

Happiness in Suffering of Systemic Lupus Erythematosus: Does It Make Sense?

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Abstract: Systemic Lupus Erythematosus (SLE) is an autoimmune disease in which the immune system attacks connective tissue in the own body systemically. SLE cannot currently be cured but can be controlled with the use of long term medication. The aim of this research was to explore and explain how people make sense living happily with potentially life span and life-threatening health conditions of SLE. The research design were mix of descriptive quantitative and qualitative study using semi-structured interviews that were conducted from 14 SLE's participants who own high subjective wellbeing. Constructivist's grounded of health psychology theories and religious coping approach were adopted to analyse interview's data. This research demonstrated that even living with such SLE's suffers, all subjects achieved well-being. Mechanism of coping strategies that often used were turning to religion, seeking social support for emotional reasons, and focusing on and venting of emotion, and also acceptance. The result showed that this condition undergoes by gratitude feeling. Gratitude for family owned, the presence of others who have helped, and grateful for positive events in their life have made subjects adapted and reconciled with the disease. People suffering from SLE should acquire a grateful heart and a tongue of remembrance.

1 INTRODUCTION

Systemic Lupus Erythematosus (SLE) is an autoimmune disease in chronic (chronic) connective tissue, systemic, and the cause is unknown. Autoimmune means that the immune system attacks the body's own tissues. In SLE, the immune system mainly attacks the cell nucleus, the body forms various types of antibodies, including antibodies against nuclear antigens (ANAs), causing damage to various organs. chronic metabolic disease (Manger et al., 2002; Petri et al., 2012).

This disease can affect various organ systems with various clinical manifestations and prognosis. Symptoms Lupus often is not specific, so the sufferers often change doctors for different diagnoses. Patients experience disruptions that affect the quality of life and life expectancy is very low (Cervera et al., 2003; Yurkovich et al., 2014).

The current management of lupus consists of pharmacology and non-pharmacology. Pharmacologic treatment is performed with non-steroidal anti-inflammatory drugs, corticosteroids, glucocorticoids, hydroxychloroquin (antimalarial),

and immunosuppressant drugs. Non pharmacology is done by administering sunscreen creams, protective clothing from sun exposure, education, social support, and physiotherapy. After a few years the individual will experience intermittent recurrence of the disease and repair, although not total, organ damage, comorbidity, chronic inflammation (Pego-Reigosa et al., 2013; Yap and Chan, 2015). Clinical manifestations of SLE vary widely in various organs including the heart, skin, gastrointestinal, hematologic, neuropsychiatric, blood vessels, lungs, kidneys, bones and joints. In advanced stage, Lupus can cause bone death called osteonecrosis. This can cause serious disability (Greenberg and Michalska, 1999).

Although the prognosis of life expectancy of lupus patients has increased over the past few decades, the side effects of corticosteroid treatment and immunosuppressant drugs (suppressing the immune system) are still a problem. Side effects arising from long-term corticosteroid administration may affect various organs such as osteoporosis, osteonecrosis, metabolic disorders, infections, weight gain, mood disorders, and hyperlipidemia (Ginzler et al., 2014)

In addition to the long-term effects of immunosuppressant drug use, lupus affects the psychiatric disorders of the sufferer. Based on the study, up to 65% of lupus patients experience neuropsychiatric symptoms one time in the course of the illness (Bosma et al., 2002). Depression disorder is a psychic disorder that is often encountered by SLE patients (Chiewthanakul et al., 2012; S. et al., 2015; Stock et al., 2013). One of the lupus disease activities is characterized by psychological disorders.

To provide support to SLE, an organization called Syamsi Dhuha Foundation (SDF) was established in Bandung in October 2003 by several SLE observers. Activities include mentoring for patients and families, public education, training, advocacy to government, research, support and cooperation of fellow support groups at national and international levels.

In the preliminary study, researchers found SLE patients who joined the SDF had life satisfaction and were able to enjoy happiness even though they knew that their illness had no cure and threatened their lives and daily lives. They show good subjective well-being (SWB).

Subjective well-being is a subjective evaluation of a person's life including concepts such as life satisfaction, pleasant emotions, fulfillment, satisfaction of areas such as marriage and work, low levels of unpleasant emotions. Diener defines SWB as an individual's personal judgment of his life, not based on expert judgment, including on satisfaction (both in general and on specific aspects), pleasant affects, and low levels of unpleasant affection. The subjective well-being is the level at which one judges the quality of life as expected and feels pleasant emotions. Subjective well-being shows life satisfaction and evaluation of important life domains such as work, health, relationships, and emotions. In other words, happiness is the name given to positive thoughts and feelings toward one's life (Diener et al., 2017; Huppert and So, 2013; Stone, 2012). In this study subjective well-being is described as a subjective evaluation of a person about his life, which includes a frequent and intense positive affective state, relative no anxiety and depression, and global life satisfaction.

This study aims to describe the characteristics of stress coping strategies used by the subject and explores how coping stress can produce good SWB in SLE patients who are members of SDF.

2 METHODS

This research uses descriptive quantitative methods of stress coping strategies used by respondents and deepened with qualitative exploratory to be able to explain how coping strategy used influences high SWB in SLE patients.

Participants of this study were 14 people with SLE with criteria of having high SWB score, active following SDF organization, SWB diagnosed more than 6 months, not undergoing hospitalization, and signing informed consent.

This research data was collected through close-ended question for demographic characteristics and coping strategy characteristics. To explore more deeply the cause of selection of coping strategies, open-ended questions were used.

This research uses semi-structured interview technique using guide question about dimension of SWB that is cognitive and affective dimension. The cognitive dimension means understanding a person about his life, a feeling of sufficiency, peace and contentment, and the gap between desire and need with accomplishment and fulfillment. Questions of the SWB cognitive dimension include subject areas of subject satisfaction in various areas of life such as areas related to self, family, peer group, health, religion, finance, work, and leisure.

To get an overview of the affective dimensions of SWB, respondents were interviewed about moods, pleasant and unpleasant emotions, reactions to others, their frequency and intensity. The positive effects of SWB include the symptoms of enthusiasm, joy, and the happiness of life. Semi-structured interviews were also conducted on the dimensions of stress coping strategies referring to The Coping Orientation to Problems Experienced (COPE) consisting of 15 questions (Rinaldi et al., 2006).

The characteristic of coping stress was observed descriptively. The data collected through the open-ended questionnaire is processed (coded and categorized) according to the respondents' answers collected. The results of in-depth interviews on the respondents are understood and explored in depth to what is meant and happened in the field. Intense understanding and interpretation is done, thus the work of collecting data is directly followed by recording, editing, classifying, reducing, and presenting.

3 RESULTS AND DISCUSSION

3.1 Results

3.1.1 Respondents' Characteristics

Respondents with SLE were predominantly female (64%). Of all female respondents, 67% had SLE for over 3 years and the remaining 1-3 years. Male respondents 20% had SLE less than 1 year, 80% for 1-3 years, and 20% for more than 3 years.

3.1.2 Characteristics of Coping Stress Strategies

Table 1 describes the characteristics of coping stress strategies of SLE patients in SDF.

Table 1: A Description of Coping Stress Strategies.

Coping Strategies	Number of SLE Respondents	Percent (%)
Turning to Religion	13	92.9
Active Coping	8	57.1
Planning	7	50.0
Suppression of Competing Activities	7	50.0
Straint Coping	9	64.3
Acceptance	11	78.6
Positive Reinterpretation and Growth	10	71.4
Seeking Social Support for Instrumental Reasons	14	100.0
Seeking Social Support For Emotional Reasons	12	85.7
Focusing on and venting of emotion	12	85.7
Humor	8	57.1
Denial	4	28.6
Behavioral disengagement	6	42.9
Mental disengagement	6	42.9
Alcohol and drug disengagement	0	0.0

From table 1, it is seen that coping strategies are widely used, namely turning to religion, active coping, straint coping, acceptance, positive reinterpretation and growth, social support, focusing on and venting of emotion. None of them vent the problem with consuming alcohol. All respondents use the social support strategy for instrumental reasons.

3.1.3 Description of Coping Factors

Based on the results of in-depth interviews to respondents, it turns out that all coping strategies are widely used based on gratitude. Gratefulness for family owned, the presence of others who have helped, and being grateful for positive events in their lives has made the subjects adapt and reconcile with the disease.

3.2 Discussion

All respondents have high SWB, they feel that everything is going well, experiencing life satisfaction, often feeling joy, and rarely feel unpleasant emotions such as sadness or anger. Although they have the possibility of SLE disease throughout their age, they can still feel good things. The twists and turns of life and the challenges facing SLE disease are part of the reason for respondents' satisfaction. Based on the characteristics of the subject, 64% were female. Although women often use emotions rather than ratios, in fact SLE sufferers use the balance of reason and liver in dealing with his body condition in a positive manner.

The most frequently used coping strategies relate to religion (turning to religion, active coping, straint coping, acceptance), emotional control (positive reinterpretation and growth, focusing on and venting of emotions), and the environment (seeking social support). None of the respondents use alcohol as a coping strategy because they know that alcohol will aggravate their illness. After an interview to explore further, the researchers found that all was based on a sense of ego. Respect on respondents is mainly in the form of gratitude for the existence of the family, the presence of others who have helped, and feel grateful for positive events in life

Gratitude can increase the SWB both directly and with a self-esteem mediator (Lin, 2015). Positive activities and the people involved in the activities affect the success of positive activities when people do the activity. Participation in positive activities supported by the SDF enhances their confidence.

Gratitude motivates people to express their sensitivity and concern for others and be compassionate to third parties who are not involved (DeWall et al., 2012). Respondents felt the togetherness and support among those who joined the SDF foundation. If there are respondents who are sad, then other respondents tried to comfort him and give him joy. This gives rise to positive emotions. Positive emotions extend people's ability to weigh

various behavioral choices, and increase endurance while releasing negative emotional effects. Gratitude has an aspect of taking wisdom / benefit over not meeting fulfillment of expectations. Through this mechanism, gratitude has the advantage of leading to social ties, thus facilitating a unique path to prosperity (Emmons and Stern, 2013).

According to Hamka, a philosopher, scholar and poet, Islam teaches humankind four ways to the happiness of *I'tikad* (self-motivated motivation), belief (strong belief in something he is doing), faith (proven by oral and deeds), and religion/*ad-diin*. The last stage is *ad-diin*, which is total surrender to God, perfect self-servitude. Those who run *ad-diin* well do not feel sad prolonged because they are absolutely sure of the path God has chosen for them (Wibowo, 2013). Similarly, respondents with SLE, they believe that God does not provide trials beyond the limits of his ability. This is also seen in their very high acceptance level. Though SLE obstructs their daily activities, yet in every condition they always think of God's blessings. They perceive the condition of SLE suffered is the way God loves them so that they always remember God and do good. This makes the subject adapt and reconcile with SLE.

4 CONCLUSIONS

SLE causes a severe manifestation of the sufferer. Until now there is no treatment that can cure SLE. This condition is exacerbated by the side effects of steroid drugs and immunosuppressants that have been used to relieve attacks. On the basis of gratitude, people with SLE who join the SDF organization choose coping strategies of religion, emotional control, and environmental support so that people with SLE can feel the ultimate happiness in the long-suffering SLE. SLE patients are always grateful in the heart, spoken, and applied in everyday life in order to get a good subjective well-being.

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