

INTERNATIONAL SEMINAR

Global Context and Indigenous Perspective on Health Issues

Salatiga, September 21-23, 2011



Hosted by
Faculty of Health Sciences, Satya Wacana Christian University
Jl. Kartini No. 11A, Salatiga, Indonesia



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Symposium Schedule

Symposium 1		Thursday, September 22, 2011	13.45	15.45
Health, illness, wellness on global and indigenous context/ local knowledge				
Name		Title	Room : G505	
S1.1	1. Teri Setiawan	Case Study Concerning Resilience Dynamics On Early Adult Women That Has Been Infected HIV/ AIDS From Their Husband In Clinic X Bandung		
S1.2	2. Robert Douglass Huntchinson	Indigenous consideration in western (European) bioethics		
S1.3	3. Vida Handayani dan Ira Adelina	Psychological well-being of HIV positive patients (age 20-34 years) in bandung		
Symposium 2		Thursday, September 22, 2011	13.45	15.45
Progress of technology , education system and government policy on health issues				
Name		Title	Room : G503	
S2.1	1. Dr. Pamela Kohlbry, RN, Ph.D, CNL	Developing Global partnership in nursing education in the united states and Indonesia : exploring quality and safety education for nursing		
S2.2	2. Fransiska Maria Susila Sumartiningasih	Building Character For Nursing Students Through Value-Based Education		
S2.3	3. Sri Yulianto J.P dan Kristoko Dwi Hartomo, M.Kom	Modeling Risk Area DHF Incidence Based Indicators Of Sociodemographic Using GI* Statistic In Surakarta		

Symposium 4		Friday, September 23, 2011	12.30	14.30
Health, illness, wellness on global and indigenous context/ local knowledge				
Name		Title	Room : G505	
S4.1	1. Ira Adelina & Vida Handayani	The Influence Of Resilience In Optimizing Quality Of Life Of Indonesian People with Lupus		
S4.2	2. Cakrangadinata Robert O. Rajaguguk Aris Budiutomo	Application Of Cognitive Behavior Therapy (CBT) In Reducing Pain Intensity Of Chronic Low Back Pain (case studies of chronic low back pain patients in Bandung)		
S4.3	3. Rizki Yuliani Sianiwati Sunarto Hendy Ginting	Type D Personality Among CHD Patients : is it exist in Indonesia?		
S4.4	4. Ns. Wulaningsih, S.Kep. and Ventry N. Wernussa	Safe sleeping for babies to reducing the risk of sudden infant death syndrome		

THE INFLUENCE OF RESILIENCE IN OPTIMALIZING QUALITY OF LIFE OF INDONESIAN PEOPLE WITH LUPUS

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Introduction

Ten years ago many people did not know about Lupus as a disease because until now this disease is not yet well socialized by government and non-governmental institutions. By the presence of Yayasan Lupus Indonesia (YLI), public awareness about Lupus increased. Many people consider Lupus as a rare disease and have few patients, but in fact, there is quite a lot of patients with this disease and is increasing. Before the existence of YLI, mortality rate due to Lupus is estimated 100 people every year. If they had a proper treatment, death from Lupus can be suppressed. The evidence after the socialization of Lupus started from 2007, mortality rate can be reduced to 50% .¹

In medical terms, Lupus is known as Systemic Lupus Erythematosus (SLE), a chronic autoimmune disease that causes inflammation and can affect various organs, including skin, joints and internal organs. On every patient, the inflammation would infect different tissues and organs. Human antibodies protect the body's use of viruses, germs, bacteria. In Lupus patients, production of antibodies becomes excessive. These antibodies are no longer serves to attack the virus, germs, or bacteria in the body, but

rather to attack its own cells and tissues. Such antibodies are called auto antibodies. It reacts with antigens to form immune complexes. Immune complex contained in the network can cause inflammation, tissue injury, and pain. Every patient has different symptoms as well as trigger factors depending on the type of genes, the body's immune system being attacked. Lupus is not contagious, but can be derived through genetic factors. Severity of the disease varies from mild to severe that cause disability, depending on the number and type of antibodies that appear and organs are affected.^{2,3}

The cause of Lupus is still unknown certainty, but environmental factors and heredity are believed to be involved. Several environmental factors can trigger Lupus include infections, antibiotics (particularly sulfa and penicillin), ultraviolet light, excessive stress, certain drugs, and hormones. But recent studies show the possibility of Lupus through environmental factors, genetic, and hormonal. One environmental factor that is thought to be the trigger of Lupus is stress. People with Lupus often experience mental distress, depression, that actually aggravate the condition of body's immune, whereas their immune system triggering the disease. In this condition, treatment becomes ineffective.^{4,5}

Moreover, the conditions to survive in a bear the pain experienced as conditions that are not easy to do and cause distress. In fact, the longer the patient is feeling the stress of suffering Lupus, the more difficult to recover.⁶ Patients who was convicted that the Lupus has spread to organs, they feel that the end is in sight and only a matter of time. These conditions make patients afraid of death. Patients relieved from pain, will undergo a period of recovery, but recovery process different individually, because as long

as they live, people with Lupus must continuously maintain and pay attention to healthy lifestyle so that their condition can be maintained optimally. ⁷

One's perspective about their illness to some extent will affect their physical health condition. Feelings of helplessness (appreciation of the circumstances / situation of environment take control of one's life) is directly related to depression, illness, disability, to deal with Lupus.^{8,9} Therefore, in these conditions, patients expected to have the ability not just to survive , but can adapt in a positive, even expected to work and live optimally with their illness. According to Benard (2004), these capabilities are known as resilience.

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What is Resilience

Resilience refers to an individual's ability to adapt successfully and function competently despite experiencing stress or adversity (Benard, 2004). According to Benard (2004), resilience change individual into survivors and growing. Resilient individuals are still able to manage their behavior in a positive way when facing obstacles and hurdles. ¹⁰

In general, resilience is reflected in four aspects, namely social competence, problem solving skills, autonomy and sense of purpose and bright future (Benard, 2004). Social competence, is patients ability to produce a positive response from the environment, establish and maintain warm relationships with others, communicate effectively, empathize with others and have sense of humor. ¹⁰ For example: although the patients positively diagnosed had Lupus, but they can still establish a good and warm

relations with other people, do not withdraw, not easily offended, can take advantage of positive relationships with others to develop themselves.

Problem solving skills is patient ability to think creative and flexible about their conditions their problems, be able to make plans and actions to be taken when facing problems with their health, able to ask others for help when needed. ¹⁰ With good problem solving skills, expected people with Lupus can address, control, and even anticipate problems that may arise due to their health condition.

Autonomy is patient ability to have initiative, self-regulating and have personal responsibility in order to maintain their health condition. ¹⁰ This can be observed through the examples do not forget to take medications as recommended by doctors, feel confident in their ability to determine their desired result, control themselves for not eating unhealthy food.

Sense of purpose and bright future is the patient ability to believe in their capability, has purpose to be achieved, to be confident in achieving goals of their life, and finding positive meaning behind the condition that they must deal. ¹⁰ This is expected to make people with Lupus can live life in passion and hope.

Factors Affecting Resilience

Resilience in every patient will be in different degrees. The degree of resilience in people with Lupus is related to protective factors provided by families and communities; in the form of caring relationships, high expectations, and opportunities for participation

and contribution. These three protective factors directly lead patients to meet the basic needs that exist within themselves, the need of safety, belongingness, respect, autonomy or power, mastery and challenge or need for meaning. After patient identified what needs do they have, naturally the power of resilience will develop.¹⁰

In circumstances that are full of pressures and challenges, family is an important factor in supporting and increased resilience in People with Lupus. Protective factors can be given in form of a close relationship between members of the family, affection, attention, moral support, acceptance, and empathy from parents and other family members (caring relationships). It meets their basic needs which seeks to find and connect with someone else (need of belongingness). People with Lupus will feel cared, accepted so they feel comfortable and safe in their environment (need of safety). With the emergence of security feeling, people with Lupus become more motivated to produce a positive response from the environment, establish and maintain warm relationships with others, communicate effectively, able to show empathy to others, and able to cheer again despite knowing he was diagnosed with Lupus.

In addition, the protective factors of family can be manifested in a clear and positive expectations (high expectations) given by family members. For example a mother who had Lupus expected by her husband and children to continue take her role as a housewife, doing housework and take care of her family. It meet their basic needs which they feel themselves meaningful (need of meaning) and able. Moreover, their will be motivated to meet the expectations and challenges to become what they want, such as recovering from the pain or achieve their goals. Expectations from family will also be

able to encourage patient to find the strength within themselves to survive so that foster their belief on their capability.

The third protective factor is the opportunities for participation and contribution. Parents or family members who provide the opportunity for people with Lupus to take their own decisions, solve problems and be responsible to do their job, will assist and train them to be able to make decisions, solve problems independently, as well as make strategies in facing problem later on.

Same as family, the community is also affecting the degree of resilience of patient with Lupus. According to Schorr (in Benard, 2004), caring community can be in the form of social support given by friends, neighbors and community assistance. People with Lupus who are part of a community will often share their experiences and feelings with other people with Lupus so they have a sense of belongingness (need of belonging) and safety (need of safety) to be part of that community, as well as having empathy for other People with Lupus.

Join in a community and strive together is an alternative for the People with Lupus to be more independent (need of autonomy) and be able to look at their experiences in a positive way. The activities provided in the community will coach them to become more competent (need of mastery) in making plans, create strategies and solutions, also be able to think critically in solving problems.

Communities that provide positive expectation to People with Lupus (high expectations) will make them feel meaningful (need of meaning) and able to foster self-confidence to perform useful activities and able to live life in the community.

Expectations from the community to become better people will motivate patient to meet these expectations and challenge them to become what they want, such as recovering from the pain or achieve its goals.

Opportunity to do fun activities, participate in counseling and training about Lupus (opportunities for participation and contribution in the community) will foster the feeling of appreciation and build their competencies and capabilities. Appreciation makes people with Lupus have belief that they can (need of autonomy) achieve their purpose, able to remind themselves to take therapy either in hospital or a particular community, lead a healthy lifestyle, and able to reframing their experience in a positive way.

In addition to family and community, the work place also plays a role in developing resilience in People with Lupus. Although most patient with Lupus is no longer working, but their experience while still working affect their resilience. Caring relationships carried out by colleagues in the work place, a working atmosphere that gives a sense of security and support, can develop independence and motivate employees. The warm relationship between people with Lupus with superiors and colleagues not only meet affiliation needs, but also can provide support and security (need of safety) when they have difficulties and obstacles in doing their jobs.

High expectations from colleagues and superiors will give them more opportunities to learn and train them to be able to think critically and creatively when faced problems. Expectations given in the work place through the involvement employee (people with Lupus) in meetings, programs or policies can also help them to find and

notice their excellence or capabilities (need of mastery), so they become more confident of his ability and be able to think critically and make solutions when faced a problem.

A climate in work place that provides opportunities to express opinions, make choices, become involved in solving problems, express themselves in a variety of business events, and work (opportunities for participation and contribution in work place) will lead patient with Lupus developing a strong and successful characters in working so that they feel competent (need of Mastery). The opportunity provided in the work place will train problem solving and decision making skills.

Conclusion

Based on those explanations, it can be concluded that resilience is one important factor affecting the quality of life people with Lupus. People with Lupus who get support from family and the environment, will be able to develop social competence, problem solving skills, autonomy, and sense of purpose and bright futures. This leads to a high resilience in people with Lupus. However, if the People with Lupus who did not get support from family, neighborhood and work place, they will be less able to develop social competence, problem solving skills, autonomy and sense of purpose and bright futures, so that their resilience is low.

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