

Setia Sampai Terbukti: A Triadic Intervention in Persons With Leprosy to Improve Wellbeing and Reduce Stigma

*Rufus Patty Wutun*¹, *R. Pasifikus Christa Wijaya*²

¹Lembaga Psikologi Terapan Kupang, ²Universitas Nusa Cendana

e-mail: 1rpwutun@gmail.com, 2pcwijaya@staf.undana.ac.id

Abstract. Persons with leprosy suffer physically, psychologically and socially. They feel punished, condemned, discarded and ostracized as the result of their stigma. We argued that leprosy management and complete healing better be done simultaneously on physiological, psychological, sociological and religious faith-spiritual levels, using triadic approach intervention. This study conducted in 2017 on Lembata District, Nusa Tenggara Timur, Indonesia. 42 leprosy cases were screened through laboratory examination conducted at Damian hospital. 28 leprosy patients agreed to received the treatment in addition to leprosy medical treatment. 14 patients refused to participate. The Leprosy intervention model successfully enhance the improvements of 24 patients' health. Spiritual/religious values can be used as base of positive view on leprosy management, empowering the family and community capacity on treating leprosy. Social integration is needed to improve the wellbeing of patients both physically and psychologically. This support help patients to cope with negative feeling, and reintegrating them into communities.

Keywords: *leprosy, psychosocial intervention, religious values, stigma*

Introduction

Leprosy is a type of disease that has long been known (Browne, 1975; Robbins et al, 2009; Mendum et al, 2014). Untreated persons with leprosy can develop deformities such as losing fingers, toes, nose and lips (Moschioni, Antunes, Grossi, & Lambertucci, 2010). This condition is often became the reason for people to avoid, being afraid to approach and communicate with persons with leprosy. People are worried of being infected because they think leprosy can be easily transmitted to others. Persons with leprosy have to suffer physically, psychologically and socially.

Inside certain cultural communities in Nusa Tenggara Timur, Indonesia, leprosy is somehow still considered a disease of punishment. The community perceive people with leprosy as offenders of certain social and cultural norms and values, even if they never do such crimes. Leprosy is a curse from God or their ancestors because some imagined violations of certain values and norms. Leprosy is the proof of their cultural guilty and sins. Sufferers feel punished, condemned, discarded and ostracized, their faces look gloomy and sad, daydreaming and pessimistic, hopeless, anxious and isolated themselves from others as the result of their stigma.

We developed a leprosy intervention model that involved patients, their families and community. The intervention counseling is oriented towards direct efforts to touch, strengthen and nourish the role of the soul as the driving force of the human body, improve wellbeing, and reduce stigma. The intervention model consist of

individual and family treatment. The triadic approach intervention conducted with activities including physiological, psychosocial, and religious aspects.

Physiological approach focused on treating the leprosy chronic wounds and ulcers. We encouraged patients to consume foods and drinks that have nutritional intake, including maize, tubers, papaya fruit and leaf, kelor leaf, and consume vitamins. The program train them to routinely treat wounds and skin with herbal ingredients, consisting of local papaya (*Carica papaya*) leaf, kelor (*Moringa oleifera*) leaf, turmeric (*Curcuma longa*).

Psychosocial approach enhance social capital needed for the treatment and facilitate improvements of patients well being. Family counselings and community dialogues provide caregivers and community members some moments to reflect their current believes about person with leprosy.

Religious/spiritual approach on this intervention counteract negative worldview that diminishing positive attitude toward leprosy treatment. Some cultures in Nusa Tenggara Timur believe that leprosy is an illness rooted in the wicked soul which is then manifested through physical pain. Therefore, actions and behaviors that prioritize the goodness of life, faithfulness, patience, grace, willingness to sacrifice, hard work, diligent and not blaming each other are believed to be the main nutrients needed to strengthen the soul. Relationship between faith, psychological and physiological actualized in the form loyalty for the good of life.

In order to reduce social stigma, we develop set of values based on christian religious and spirituality as bases of spiritual approach including faithful/fidelity, hope and love. Faithful means obedience, strict to a task or promise. Either faithfulness or loyalty both have a charge of commitment and determination in an establishment, promise or contract (Ross, 2004). In marriage life for example, there is an expression of loyalty to a marriage partner until death. In the context of lay religiosity and monastic life in the Catholic monastic tradition, faith is related to promises (vow) and commitment to the vocation of religious life, especially loyalty to the three vows of monastic life namely obedience and purity and poverty.

Hope is an optimistic state of mind that is based on an expectation of positive outcomes with respect to events and circumstances in one's life or the world at large. Christian Scriptures have written that leprosy can be cured. The Leper was cleansed by Jesus Christ only because of his faith in God (Matthew 8: 1-4, Mark 1: 40-45, Luke 5: 12-16). On this point of view, leprosy is healed because of total faith in God.

Loyalty is seen as a principle that underlies all forms of human relations, as in relations with oneself, others, the universe and even human relations with the Creator. Faithful and social solidarity is the nature of the good-self that is presented in each

person for the good of life, concretely by helping others, giving sympathy and empathy to people who suffer and maintain all forms of human loyalty relationships. Loyalty build social reinforcement support for those who are suffering from natural disasters, social disasters and suffering from illness and disease, like leprosy.

We argued that leprosy management and complete healing better be done simultaneously on physiological, psychological, sociological and religious faith-spiritual levels. We have to address this task by touching the mind, soul, body, and community.

Method

This study conducted in 2017 on Lembata District, Nusa Tenggara Timur, Indonesia. 42 leprosy cases were screened through laboratory examination conducted at Damian hospital. 28 leprosy patients agreed to received the treatment in addition to leprosy medical treatment. 14 patients refused to participate because of sense of difficulty finding the recommended types of food, no transportation costs to Damian Hospital on Lewoleba, and refusing food restrictions.

The family caregivers learn to routinely provides the recommended types of healthy food and drinks, controls and prevents the types of food and drinks that are prohibited from being consumed by patients, routinely provides vitamins that are recommended for patients, and routinely treats wounds. Local herbal ingredients for chronic wounds and ulcers include papaya leaves, moringa leaves and turmeric. 5 grams of each ingredient is mixed with 1 gram of salt. The material is crushed or blended together, then used to be scrubbed and taped to the wound and bandaged. Replacement is done regularly per day.

Family counseling sessions and focus group dialogue aim to change the way they think and behave, adopting positive values and life meaning, such as loyalty, faithful to their action, hope, patient, willing to sacrifice and not look for the patient's mistakes, not complaining and grumbling, must not be angry, hate and revenge. Patients are encouraged to smile and laugh, be obedient, steadfast and patient, refrain and not greedy, not jealous, do not complain and grumble, diligent and generous in the atmosphere of the joy of life.

In religious and spiritual session, patients are encouraged to be faithful and routinely pray privately, diligently go to church on Sundays, diligently and faithfully attend joint prayer activities, diligently read and hear the Bible, diligently meditating, recollecting, fasting and abstinence. This practice improve social relations with the community, increase social contact, and reduce the stigma of patients as social and spiritual outcasts.

Spiritual sessions were also conducted among caregivers from the intervention team to internalizing values of seriousness at work, not be afraid and disgusted when treating patients' wounds, work sincerely, may not nag and complain, must not be angry, offended, do not blame each other, must not hurt the patient's heart, cast away doubt and anxiety.

Research data obtained by photos, observation, and interview. The main questions theme are the improvements on the the wellbeing of leprosy patients. Second questions theme are the aspects of community that may improve the wellbeing of leprosy patients incuding social support, care, believes, values and stigma. Data was analyzed using descriptive qualitative method.

Result

There were 24 patients who were successfully intervened at the of the programme. The improvements indicated by healed wounds, clean face and skin, some pain nerves revived, a fresher and healthier face, complaints that have been experienced are no longer felt and the results of laboratory tests show negative BI status. 4 patients report low improvements on their condition.



Figure 1. The leg ulcer gradually healed after 7 months of intervention. The patient's feet after full recovery (right).

We interviewed 24 patients and their family. Qualitative themes list can be seen on table 1.

Table 1.
Thematic Analysis Main Themes

Main Themes	Meaning
Positive feeling	Smile and laugh, cheerful. Reduced intensity of daydreaming, sadness, avoiding relationships with others, anxiety, shame, fear and hesitation. Hopes of healing and feeling of peace.
Social companionship	Seriousness on conducting treatment, sincerity, simplicity, patience, an atmosphere of friendship and joy, smiles and laughter
Social acceptance	Feel welcome to community activities, can start a chat with others
Spiritual	Allowing God to be involved in His way of completing aspects that are lacking due to human limitations.

Discussion

Involving family and community in the process of treating leprosy causes a feeling of empathy. Spiritual meaning using religious virtues provides a framework for positive thinking in the social environment. The burden felt when faced patients is transformed into a social task given by God (Wutun et al, 2018). This feeling is needed to reduce stigma. Positive attitude toward persons with leprosy improve chance of successful treatment. Regular treatment for wounds and ulcers increases the chance for recovery.

The spirit of loyalty is one aspect of goodness needed in living with others, which is considered by caregivers as a power given from God. Facing heavy burden and problems, everyone is expected to see and perceive pain, not merely as suffering but also as a sacrifice that is borne for the good of life. Social acceptance through communal activities, such as joint prayer participation, is a space for necessary social contact. This support help patients to cope with feeling of losses, and reintegrating them into communities.

Conclusion

The Leprosy intervention model that has been used in Lembata District has successfully helped heal and strengthen patient health. Spiritual/religious values can be used as base of positive view on leprosy management, facilitate improvements for the family and community on treating leprosy. Social integration is needed to improve the wellbeing of patients both physically and psychologically.

Reference

- Browne, S. G. (1975). Some aspects of the history of leprosy: the leprosie of yesterday. *Proc R Soc Med*. Aug; 68(8): 485–493. PMID: PMC1863843
- Mendum, T. A., Schuenemann, V. J., Roffey, S., Taylor, G. M., Wu, H., Singh, P., & Nieselt, K. (2014). *Mycobacterium leprae* genomes from a British medieval leprosy hospital: towards understanding an ancient epidemic. *BMC genomics*, 15(1), 270.
- Moschioni, C., Antunes, C. M. D. F., Grossi, M. A. F., & Lambertucci, J. R. (2010). Risk factors for physical disability at diagnosis of 19,283 new cases of leprosy. *Revista da Sociedade Brasileira de Medicina Tropical*, 43(1), 19-22.
- Robbins, G., Tripathy, V. M., Misra, V. N., Mohanty, R. K., Shinde, V. S., Gray, K. M., & Schug, M. D. (2009). Ancient skeletal evidence for leprosy in India (2000 BC). *PloS one*, 4(5), e5669.
- Wutun, P. Rufus, dkk. 2018. Evaluasi riset intervensi penyakit kusta di Kabupaten Lembata. Laporan hasil. Lembaga Jasa Psikologi Terapan Kupang (LPTK) Tahun 2018.