



Development of Mentoring Model through Social Engineering to Improve Quality of Lifestyles of Leprosy Patients

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Abstract

Stigma and discrimination often inhibit early leprosy detection, treatment in patients, and treatment of medical problems experienced by patients or people who have had leprosy, therefore in the effort to eliminate stigma and discrimination required a strong motivation and commitment both from sufferers and society. Because of that researcher is interested to create a model of assistance through social engineering so that the community of lepers who experience discrimination can interact with the community. The type of this study was qualitative research using descriptive approach which is how to tell the reality of the daily life of lepers with 11 informants. Result: For the objective and subjective reality of society there is still a justification of the statement that the lepers as a cursed person, it is constituted by several things including the information possessed by the community. For the leprosy public services, the lepers feel uncomfortable and humiliated because all of the people in the examination room will know the disease, especially if gender-biased health workers provide advice relating to their status. Therefore it is not surprising that leprosy patients choose not to come to the health center or they choose a health center in other villages where people do not know about them, due to limited funds. While for the acceptance of families to leprosy patients play a role in the healing process of leprosy patients, home conditions based on temperature, lighting and ventilation is stated that the whole house of leprosy patients being sampled is unqualified while for ventilation according to informants that most ventilation is also unqualified. This can be influenced by some requirement, especially socio-economic factor because almost all informants have social economy problem, where they prefer the need for food to live.

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Conclusion: It is very difficult to be able to interact normally with the community. This is because of the lack of confidence and the stigma that is inherent in the community that leprosy is an infectious and dangerous disease. While for public services, the same thing is felt by former leprosy patients that it is difficult for accessing health services because not all health services are willing to accept former leprosy patients to come for treatment. The factor that exacerbates their condition is economic factor that causes the former lepers to live close together in a slum location and this causes the easy growth of leprae mycobacterium because of the density of occupancy so that air circulation and lighting is not good.

Keywords: social engineering; living standard of leprosy patients.

1. Introduction

The number of leprosy patients in the world at this time is estimated 12 million more people, 80% of which come from the tropics. Leprosy is still haunting 14 provinces in Indonesia, four of which are East Java, Central Java, West Java and South Sulawesi. There are more than 1,000 cases reported every year [1].

The number of leprosy patients in Indonesia is the 3rd largest in the world after India and Brazil, in 2010, the number of new cases recorded 10,706 (new case finding rate / CDR: 4.6 / 100.000) and the number of registered cases as many as 20,329 people with the prevalence of 0.86 per 10,000 population. Leprosy is a disease targeted for elimination and eradication because it can lead to disability so that leprosy monitoring should be effectively carried out by the government through hospitals and health center [2].

Naturally, humans are monodualistic beings, meaning other than as individual creatures, humans also act as social beings. As social beings, humans are required to be able to cooperate with others so as to create a peaceful life. According to Aristotle, social beings are zoon politicon, which means humans are destined to live in society and interact with each other. Humans interact in each environment both in the family and in society. Individuals have a family environment, school environment, neighborhood or community. In these environments people will always interact [3].

The existence of former lepers in general is still much feared and ostracized into attention. Considering the surrounding community think the disease is a frightening disease and the patients and former sufferers should be shunned. Such unfair treatment can lead to social problems that will ultimately affect social interaction especially for former lepers [4].

The problem that arises is the former leprosy patients are patients who have imperfection in physical but they are also individuals who need to interact with other individuals. This discussion is still much discussed by people from various sciences. Most leprosy patients are disabled due to delays in taking the drug, taking the drug imperfectly or the treatment is incomplete. Disabled due to dead nerves can be prevented with drugs and quick treatment. Former leprosy patients should not be shunned because it has been declared cured medically and if there is a thought that it can be contagious, transmission is not as easy as imagined [5].

The view of most people against former lepers is still underestimating. In modern era like this, when the medical

sciences develop rapidly, some people still look at the former lepers as the scourge of society, even the family often exclude former leprosy patients. Many found the former lepers became beggars on the road. It happened because of the rejection in the origin of former lepers [4].

The main problem faced by former lepers is the difficulty of getting a decent job. The Ministry of Social Affairs and the Ministry of Manpower and Transmigration are often out of hand. The only reliable job is as street beggars and many of them become beggars to survive [6].

on the results of preliminary observation to leprosy patients some lepers say that by looking at the condition, they themselves also feel ashamed, embarrassed to the neighbors, the community and even his own family. Activities that can then be done are limited because of the disease experienced even eating, drinking and defecating has difficulty. They also consider themselves to be useless, so there are some who prefer to stay in the hospital rather than returning home with their families, but because of the economic limitations that they should return home at the end. In addition there is a change in lepers both in terms of physical and in terms of the role that they usually do everyday before experiencing illness, such as earning a living for their family.

Age that develops progressively does not guarantee the mindset of society is also progressed. This thing seen that society still just perceives leprosy is caused by curse and decrease. This thought inherited by ancestors of ancient thoughts that relate it to the mystical and taboo. The absence of scholarship and logic in perceiving leads to misguided actions [7]. The life story of lepers is still colored by unpleasant treatments. Blasphemed, reviled, exiled will be obtained for anyone who has leprosy. The frightening specter of leprosy gives rise to the term leprophobia, that is, excessive fear in lepers. Leprophobia is due to errors in interpreting the cause of leprosy where someone feels disgust, fear reactions in leprosy patients without a rational reason [8].

2. Material and Methods

unpleasant treatment affects the social life of lepers. Leprosy problems have shifted from health problems to complex problems that are not influenced by religion, social and culture. Leprosy affects the patient psychologically and the family and the environment. Leprosy is no longer a problem for individuals who are experiencing it but also a national problem, the government must support people affected by leprosy. Problems that spread to all social aspects, making the sufferer or the former leprosy become drifter, homeless, unemployed and their worst chance they commit crime to disturb the peace of society.

Therefore, research in the first year of the study formulates three formulas namely:

1. See the phenomenology of lepers based on objective and subjective reality
2. Knowing the characteristics of home conditions based on the tribe in former lepers
3. Having a portrait of discrimination experienced by leprosy patients both in family environment and in public services.

At this stage the method used is qualitative by using descriptive approach with focus on social engineering to improve the quality of life of leprosy patients.

In the second year people who have experienced leprosy until now still experience social discrimination due to stigma in the disease they have ever experienced. In their daily lives, they have difficulty accessing social rights such as education, health, public transportation to worship facilities and spouses. The main cause is the lack of public knowledge about leprosy that they fear of contracting and away from patients or people who have experienced it. Therefore, it is deemed necessary to create a model of community assistance on endemic leprosy by way of developing a model of assistance with the analysis of coaching schemes through the application of productive activities model with the pattern of parallel partnership with stakeholders through:

1. Leprosy care movement, which is conducting community assistance on endemic leprosy, socialization early detection of leprosy, stop discrimination campaign and help the patient to immediately get medical services.
2. Disability care movement for economic independence and other social needs through job training, job placement and encouraging entrepreneurship

3. Results and Discussion

3.1 Characteristics of Informants

Participants in this study amounted to 11 adult informants who were divided in two research points that is 7 informants on Jl. Dangko and 4 informants in Tamalanrea Jaya. The age of informants vary between the ages of twenty-eight years old up to fifty-four years. High level informant education level is primary school. The work of informants was traders, entrepreneurs, housewives, beggars, did not work. While the expert informants were added to enrich the information such as: community leaders (RT, RW) and religious leaders residing in Jl. Dangko and Tamalanrea.

3.2 Phenomenology ex Leper Patients

Man or society that creates a discourse will experience or feel what he is discouraging himself. The objective process in this research is the society's view on leprosy patients in accordance with the initial knowledge of the society about leprosy which then as an objective relativity. In this process of objectivation, the society's view of leprosy suffers from different biases, their views can be based on the knowledge and experience they then get, where the knowledge and experience that each individual finds is different from each other.

"In my point, a community out there is indeed disgusting to see us but now they no longer regard leprosy as a curse, but people out there know that leprosy is a contagious disease caused by bacteria" (AA)

In many Health center in Indonesia with limited service facilities, there is no special consultation and examination room available. People with leprosy feel uncomfortable and humiliated because everyone in the examination room will know the illness. Especially if gender-biased health workers provide advice relating to

their status. It is therefore not surprising that leprosy patients choose not to come to the health center or to choose health center in other villages where people do not know about them, due to limited funds.

Such as the informant's response below:

"Not all health services will accept us if we are known that we are suffering the leprosy diseases, so we are sometimes difficult if we want to come for treatment, fortunately there is now a special leprosy hospital in Makassar, so if we want to seek treatment there, but the distance is too far (WW) "

Family acceptance of leprosy is very important in the healing process of leprosy patients. Family acceptance also affects the acceptance of self in leprosy patients, because the family is the closest community of the patient. The people closest to leprosy other than the family are the neighbors. Most leprosy patients do not give negative stigma for leprosy patients. The lepers can still mingle in the community around and do activities like people in general.

In accordance with the informant statement as follows:

"Only family who can accept us forever, only them who support and do not feel disgusted towards us, the support of the family that makes us spirited again (Rs)"

3.3 Home Condition

The results of the temperature and lighting measurements obtained by using the thermo hygro tool are as follows:

- a. Temperature and lighting

Table 5.1: Temperature and Lighting

Variables	Frequency	
	n	%
Temperature		
Qualified	0	0
unqualified	26	100
Total	26	100
House lighting		
Good Lighting	7	27
Bad Lighting	19	73
Total	26	100

Source: primary data

good ventilation requirement is as follows: the ventilation area shall remain at least 5% of the floor area of the floor space, while the incidental vent area (can be opened and closed) is at least 5% of the floor area. The amount of both becomes 10% of the floor space. Incoming air must be clean, not polluted by smoke or factories, exhaust of vehicles, dust and others. Air flow shall not be prevented from being blocked by large items, such as cabinets, walls, bulkheads and others

Informant statement below:

"You saw it anyway here the house was so close to each other. Not only opening the window so that the air enters through our ventilation, the people around here is also bumping to each other if we pass the alley at the same time. Not only that. Not just getting a decent home, to get any food we have to save money. Even in fasting month some of us suddenly became a beggar to gain extra income to make it enough for us." (Rb)

For ventilation based on the results of research conducted through direct observation in the field, it is found that the light entering through the ventilation is not maximal is caused by the densely populated settlement besides the economic factor as the main support to get a decent living and shelter very far from the word enough.

3.4 Phenomenology ex lepers

3.4.1 Objective reality and subject reality

At this stage, it is found some views of the informant can then be classified as follows:

1. The objectivation of the society who views the leper as a person who is exposed to the curse
2. Objectivation of people who view leprosy sufferers as a hereditary disease
3. Objectivation of people who see lepers as a dangerous infectious disease
4. Objectivation of people who see leprosy sufferers as infectious diseases that can be cured.

3.5 Discrimination Environment

3.5.1 Public service

Health services obtained in health center or in hospitals are still very far from the standard word and humane. For service at health center, leprosy patients if they sick are very difficult to get health center services because those who come for treatment at the health center are the general public who do not suffer from leprosy. They more often go to Special hospitals that deal with leprosy because in the health center they feel not confident to come and seek treatment. It is different if they come to the hospital treatment they feel confident even though the hospital is also open to patients who do not suffer from leprosy, but indeed most of the people who come to the hospitals for treatment are leprosy patients.

3.5.2 Family

Families provide real-life relief resources such as direct assistance from dependable people such as giving material, energy and advice. Helpful assistance may include meeting of food, drinking, resting, and providing facilities or tools for treating leprosy. The benefits of providing this support i.e. individuals feel the attention and care from the family environment. Family as a support system of leprosy patients are expected to provide full support in the efforts of care for leprosy patients.

Emotional support given in the form of a sense of empathy and attention to the individual, thus making him feel better, regain his confidence, feel owned and loved by others.

3.6 Home Condition

3.6.1 Temperature

Temperature is the heat or cold of air expressed in units of a certain degree. In general, the room temperature assessment is measured by using thermohygro. Based on the measurements of room temperature that are eligible for health are between 25-30 ° C, and home temperatures that do not meet health requirements are <25°C or >30 ° C (Walton, 1991)

Based on observation while doing research on Jl. Dangko sub-district Tamalate, urban village Balangbaru RT 05 RW 04 and tamalanrea Jaya listed in Table 5.1, that most home leprosy patients do not meet the health requirements of (100%). If the house room temperature of leprosy patients up and down and does not meet the health requirements it is not easy to kill the bacteria *Mycobacterium leprae* in the house of leprosy patients. This causes room temperature affect the health condition of leprosy patients.

3.6.2 Lighting

There are two kinds of light that is natural light that is the sun and artificial light that is lamp. Light is important because it can kill pathogenic bacteria in the house, including: Leprosy, Pulmonary TB, therefore, a healthy home should have good lighting.

Based on the results of research at Jl. Dangko sub-District Tamalate, urban village Balangbaru RT 05 RW 04, the lighting entering the house of leprosy patients is largely ineligible at 73% because most of the leprosy sufferers are not ventilated. There are also some who live only in the private houses they usually refer to as wards and the ward has only one door for source of lighting entry. This causes an influence on the development of *Mycobacterium leprae*, because one of the ways to kill pathogenic bacteria is through lighting.

3.6.3 Ventilation

Impact of ventilation that does not meet the requirements of the oxygen exchange in the house can be reduced so that it can cause diseases that can be transmitted by air infected with people with a home with the patient. By the

use of ventilation in accordance with its intended use, then sunlight and air will enter to prevent bacterial growth.

4. Conclusion

Based on preliminary observation, in-depth interview and measurement on air quality can be stated that the sufferer to be able to interact normally with society is very difficult, this is because of the feeling of lack of confidence and stigma that has been attached in the community that leprosy is a contagious disease and dangerous, while for public services the same thing is felt by former leprosy sufferers that the difficulty of accessing health services because not all health services are willing to accept former leprosy patients to come for treatment, and the factor that exacerbate the situation is a weak economic factor that causes the former leprosy patients remain living in a density in a slum location and this causes the easy growth of *Mycobacterium leprae* because of the density of the dwelling so that air circulation and lighting is not good. Based on the results of that basic research can be developed a concept in order to change and improve the livelihood of people with leprosy.

Acknowledgement

The authors would like to acknowledge to friends and family for supporting me during this study.

Competing Interest

The authors declare that they have no competing interests.

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