

Experiences of Post-Treatment Patients with Systemic Lupus in Indonesia

Mohamad Judha^{1*}, Elizabeth C. Baua², Josephine D. Lorica²

¹School of Nursing, Universitas Respati Yogyakarta 55281, Indonesia

²School of Nursing and Allied Health Sciences, St. Paul University Cagayan 3500, Philippines

*Corresponding Author's Email: judha.fikes@respati.ac.id

ABSTRACT

Background: Indonesia is currently associated with lupus disease which is increasing in number. Most of the people with lupus were of the gender women (90% of women). Most women with reproductive status as inactive, and most of the patient want to have basic needs fulfillment to overcome the disorders. As a result of the changes that arise and because of the long healing process and the disruption basic needs can cause prolonged sadness for the sufferer. **Aims:** The study will help to develop the concept of nursing theory through research on participants suffering from Lupus. **Methods:** This research is qualitative research to explore the experience of participants looking for the meaning of life. There were nine study participants with purposive samples. **Results:** From this study nine themes was obtained, among others: (1) Responses experienced to Lupus disease, (2) Types of support obtained from the environment 3) Discrimination experienced (4) Efforts made to achieve recovery, (5) Ability to recognize signs and symptoms, (6) Changes in basic needs, and Effects of Lupus on activities (7) The effect of using drugs (8) Health services and resources(9) Changes in values, and beliefs. **Conclusion:** The results of the study contained the response of patients in dealing with Lupus disease related to physical activity, psychological and environmental changes as well as changes in the value, beliefs, and beliefs of Lupus sufferers. **Recommendation:** The results suggest that healthcare workers perform comprehensive care. Education personnel should also provide training to conduct holistic nursing care to learners and for other researchers to increase the gender variation of participants in order to obtain a variety of themes.

Keywords: *Lupus Patient; Experiences Post-Treatment; Nursing*

INTRODUCTION

Lupus disease is a condition where the immune system attacks own tissues and organs (autoimmune disease). Inflammation caused by lupus can affect many different body systems causing the body's cells to experience inflammation and damage. When lupus attacks a person, the body produces excessive amounts of antibodies.

In such cases 80% of the lupus patients receive long-term steroid therapy, then it will have an impact on neutrophil function (white blood cells). Steroids can help to reduce pain and inflammation. They work by decreasing the activity of overactive white blood cells. This prevents them from causing inflammation that leads to lupus symptoms (Wallace, 2007).

In Indonesia, lupus disease tends to increase in

number, in some hospitals in DKI Jakarta, based on data from the Lupus Indonesia Foundation, people with lupus consist of 90% of women. The disease is more common in women, particularly those of child-bearing age. This increased incidence may be attributed to hormones, namely estrogen. Current research show is aimed towards improved quality of life and increased survival mainly among women (Judha, & DI, 2015; Porter, 2000).

Some of the problems caused by Lupus disease, are in the form of hypertension, edema, nephrotic syndrome or even progressive renal failure disorders, or other physical changes that will affect the psychological condition. Thus, weakening the mental state that will further decrease the quality of life (Shirato, 2005).

As a result of the changes that arise and because of the long healing process and the disruption of basic

Received 12 August 2021; Received in revised form 10 October 2021; Accepted 17 January 2022

needs. This can cause prolonged sadness for the sufferer called chronic sadness (Ross, 2002). From the results of research in Indonesia, especially Jakarta, the number of people who do not know the term lupus is 56.4%, the risk that can increase lupus disease, in general, many do not know up to deal with the disease (79.2%), and how to behave (Komailing *et al.*, 2008).

According to Breitkopf *et al.*, (2020), lupus causes various damage to the organ system and requires long treatment so that it sometimes elicits a psychological response and requires support. This is supported by Judha, & DI (2015) that reported lupus patients need the support of those around the patient to stay afloat with the disease.

METHODOLOGY

The design of this study uses a phenomenological approach. Researchers try to illustrate qualitatively about what happens among Lupus sufferers by focusing questions on physical, psychological, social, and spiritual problems. In this study, researchers use the snowball technique, saturation is achieved till data is obtained.

RESULTS

In this study, nine participants were found, all of whom were women in a productive age range. All participants lived in Indonesia in Jakarta, Yogyakarta, Surakarta, and Palembang. The characteristics of their work consist of one public health nurse, one student, one student, and two merchant jobs. All participants were Muslim, having experienced lupus for more than six months and a minimum of four years.

This study obtained nine themes, among others: (1) Responses experienced in dealing with Lupus disease, (2) Types of support obtained to deal with lupus, (3) Discrimination experienced, (4) Efforts made by Lupus patients to recovery, (5) Ability to recognize physical changes, (6) Changes in basic needs, and Effects of Lupus on activities (7) Effect of using therapy (8) Health services and resources for Lupus participants (9) Changes in values, beliefs and expectations of Lupus patients.

DISCUSSION

Some ways to meet sociocultural needs are to create therapeutic relationships with clients, respect clients' rights regardless of social or cultural status, encourage clients to express their feelings, and facilitate teamwork that addresses the possibility of conflict between the

healing process and the client's culture (Kolcaba, Tilton, & Drouin, 2006).

The whole concept is related to clients and families. Comfort theory consists of three types, namely (1) relief: recipients condition that requires specific and immediate treatment, (2) ease: to calm the condition for the satisfaction of the client that occurs due to loss of physical discomfort felt in all needs, (3) transcendence: the state in which an individual is able to overcome the problem of discomfort that occurs.

According to Dimarco, & Kolcaba, (2005) comfort is the basic needs of an individual that is holistic, including physical comfort, psychospiritual, sociocultural, environmental. Physical comfort is associated with the mechanism of body sensation and homeostasis, including a decrease in the body's ability to respond to invasive disease or procedure.

Experience in Dealing with Lupus Disease

The results of the study obtained various reactions about the reality felt by the participants suffering from Lupus Disease. There were five categories of responses felt by participants, the first category of feelings of disavowing expressed by participant one, two, and three. The second category is anger, this expression of feeling is an expression of dissatisfaction regarding the present status of the participants, this was felt by participants four and five. The third category is the feeling of negotiating for what is experienced. There is also a response in the form of depression and participants accepting their present condition.

According to Bratawijaya, (2002), age has a major influence on the emotions, social function, mental health, physical, and general health of Lupus patients. In this study, the age category of participants was in the range of 17 to 40 years, this means that all participants in this study are in the productive age range so that it will affect the response related to social, economic, biological, psychological and spiritual aspects of the participants.

This is in accordance with the results of research from Avendano, de Coulon, Nafilyan, (2017) which stated that age becomes an important part of a person in dealing with problems due to personal experience gained in addition to education. According to Meller, Homey, & Ruzicka (2005), there is a close relationship between coping and the response to lupus depending on the person's education, type of work, as well as socioeconomic as well as health insurance owned. The

higher the level, the better the response and coping.

Types of Support Obtained

The participants showed great interest in the problem of Lupus disease suffered by them. According to Bastaman (1996), the support system by people around the participants will influence positive feelings by validating existing beliefs, encouraging them to provide information and suggestions, and with material assistance.

According to Peterson & Bredow, (2009) the completion of a nursing phenomenon can be achieved by the approach of human concept, health, nursing, and the environment. In this case, there is an inseparable relationship between philosophy, paradigm with the conceptual model or nursing theory (Dickson & Wright, 2012).

Feeling Discrimination

Some participants felt the stigma in society, even one participant felt discrimination from health workers in providing services. On the other hand, some participants who felt the delamination because it was a common belief that said that people with Lupus disease will not be cured.

The existence of discrimination and stigma caused psychological disruption of participants and there was a feeling of discomfort among the participants, then if this does not get good intervention support it will lead to new stressors for participants. Stigma in society caused insecurity and discomfort for participants, if this continued, participants will not feel free in expressing their feelings and consequently this will pose distress and curiosity of Lupus disease and result in slow recovery.

Efforts made by Lupus Patients to Recover

In this study, various methods are suggested so that participants could recover or avoid the recurrence of Lupus. The purpose and objectives of the participants is to make an effort to achieve recovery. The activities carried out were based on consciousness to be healthy by manipulating themselves and their surrounding environment.

Still according to Sriyuktasuth (2002) education plays an important role in improving lifestyle against diseases suffered and become healthy. This means that a high level of education increases the desires and chances of living healthy lifestyle and the chances to avoid the disease becomes higher, in the sense that with

higher education improves one's rational ability.

The participants were aware of the disease suffered, seeking or trying to obtain information from health services, and see the problem of lupus as something that must be addressed by adapting to healthy lifestyle.

Ability to Recognize Physical Diseases

Some signs and symptoms can appear in Lupus disease, but the kinds of signs and symptoms vary. Lupus sufferers can show signs such as spots on the face to joint abnormalities, while the symptoms perceived are subjective depending on the organ or part affected.

The signs and symptoms of Lupus from what some participants expressed differed, but broadly speaking it can be seen that in essence there are only two things, namely, the so-called signs, and what the symptoms mean, in addition to signs and symptoms among all women also presented changes in the reproductive and sexual systems considering that the participants in this study were in the reproductive age.

Due to health conditions that were considered weak and harmful for the participants, there was a sexual pattern. This was stated by the second participant, as stated by participants that there was a change in sexual patterns regarding their sex life before illness but because of the sick condition there was a change in patterns and methods.

Changes in basic Needs and the Effect of Lupus on Activity

In this study, there was a change in nutrition and diet of the patient intended to reduce the risk of recurrence. Some of the agents that cause recurrence of Lupus are hydralazine and dyes mainly affect the skin (Acne Blemish Control, 2010). Therefore, there are types of food that can ward off free radicals such as foods containing vitamins A and E that serve as an antidote to free radicals.

Lupus disorders occur in the reproductive and sexual systems during the initiation lupus disease, although this vary with very individual. People tend to be afraid to have sexual activity when they suffer from Lupus. The focus of the sufferer's orientation is only on herself; the sufferer feels it is impossible to have sexual intercourse with her partner.

According to Moghadam *et al.*,(2019), there are potential problems that occur in people with Lupus related to sexual problems, including lack of confidence and impaired body image. Therefore, it was advised to

talk to the husband and consider that (1) the sex activity starts from the brain instead of the bed only, begins to talk about what can be done. (2) allow couples to know their limitations, must not be brave, and speculate on what can be done. Sexual activity is also what can be done and felt. (3) teach couples to learn to understand, to bring about changes in couples with Lupus.

Effect of Using Therapy

Some participants expressed boredom in taking medication every day, because it is chronic, and the medication is for every day for a long period of time. Due to this boredom in people with Lupus, they will also feel isolated from the surroundings because the disease requires taking the medication regularly.

The desire to continue therapy in the participants depends on the motivation that exists from their family members. According to Rouse (2004) the activities carried out in everyday life are not sufficient because they are motivated to meet the five basic needs of the Maslow hierarchy, but other motivations are needed based on emotions and beliefs a person's abilities, and goals from the surrounding environment.

According to Krinsky, Murillo, & Johnson, (2014), it is necessary to explain everything about the drugs, so that participants realize there are abnormalities or disorders caused by drug's side effects and learn to actively achieve maximum treatment.

Health Services and Resources for Lupus Participants

Some participants said that they obtained information from the internet, books, and people around them, including families and doctors. Various sources to obtain information in order to overcome Lupus disease were presented by some participants. Others obtained from reading, internet, doctor's instructions, instructions from people closest to them, includes people closest to her like family and husband.

Health care is a series of actions taken by professionals whose purpose is to prevent, diagnose, treat and prevent complications of certain health problems (Wilson & Kolcaba, 2004). The government in conducting health efforts is divided into four aspects, namely preventive, promotional, curative, and rehabilitative.

According to Krinsky, Murillo, & Johnson,(2014) Health care received in hospital settings is more focused on curative services, while preventive and promotional services is less prevalent. Based on the existing reality,

and the expectations of lupus sufferers the reality is that the health services in hospitals are not integrated and systematic.

According to Ross (2002) patients with chronic illness and with needs for professional treatment from health workers or other professionals as a way to suppress stress because stress can make the disease more difficult. The delivery of this information is actually the duty of the nursing service. In the theory of caring behavior, a nurse provides both verbal and nonverbal care. Verbal behavior includes providing information, responding in words to patient complaints, briefing clients before and after taking action (Sitoru, 2006).

The purpose of nursing is to respond to the client's behavior in meeting the client's needs immediately, interacting with the client as quickly as possible by identifying the client's behavior, with rapid nursing actions performed (Dochterman, & Bulechek, 2008).

Changes in Values, Beliefs and Expectations of Lupus Patients

Some participants said that their condition was natural, others said that what happened made her more submissive and peaceful. The participants considered it as something ordinary which was associated with the level of education.

According to Jones (2003), a high level of formal education will reduce the impact of depression. The fulfillment of awareness is achieved with knowledge of the disease and its meaning. The lack of education makes the patient unaware of the disease that occurs from the events of his illness.

In Burkhardt's (1993) spirituality covers several aspects including (1) Relating to something unknown or uncertain in life, (2) Discovering the meaning, and purpose of life, (3) Realizing the ability to use the resources and forces that exist within (4) And have a feeling of attachment to one's own and also to God.

According to the concept of nursing, spiritual meaning still has to do with words such as hope, sense, harmony, and belief (March & McCormack, 2009). Some nurses found the spiritual aspect of one's relationship with one's self, as well as others and with God. According to Reed (1992), spirituality includes interpersonal relationship between one's self and interpersonal relationship between others and the environment, as well as transpersonal. According to Judha (2020), spirituality is defined as the essence of man entering and also influencing the life that is

manifested in the form of thought and behavior as well as in relation to herself, and others.

Spiritual Concepts in Nursing – according to Dickson, & Wright, (2012), Nurses view clients as biological, psycho-sociocultural, and spiritual beings who respond uniquely to health changes or in conditions or in crisis circumstances. Nurses seek to help facilitate the spiritual needs of the Lupus patient, meeting the spiritual needs of clients, by facilitating the fulfillment of the spiritual needs of such clients, though nurses and clients have different spiritual or religious beliefs.

CONCLUSION

Thus the client's recovery process will be faster so that it can lower the cost of care and the length of the of treatment, increased security of the client during

treatment, increased economic stability, and many other public interests. This can be facilitated by the health workers specially the nurses by following the above nine themes. The great benefits derived from the implications of this comfort theory will also help Hospitals make policies to develop a center of study and research based on this concept so that more interventions based on evidence can be provided to meet the client's holistic need for comfort.

Conflict of Interest

The authors declared no conflicts of interest.

ACKNOWLEDGEMENT

The authors are thankful to the Universitas Respati Yogyakarta for funding this project.

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