

SYSTEMIC LUPUS ERYTHEMATOSUS : CORRELATION BETWEEN SENSORY KNOWLEDGE, SELF-EFFICACY, PREVENTIVE ACTION TOWARDS TRIGGER FACTORS, SELF-CARE PRACTICE AND QUALITY OF LIFE

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ABSTRACT

Introduction: Systemic Lupus Erythematosus (lupus) and its complications could lower individual's health-related quality of life (HRQOL). Self-care is highly needed for sustaining self-involvement in lupus management. People with lupus need to have proper sensory knowledge and high self-efficacy for implementing preventive action towards trigger factors and self-care practice. This study aims to explain the correlation between sensory knowledge, self-efficacy, preventive action towards trigger factors, self-care practice and HRQOL in lupus patients. Method: This is a cross-sectional study mixing the model of Self-Care and Precede Proceed. Population was all lupus patients doing regular check up in Rheumatology Unit of Dr. Soetomo Hospital in October-December 2014. Sample size was 36 chosen by total sampling. Independent variables: sensory knowledge, self-efficacy, preventive action towards trigger factors and self-care practice; dependent variable: HRQOL. Instruments: ODAPUS-HEBI and LUPUSPRO. Data analysis: regression test; $\alpha \leq 0.05$. Result: 36 females respondents participated; suffered disease for 0.5 – 12 years.. Age range: 20-44 years old. Mostly were high school graduates, married and actively working. Most respondents have high sensory knowledge and self-efficacy; optimum preventive action and self-care practice, but HRQOL was not optimal. All data were normally distributed. Only sensory knowledge proved to be linear with HRQOL. There was a weak significant correlation identified between sensory knowledge and HRQOL ($r=0.344$, $p=0.040$); while self-efficacy, preventive action and self-care practice proved to have no correlation with HRQOL ($p>\alpha$). Conclusion: Sensory knowledge is correlated with HRQOL in people with lupus. Self-efficacy, preventive action towards trigger factors and self-care practice were proved to have no correlation.

Key words: Systemic Lupus Erythematosus, correlation, knowledge, self-efficacy, preventive action, self-care, HRQOL

BACKGROUND

Lupus is a disease where the immune system which normally fight infection, starts attacking healthy cells in the body or autoimmune phenomenon (DeLong, 2012). In Indonesia people with lupus are often called odapus. Lupus can be a burden and source of disability and also poor HRQOL (Cho *et al.*, 2014). Lupus is a chronic autoimmune disease which signs and symptoms may persist for more than six weeks and often up to several years (Lupus Foundation of America, 2012). However, there are also odapus who can manage the symptoms of lupus so well, so that she looks like a healthy person (quiescent). Increased intensity of exposure to the trigger factors will surely cause lupus symptoms more

often. In anticipation of this, odapus need to have adequate sensory knowledge about lupus and high self-efficacy in order to facilitate preventive action toward trigger factors and self-care practice at home. The goal is odapus can achieve a high HRQOL. The correlation between sensory knowledge, self-efficacy, preventive action towards trigger factors and self-care practice with HRQOL in odapus remains unclear.

Lupus has suffered by at least five million people worldwide. Lupus can affect men and women at any age, but 90% of those diagnosed with lupus are women and lupus prone age is 15-44 years old. 70% of lupus cases is SLE (Systemic Lupus Erythematosus) (S.L.E. Lupus Foundation, 2012). In Indonesia,

the estimated number of people with lupus are about 200-300 thousand people, the trend is increasing every year, the ratio of male and female is 1:6-10 (Yayasan Lupus Indonesia, 2012; Utomo, 2012).

Trigger factors of lupus symptoms such as pregnancy, stress, fatigue, exposure to sunlight and chemical substances (Cooper, *et al.*, 2010). Frequent symptoms reported by odapus are fever, skin rash (photosensitive), joint swelling/ pain, weakness/fatigue, and kidney disorders (NIAMS, 2012). Renal, neurological and haematological complications are the most often found in odapus (Kannangara, *et al.*, 2008). As a result, lupus proven to reduce odapus HRQOL significantly, such as depression by 8-44% (Jarpa, *et al.*, 2011), infertility (Baker, *et al.*, 2009), limitations in daily activity especially when joint pain relapse (McElhone, *et al.*, 2010), environment withdrawal (Seawell & Danoff-Burg, 2005) discrimination, difficulties in finding jobs, changes in interpersonal relationship (de Barros, *et al.*, 2012), obstacles in social roles (Wahyuningsih, *et al.*, 2013).

Odapus need to have a high sensitivity to what was going and aware of the impact in many areas of life. Lupus symptoms that arise from time to time have the potential to interfere with daily activities and cause many other problems. In order to achieve optimal health status and high HRQOL odapus must be proactive in managing lupus. One way is to adopt healthy behaviors and manage lupus independently through preventive action towards trigger factors and self-care practice. This study aimed to analyze the correlation between sensory knowledge, self-efficacy, preventive action towards trigger factors and self-care practice with HRQOL in odapus.

METHODOLOGY

This is a cross-sectional study mixing the model of Self-Care (Orem, 1971) and Precede Proceed (Green & Kreuter, 1991). Population was all lupus patients doing regular check up in a Rheumatology Unit of one big public hospital in East Java, by period of October-December, 2014. Sample was determined by inclusion criteria: pure lupus (code: M32), adult women (19-44 years old), disease duration at least 6 months, at least high school graduated, monthly income at least minimum wage. Exclusion criteria: lupus with complication (code: M32.0, M32.1, M32.9),

experiencing mental disorder and/or psychological disturbance (depression, anxiety, burned out), resigned and/or hospitalized by the time of study, refusing home visit, rejecting informed consent, working as health care professional. Sample size was 36 chosen by total sampling.

Independent variables: sensory knowledge, self-efficacy, preventive action towards trigger factors and self-care practice; dependent variable: HRQOL. Researcher developed her own instrument for measuring all independent variables, namely ODAPUS-HEBI which consists of four parts. Instrument testing in 18 odapus proved that ODAPUS-HEBI was valid and reliable by result: 1) sensory knowledge: $r= 0.477-0.774$; $\alpha=0.519$; 2) self-efficacy: $r= 0.503-0.903$; $\alpha=0.927$ (high reliability); 3) preventive action towards trigger factors: $r=0.547-0.908$; $\alpha=0.945$ (high reliability); 4) self-care practice: $r=0.470-0.885$; $\alpha=0.949$ (high reliability). Dependent variable was measured by LUPUS-PRO (Jolly, *et al.* 2012). This instrument assesses quality of life specifically in odapus, consist of 42 items. Instrument testing in 25 odapus proved that LUPUS-PRO WAS valid and reliable ($r=0.408-0.764$ and $\alpha=0.803$; high reliability). Data analysis was started with normality and linearity test then regression test; $\alpha \leq 0.05$. Ethical concern: informed consent, anonymity and confidentiality.

RESULT

36 respondents participated in this study. Mostly late adulthood (44.4%) who was married (77.8%) and lived with spouse (77.8%). Respondents were mostly high school graduated (83.3%) working as entrepreneurs (33.3%) and private employees (33.3%) with independent income of more than Rp. 1.5 to 2 million per-month (33.3%). Disease duration was mostly 1-2 years (33.3%). Arthritis was reported as the most frequent lupus symptom (61.1%) and fatigue was mostly reported as trigger factor (66.7%).

All respondents was categorized as stable according to indicators in Ferenkeh-Koroma (2012) and mild lupus according to PRI indicators (2011). They were rarely experienced lupus flare, 16.7% with skin rash and 5.6% with chest pain in deep breathing. Respondents usually meet health personnel during her routine control and other respondents have a personal physician. Methylprednisolone

and Cyclosporine were identified as the most frequent to be consumed. Dias & Isenberg (2014) found in mild lupus, the joint is the primary organ affected. Gordon (2013) argues that fatigue is the originator of the most common lupus symptoms. These matched to the study result.

All data were normally distributed ($p=0.674$). Only sensory knowledge found to be linear with HRQOL ($p=0.299$), then tested by simple linear regression; while the other variables were tested by nonlinear regression. Sensory knowledge proved to be correlated with HRQOL in odapus ($r = 0.344$ and $p = 0.040$); it affected HRQOL by 11.8%, while the remaining 88.2% is influenced by unidentified factors. Self-efficacy, preventive action and self-care practice were proved to have no correlation with HRQOL in odapus ($p=0.212$; $p=0.130$; $p=0.053$ respectively).

DISCUSSION

1. Sensory Knowledge and HRQOL

Sensory knowledge was identified as the only independent variable that has a linear correlation with HRQOL in odapus. Study results showed that only 66.7% from 72.2% respondents who possess high knowledge and perform self-care optimally at home. The resulting correlation coefficient is quite low ($r=0.344$). Knowledge has been identified specifically in the domain of health behaviors specifically in predisposing factors affecting individual HRQOL indirectly (Green & Kreuter 1991). This is consistent with study result showing that knowledge affecting HRQOL in odapus by 11.8% only; a value that is less representative.

Thumboo & Strand (2007) concluded that knowledge of lupus is one of the factors proved to be associated with HRQOL in odapus. Other factors are age, disease duration, educational status, disease activity, organ damage, self-efficacy, social support / psychosocial factors, the use of corticosteroid/cytotoxic agents and specific manifestations such as kidney failure or fibromyalgia.

Mancuso, *et al.* (2010) in the study of asthma stated that the cognitive variables such as knowledge, attitude, and self-efficacy can affect asthmatic client ability to be an effective self-manager. Being able to be an effective self-manager is very important in the process of managing chronic disease at home.

Most respondents proved to have high knowledge about lupus. This could be used as a basis for building commitment in lupus management at home. The positive correlation between sensory knowledge and HRQOL proved that knowledge about lupus as a chronic disease has a little more influence on HRQOL through subjective perception. Knowledge can affect the living standard set individually, in which this variable was not measured in this study because of instrument limitation (LUPUS-PRO).

2. Self-efficacy and HRQOL

This study result showed that self-efficacy is not correlated with HRQOL in odapus. Self-efficacy was proved to be nonlinear with HRQOL; 61.1% respondents who have high self-efficacy possess non-optimal HRQOL. This has led to statistically insignificant correlation between self-efficacy and HRQOL. Self-efficacy potentially associated with the specified individual standard of life which is closely related to general quality of life. This living standard was not measured because of instrument limitation. The feelings can control the disease is able to give satisfaction to odapus and potentially could improve the perceived HRQOL significantly.

3. Preventive Action towards Trigger Factors and HRQOL

The study result indicated that preventive action towards trigger factors uncorrelated to HRQOL in odapus. Preventive action towards trigger factors proved to be nonlinear with HRQOL; 77.8% respondents who took optimal preventive action possess non-optimal HRQOL. This has led to statistically insignificant correlation between preventive action and HRQOL. No correlation identified potentially due to high living standard set by respondent

In this study, the identified trigger factor of lupus includes physical stress (mostly), emotional stress, sunlight, irregular meal time, lack of sleep and hormonal changes. Respondents find it difficult to keep her body from fatigue due to work or carry out her role as a mother who must manage the household chores. Regarding physical stress, respondents expressed some difficulties in preventing exposure due to high role demands, because of self-limitation, limited resources and lack of family support. Other trigger factors which considered hard to prevent: emotional stress

(depend on coping mechanisms), sunlight (depend on activity), etc.

4. Self-care Practice and HRQOL

Study results showed that self-care practice uncorrelated to HRQOL in odapus. Self-care practice proved to be nonlinear with HRQOL; 72.2% respondents perform optimal self-care practice but possess non-optimal HRQOL. This has led to statistically insignificant correlation between self-care practice and HRQOL. Self-care practice can be promoted as an alternative for managing lupus in community context though, mainly because of the high involvement of odapus in disease management process.

Study limitations: 1) varied demographic characteristic; 2) retrospective survey allows emerging doubts; 3) cross-sectional design also has drawback/bias; 4) internal consistency and content validity of ODAPUS-HEBI should be tested in larger clinical trial; and 5) there is no instruments measuring HRQOL specifically in lupus patients which contains items examined the individual living standards.

Psychological status, level of independence, social relationship, social determinants (employment, housing, education), culture, shared values and spirituality should be investigated also in conjunction with sensory knowledge and self-efficacy because all of these variables can affect individual overall HRQOL. Motivation and self-awareness should be examined also in conjunction with self-efficacy for these three variables potentially affecting self-care practice in odapus, especially in community context.

CONCLUSION

Sensory knowledge correlated with HRQOL in odapus and affects it by 11.8%. Self-efficacy, preventive action towards trigger factors and self-care practice have no correlation with HRQOL in odapus.

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