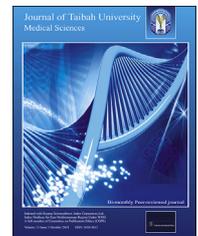




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Original Article

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



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المخلص

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 تصميمًا تجريبيًا مسبقًا مع مجموعة واحدة قبل الاختبار - وبعد الاختبار. تم اختيار ستة وثلاثين مستجيبًا باستخدام أسلوب أخذ العينات الكلي. كما تم إجراء تدريب إدارة الرعاية الذاتية على المجموعة التجريبية التي تمت متابعتها كزيارة منزلية أربع مرات أسبوعيًا. 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 اختبارات - المزدوج مع الفا أقل من 0.05.

النتائج: معظم من يعانون من الذئبة الحمامية الجهازية سيدات عاملات نشطات متزوجات في عمر الإنجاب. معظمهن لديهن الذئبة الحمامية الجهازية منذ 1-2 عامًا (33.3%)، تم تسجيل التهاب المفاصل من الأعراض الأكثر شيوعًا لدى 61.1%. وكان العامل المحفز للظهور عند الغالبية هو الإجهاد البدني (66.7%) الذي أدى إلى التعب. في المتوسط، تطبيق نموذج الرعاية الذاتية ممكن أن يحسن قوة الرعاية الذاتية 19.93%، وعملية الرعاية الذاتية 17.53% وجودة الحياة 12.19%. 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 improve SCA by 19.93%, self-care operation by 17.53%, and QoL by 12.19%. It was significantly effective in

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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

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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.

Before creating a training module, the researchers conducted interviews with 25 people with SLE to determine

the epidemiology of the recurrence of SLE symptoms and determine appropriate self-care for managing symptoms. The training modules in this study included the four dimensions of self-care according to Becker et al. (1993)²³ and were based on the recommendation of the Rheumatology Association of Indonesia (PRI, 2011) regarding SLE management. The modules were divided into five parts: 1) lupus, 2) physical activity, 3) healthy diet, 4) stress management, and 5) managing SLE symptoms independently. Home visits were conducted to evaluate the recurrence of SLE symptoms, relapses of trigger factors, self-care activities performed at home, and the problems encountered in doing self-care. Counselling and additional health information were given to respondents in need.

The dependent variables consisted of SCA, self-care activities, and quality of life. The SCA was measured using the Exercise of Self-Care Agency Scale of Kearney and Fleischer (1979).²⁴ The validity and reliability of this instrument were $r = 0.420-0.822$ and $\alpha = 0.917$. Self-care activities were measured using the Self-Rated Abilities for Health Practices Scale.²³ This instrument was tested for validity and reliability with the result of $r = 0.425-0.700$ and $\alpha = 0.894$. Finally, the quality of life was measured with LupusPRO,²⁵ which was found to be valid and reliable with $r = 0.408-0.764$ and $\alpha = 0.803$. The instrument was tested on 25 SLE patients of the Rheumatology Unit of the Dr. Soetomo Hospital in February 2015. The instruments used in this study were adopted from the available literature and translated by the researchers. NPWPS (the second researcher) provided the first translation, which was then agreed upon by the other members.

Prior to study intervention, the researchers received ethical clearance and approval from the Ethical Committee of the Faculty of Public Health, Universitas Airlangga, Surabaya. Participants were informed that this study was voluntary and that they could withdraw at any time without seeking permission from the researcher. All the participants agreed and completed consent forms prior to the study. Paired *t*-tests were used to analyse the effectiveness of the application of the self-care model in improving SCA, self-care activities, and quality of life.

Kolmogorov–Smirnov test results showed that all pre-test and post-test data were normally distributed ($p > \alpha$). Thus, a paired *t*-test was used for data analysis.

Results

Initially, based on data from the Rheumatology Unit of Dr. Soetomo Hospital and sampling technique chosen, the sample size of this study should have been 42; but as only 36 respondents participated on the day of self-care management training, this was the sample size. Table 1 below presents the demographic characteristics of the study participants.

Most respondents were high school graduates (83.3%), in late adulthood (44.4%), legally married and living with their spouse (77.8%), and actively working as private employees (33.3%) and entrepreneurs (33.3%), with an independent income of Rp. 1.5 to 2 million/month (33.3%). In this study, many of the SLE patients were women of childbearing age with a high school educational background who are married and actively working.

Table 1: Demographic characteristics.

Characteristic	<i>n</i>	%
1. Age		
a. 17–25 years old (late adolescence)	8	22.2
b. 26–35 years old (early adulthood)	12	33.3
c. 36–45 years old (late adulthood)	16	44.4
2. Marital status		
a. Married	28	77.8
b. Single	8	22.2
3. Educational background		
a. High school graduate	30	83.3
b. Bachelor's degree	6	16.7
4. Occupation		
a. Housewife	8	22.2
b. University student	4	11.1
c. Entrepreneur	12	33.3
d. Private employee	12	33.3
5. Salary (in rupiah per month)		
a. None	12	33.3
b. 500 thousand – 1 million	2	5.6
c. > 1–1.5 million	6	16.7
d. > 1.5–2 million	12	33.3
e. > 2 million	4	11.1
6. Living with		
a. Spouse	28	77.8
b. Children	20	55.6
c. Parents	10	27.8
d. Brother/sister	2	5.6

As shown in Table 2, most respondents were diagnosed with SLE 1–2 years ago (33.3%). The most common SLE symptom was arthritis (61.1%), and the precipitating factor was mostly physical stress/tiredness (66.7%).

Table 3 shows that the SCA value on the pre-test was largely sufficient (94.4%), and there was a high value on the post-test (100%). Paired *t*-test results showed that $p \leq 0.001$, which means that the application of the self-care model could improve SCA in SLE patients. The application of Orem's Self-Care Model was able to increase the SCA of respondents by an average of 19.93%. This also shows that the self-care activity value of the pre-test was largely sufficient (88.9%) and that the post-test was nearly optimal (77.8%). It was also found that 16.7% of the respondents experienced stagnancy in doing self-care activities at home (stable), which decreased to 5.6% at the end of the study. The results of a paired *t*-test for these rates were significant at $p \leq 0.001$, which means that application of the self-care model could improve self-care activities in lupus patients by 17.53%.

Results further showed that 77.8% of respondents managed to implement an optimal self-care activity post-intervention, but this was not always followed by the absence of SLE flares. Results of the four-week home visits showed that in the first week of post-training, all respondents (100%) had a recurrence of symptoms; three of the most common symptoms experienced were arthritis (77.8%), fatigue (72.2%), and hair loss (61.1%). This condition improved weekly: In the second week, only 4 respondents (11.1%) experienced an absence of SLE flares, while in the third and fourth weeks, there were 8 (22.2%) and 12 respondents (33.3%), respectively, who did not experience a recurrence of lupus symptoms.

Table 2: Disease duration, lupus symptoms, and precipitating factors.

Characteristics	N	%
1. Disease duration		
a. < 1 year	4	11.1
b. > 1–2 years	12	33.3
c. > 2–3 years	8	22.2
d. > 4–5 years	2	5.6
e. > 5 years	10	27.8
2. SLE symptoms		
a. Fever	8	22.2
b. Headache	6	16.7
c. Confusion	2	5.6
d. Arthritis	22	61.1
e. Fatigue	12	33.3
f. Skin rash	6	16.7
g. Aching in deep breathing	2	5.6
h. Myalgia	2	5.6
i. Anemia	4	11.1
3. Precipitating factors		
a. Emotional stress	16	44.4
b. Physical stress	24	66.7
c. Sunlight	4	11.1
d. Irregular eating patterns	4	11.1
e. Lack of sleep	4	11.1
f. Hormonal changes	2	5.6

Table 3: Paired *t*-Test: Self-care agency, self-care activity, and quality of life.

Category	Pre-Test		Post-Test	
	n	%	n	%
Self-care agency				
Low	2	5.6	0	0
Enough	34	94.4	0	0
High	0	0	36	100
	36	100	36	100
Mean ± SD	Std. Error Mean (SEM)		Paired <i>t</i>-Test Sig. (2-tailed)	
25.33 ± 14.751	2.459		$p < 0.001$	
Self-Care Activity				
Less	4	11.1	2	5.6
Enough	32	88.9	6	16.7
Optimum	0	0	28	77.8
	36	100	36	100
Mean ± SD	Std. Error Mean (SEM)		Paired <i>t</i>-Test Sig. (2-tailed)	
17.00 ± 16.406	2.734		$p < 0.001$	
Quality of life				
Low	14	38.9	4	11.1
Enough	20	55.6	30	83.3
High	2	5.6	2	5.6
	36	100	36	100
Mean ± SD	Std. Error Mean (SEM)		Paired <i>t</i>-Test Sig. (2-tailed)	
12.61 ± 12.288	2.048		$p < 0.001$	

While the quality of life value on the pre-test was largely sufficient (55.6%) and the post-test showed a good value (83.3%), it was also found that 61.1% of the respondents perceived stagnancy in quality of life (stable), decreasing to

5.6% by the end of the study. Paired *t*-test results thus showed that the application of self-care model could enhance quality of life in patients with lupus. The application of the self-care model could improve quality of life of respondents by an average of 12.19%.

Discussion

The self-care model was applied in this study and showed a potential for future benefits for Indonesians. The SLE patients in Surabaya in particular have a high capacity and high SCA to carry out self-care. The method by which the self-care model was implemented in this study consisted of facilitating self-care management training for people with SLE, which was continued in four weekly home visits. During the training, various nursing instructions were given to study participants on how to independently handle their SLE symptoms at home; a written version was available in the training module. Home visits as follow-up sessions were important to ensure the provision of continuous care, which could significantly improve SLE patients' knowledge levels and their perception of their family members' awareness of SLE.³⁴ The knowledge level was important in forming the SCA to be used in self-care operations at home, while a positive perception of all family members' awareness of SLE could enhance the feeling of support from loved ones, which is important in forming the internal motivation needed for self-care.

Orem²⁰ states that delivering the self-care model includes doing for others, leading others, providing support and motivation, and teaching or educating others, all of which were accommodated in the study intervention. Researchers assigned nursing agency through educational support and intensive assistance, i.e., counselling at home. All (100%) of the respondents showed an increase in SCA after 4 weeks of self-care model implementation; no respondent with stagnant SCA was found at the end of the study. This shows that educational programs and assistance given by nurses can improve the sense of capability, belief, strength, and confidence of people with SLE to carry out self-care activities at home.

This study result is supported by the theory of self-care deficit nursing theory proposed by Orem,²⁰ which states that the provision of nursing agency in a supportive educational system can improve SCA clients.²⁸ According to Orem,²⁰ nursing agency is given by nurses in the belief that everyone has the ability for self-care so that nurses can assist individuals in meeting life, maintaining health, and achieving well-being. Nursing agency is given through a nursing system in such a way that nurses and their clients can collaborate to identify and meet the needs of therapeutic self-care demands as well as maintaining the clients' ability to implement self-care (SCA) in order not to create a self-care deficit.²⁸ Orem stated that as self-care deficit is the inability of the client to meet therapeutic self-care demands due to low SCA, in such conditions it is an indispensable nursing agency.²⁰

Increased SCA in this study was owing to the provision of intensive nursing agency (training program and weekly home visits) and the existence of basic conditioning factors, which naturally affects SCA. The provision of nursing agency

covers the therapeutic communication process and fosters a relationship of trust with the aim of increasing the motivation, self-confidence, sense of ability, and strength and belief of respondents, which also supports cooperation between nurses and clients in the implementation of self-care. Orem argues that the SCA is naturally influenced by basic conditioning factors. The basic conditioning factors expected to affect the increase in SCA of respondents in this study are the age-related stage of development (maturity), health status (related to illness and relapse), lifestyle (adoption of healthy behaviours), family support (social support, support systems, availability and adequacy of resources), the health care system (interactions of the nurse and client, communication, nursing system), and environmental factors (physical and social).

This study also showed that the self-care model application was not optimal in improving the self-care activities of the respondents. SCA values could be indicators of self-care activities; ideally, high SCA predicts optimal self-care. However, in this study, a high SCA was not found to be followed by optimal self-care 100% of the time. The provision of nursing agency in a condition of self-care deficit is considered able to help the patient meet self-care demand,²⁸ which generally consists of four domains: nutrition, exercise, psychological conditions, and accountable health practices.²³ In addition, introducing the matter of trigger factor prevention as a part of daily self-care activities is also essential for individuals with SLE. Its function is to minimize flares that constrain the health-related quality of life for people with SLE. This aspect was not assessed optimally in this study because of the limitations of the instruments.

Green and Kreuter argue that the implementation of health behaviours by adults is affected by specific knowledge of their application.²² In line with this, Orem²⁰ also found that individuals do self-care based on such knowledge. Study results showed that 66.7% of the respondents had proper knowledge before training, and this number increased to 100% after training, indicating that prior to study intervention, most of the respondents already had sufficient knowledge to perform self-care at home. Besides such knowledge (one of the predisposing factors), health behaviour is also affected by enabling and reinforcing factors.²²

Self-care in the context of chronic disease is complex. Respondents revealed problems they often encountered when carrying out self-care activities, namely: 1) a reluctance to exercise (16.7%), 2) a lack of sports facilities (5.6%), 3) boredom regarding taking medication (11.1%), 4) difficulties in setting a time for self-care (11.1%), 5) the demands of the role (33.3%), 6) financial problems (11.1%), 7) family problems (22.2%), 8) long queues for regular check-ups (5.6%), and 9) being embarrassed by the environment (11.1%). During home visits, researchers provided counselling to motivate respondents as well as alternative solutions to the problems they faced. Moreover, additional health information was also provided to respondents who needed it.

Self-care can facilitate SLE patients in achieving improvements in living independently. Quality of life refers to the functional effect of a medical condition or treatment undergone by the patient. Quality of life is subjective and multi-dimensional, including physical and occupational

status, psychological status, social relations, and somatic impressions.²⁹ This study of 36 respondents indicated an increase in the quality of life in a third of the respondents after four weeks of applying the self-care model; in addition, it was also found that 61.1% of the respondents had a stable quality of life and 5.6% of the respondents experienced a decline by the end of the study. This shows that application of the self-care model was not optimal in helping lupus patients to achieve a high quality of life independently. In connection with the value of self-care activities, a high quality of life cannot be achieved by the implementation of optimal self-care activities.

The results of statistical tests showed that self-care model application can significantly enhance the quality of life for people with SLE. These findings demonstrate the value of a combination/modification of the self-care model of Orem²⁰ and the precede-proceed model of Green and Kreuter in cases of SLE, although the quality of life improvement achieved was not maximized. Improved quality of life possibly occurs due to a potential increase in the values along the other dimensions, namely reductions in SLE flares, improved general physical health, decreased joint and muscle pain, increased vitality, emotional stability, and adaptive coping.

The difficulty in achieving a high quality of life during symptom recurrence caused by SLE flares is that such symptoms are hard to predict.¹ Results of weekly home visits showed that the majority of respondents continually suffered relapses of SLE symptoms; the amount, type, and intensity of the symptoms appeared relatively unchanged. Gallop⁸ found that a recurrence of SLE can affect the quality of life in SLE patients in all respects. For example, fatigue was noted by 27.8–72.2% of the respondents during home visits. Fatigue can affect patients' cognitive aspects through declines in memory and sharpness of thought, difficulty in concentrating, a decreased ability to solve problems, and inexplicable confusion, thus ultimately adversely affecting their work, emotions, social relationships, independence, and daily functioning.⁸ Fatigue has been identified as having the greatest impact on the quality of life of people with lupus, especially in the physical and mental health domains.³⁰

The results showed that 5.6% of the respondents saw a decrease in their quality of life. This decrease was possibly because of changes in status with respect to the living goals, expectations, concerns, and standards set by the patients themselves. Wyrwich and Wolinsky³¹ found weaknesses in various instruments used to measure health-related quality of life (HRQOL) due to a lack of indicators/items assessing changes in individual living standards. The version of LupusPRO used in this study also lacks any item that assesses the living standards of people with lupus, making it difficult to determine whether an increase, decrease, or stagnancy of the quality of life of respondents was affected by any changes in their respective living standards.

Tamayo et al.³² found a high activity/progression of SLE diseases that contributed to SLE flares and showed a significant role in determining the quality of life for SLE patients. Reported recurrences of SLE symptoms in the past three months and the types of drugs consumed (primary immunosuppressive agents) proved to be relevant as determinants of quality of life for people with SLE.³² Results

of home visits showed diminishing SLE flares from week to week, and the clinical condition of the respondents seemed to improve; moreover, respondents remained as active as usual (66.7% of respondents were still actively working).

In addition to a decrease in SLE recurrence, the self-care activities that had been implemented also increased quality of life, although they could not be enhanced in this study. Erlich-Jones found that self-care activities are carried out to reduce the arthritis pain often experienced by people with rheumatology disorders, such as SLE. Performing physical exercise or sports may increase a patient's vitality, primarily by helping them to overcome fatigue, while effective stress management can help patients maintain emotional stability and increase adaptive coping.³³

This study also found that 61.1% of respondents experienced stagnation in their quality of life with the following details: 5.6% remained low, 50% remained fair, and 5.6% remained high. In addition to the standard of living, which was relatively fixed, this stagnation might also have been caused by SLE patients' fixed perspectives on the effects of SLE on their daily life, so that the perceived quality of life was also unchanged. Tamayo et al.³² found that measuring quality of life is one way to evaluate patients' perspectives on the effect of SLE on their lives. His study results showed that the quality of life in the previous year could affect the current quality of life of people with SLE. A limitation of this study is that the quality of life of respondents in the previous year was not identified, and we performed a quality of life evaluation only 1 month after the intervention. To show a meaningful change in quality of life, the self-care model should be applied for at least 6 months in SLE patients.

Conclusion

The Orem self-care model can be applied in patients with SLE, especially in adults having a higher capacity and self-care agency for carrying out self-care activities. The model is applicable to and effective in increasing self-care agency, self-care activities, and quality of life. The optimal self-care activities were insufficient to help people with SLE in achieving a high quality of life because individual living standards were fixed and the patients' perspectives about the impact of SLE on their life and functioning had not changed. A multi-centre trial approach should be considered to reach a greater number of respondents.

Conflict of interest

The authors have no conflict of interest to declare.

Ethical approval

Prior to study intervention, the researchers received ethical clearance and approval from the Ethical Committee of the Faculty of Public Health number 98-KEPK, Universitas Airlangga, Surabaya.

Authors' contributions

NPWPS, KK, and HH conceived and designed the study, conducted research, provided research materials, and

collected and organized data. NPWPS, KK, and HH analysed and interpreted data. All authors participated in general discussions and critically reviewed the manuscript. All authors have critically reviewed and approved the final draft and are responsible for the content and similarity index of the manuscript.

References

1. Dias SS, Isenberg DA. Advances in systemic lupus erythematosus. *Medicine (Baltimore)* 2014; 42(3): 126–133.
2. Schur PH, Hahn BH. Epidemiology and pathogenesis of systemic lupus erythematosus. Available at: <http://www.uptodate.com>. [Accessed 22 January 2018].
3. Papalia DE, Sterns H, Feldman RD, Camp C. *Adult development and aging*. 3rd ed. New York: McGraw-Hill Humanities/Social Sciences/Languages; 2006.
4. Pons-Estel GJ, Alarcon GS, Scofield L, Reinlib L, Cooper GS. Understanding the epidemiology and progression of systemic lupus erythematosus. *Semin Arthritis Rheum* 2010; 39(4): 257–268.
5. Alamanos Y, Voulgari PV, Papassava M, Tsamandouraki K, Drosos AA. Survival and mortality rates of systemic lupus erythematosus patients in Northwest Greece. Study of a 21-year incidence cohort. *Rheumatology* 2003; 42(9): 1122–1123.
6. Cho JH, Chang SH, Shin NH, et al. Costs of illness and quality of life in patients with systemic lupus erythematosus in South Korea. *Lupus* 2014; 23(9): 949–957.
7. Maida CA, Marcus M, Spolsky VW, Wang Y, Liu H. Socio-behavioral predictors of self-reported oral health-related quality of life. *Qual Life Res* 2013; 22(3): 559–566.
8. Gallop K, Nixon A, Swinburn P, Sterling KL, Naegeli AN, Silk MET. Development of a conceptual model of health-related quality of life for systemic lupus erythematosus from the patient's perspective. *Lupus* 2012; 21(9): 934–943.
9. DeLong LK. Vitamin D status, disease specific and quality of life outcomes in patients with cutaneous lupus. Available at: <http://www.clinicaltrials.gov>. [Accessed 23 January 2018].
10. De Barros BP, De Souza CB, Kirsztajn GM. The structure of the "lived-experience": analysis of reports from women with systemic lupus erythematosus. *J Nurs Educ Pract* 2012; 2(3): 120.
11. Abu-Shakra M, Mader R, Langevitz P, et al. Quality of life in systemic lupus erythematosus: a controlled study. *Learning* 1999; 5: 1–7.
12. Seawell AH, Danoff-Burg S. Body image and sexuality in women with and without systemic lupus erythematosus. *Sex Roles* 2005; 53(11): 865–876.
13. Savitri T. *Aku dan lupus: Lupus and I*. Jakarta: Puspa Swara; 2005.
14. McElhone K, Abbott J, Teh LS. A review of health related quality of life in systemic lupus erythematosus. *Lupus* 2006; 15(10): 633–643.
15. Baker K, Pope J, Fortin P, et al. Work disability in systemic lupus erythematosus is prevalent and associated with socio-demographic and disease related factors. *Lupus* 2009; 18(14): 1281–1288.
16. McElhone K, Abbott J, Gray J, Williams A, Teh LS. Patient perspective of systemic lupus erythematosus in relation to health-related quality of life concepts: a qualitative study. *Lupus* 2010; 19(14): 1640–1647.
17. Jarpa E, Babul M, Calderón J, et al. Common mental disorders and psychological distress in systemic lupus erythematosus are not associated with disease activity. *Lupus* 2011; 20(1): 58–66.
18. Wahyuningsih A, Surjaningrum ER, Psych MA. Kesejahteraan psikologis pada orang dengan lupus (odapus) wanita usia dewasa awal berstatus menikah: psychological

- wellbeing in people with lupus (odapus) in married early adult women. **Jurnal Psikologi Klinis dan Kesehatan Mental** 2013; 2(1).
19. Aberer E. Epidemiologic, socioeconomic and psychosocial aspects in lupus erythematosus. **Lupus** 2010; 19(9): 1118–1124.
 20. Orem DE. *Nursing: concepts of practice*. New York: McGraw-Hill; 1971.
 21. Becker G, Gates RJ, Newsom E. Self-care among chronically ill African Americans: culture, health disparities, and health insurance status. **Am J Public Health** 2004; 94(12): 2066–2073.
 22. Green L, Kreuter M. *Health promotion planning: an educational and environmental approach*. 2nd ed. California: Mayfield Publishing Company; 1991.
 23. Becker H, Stuijbergen A, Oh HS, Hall S. Self-rated abilities for health practices: a health self-efficacy measure. **Health Val J Health Behav Educ Promot** 1993; 17(5): 42–50.
 24. Kearney BY, Fleischer BJ. Development of an instrument to measure exercise of self-care agency. **Res Nurs Health** 1979; 2(1): 25–34.
 25. Jolly M, Pickard AS, Block JA, Kumar RB, Mikolaitis RA, Wilke CT, et al. Disease-specific patient reported outcome tools for systemic lupus erythematosus. **Semin Arthritis Rheum** 2012; 42(1): 56–65.
 28. Alligood MR. *Nursing theorists and their work*. 8th ed. Netherlands: Elsevier Health Sciences; 2014.
 29. Post M. Definitions of quality of life: what has happened and how to move on. **Top Spinal Cord Inj Rehabil** 2014; 20(3): 167–180.
 30. Nuttall A, Isenberg DA. Assessment of disease activity, damage and quality of life in systemic lupus erythematosus: new aspects. **Best Pract Res Clin Rheumatol** 2013; 27(3): 309–318.
 31. Wyrwich KW, Wolinsky FD. Identifying meaningful intra-individual change standards for health-related quality of life measures. **J Eval Clin Pract** 2000; 6(1): 39–49.
 32. Tamayo T, Fischer-Betz R, Beer S, Winkler-Rohlfing B, Schneider M. Factors influencing the health related quality of life in patients with systemic lupus erythematosus: long-term results (2001–2005) of patients in the German Lupus Erythematosus Self-Help Organization (LULA Study). **Lupus** 2010; 19(14): 1606–1613.
 33. Thompson RJ, Mata J, Jaeggi SM, Buschkuehl M, Jonides J, Gotlib IH. Maladaptive coping, adaptive coping, and depressive symptoms: variations across age and depressive state. **Behav Res Ther** 2010; 48(6): 459–466.
 34. Sahebalzamani M, Farahani H, Jamarani MT, Faezi ST, Moradi K, Paragomi P. Effects of a continuous care model on patients' knowledge and health-related quality of life in systemic lupus erythematosus. **Rehabil Nurs** 2016; 42: E9–E18.

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