ damage) registered at the rheumatology unit of Dr. Soetomo Hospital, a public hospital in Surabaya, Indonesia. The target population comprised all SLE patients undergoing regular check-ups in that unit during the period October−December 2014, which included up to 54 patients. The sample inclusion criteria were adult women (19−44 years), suffering from SLE without any complication (diagnosis code: M32), and whose SCA and self-care activities were not optimal (they had a self-care deficit). Only women were included in the study to ensure sample homogeneity, as hormonal changes due to menstruation could be a flare trigger. The exclusion criteria were SLE patients with complications or organ damage (diagnosis codes: M32.0, M32.1, M32.9), who resigned or should be treated in the hospital at the time of study, who did not attend all the training sessions of self-care management, who refused to accept home visits, and who experienced mental disorders. Of the 54 members of the target population, 36 SLE patients met the criteria. The sample in this study was the total population (total sampling), so the 36 patients who fulfilled the criteria were the respondents in this study.

The independent variable was the application of Orem's self-care model.[20] Programs implemented in this study included education and counselling (part of the three pillars of the treatment of patients with SLE, according to the recommendation of the Rheumatology Association of Indonesia in 2011). Application of the self-care model took up approximately 4 h in the self-care management training program (the education part), followed by four weekly home visits of about 30 min each (the counselling part). During home visits, the researcher asked about SLE symptom recurrence in the previous week and precipitating factors of symptoms, then assessed the self-care activities that had been implemented, the problems that had been encountered, discussed alternative solutions, gave counselling when needed, and made progress notes.