

Self-care Behaviors in a High Risk Group for Leprosy of Thambol Landokmai, Muang District, Kamphaengphet Province

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ABSTRACT: The aims of this study were to study the perception of the knowledge of leprosy in high risk groups and the self-care behaviours in high risk groups for leprosy. This multi-case study used both patients and household contacts of leprosy patients in Thambol Landokmai, Muang District, Kamphaengphet Province. The study involved 12 participants consisting six participants who were diagnosed with leprosy and were still under physician's supervision and another six who were household contacts but had no symptoms of leprosy. Data collection involved the patient records, surveys and community visits, questionnaire interviews using snowball technique, and data validation using triangulation technique. The results revealed that both patients and household contacts of leprosy patients did not know what leprosy was. They only knew that leprosy was one kind of dermatologic symptoms in the name of "keetudkudtung" (that was told by the ancestor and was composed in some folksongs to tease among friends). Later, they knew about leprosy clearly when a case occurred to their family member. The results also indicated that both the parties did not pay attention at first stage of disease such as pale-colored skin sore, bump and rash especially no itching but numbness. They also did not know that leprosy causes nerve damage resulting in numbness and finger disfigurement and they believed that the disease is transmitted by contacting patients but did not know that it is also able to transmit via respiratory system including coughing and sneezing. Lastly, the results also showed that the patients and household contacts knew that it takes about 2 years for treatment.

Most patients did not seek for treatment but tried to solve the problem by themselves until they were suffered with finger disfigurement.

Keywords: Leprosy, household contacts, self-care behaviors, high risk group, nerve damage, disfigurement, numbness

Introduction

Leprosy is a chronic infectious disease that causes the symptoms to be clearly shown on skin and peripheral nerves. The progression of the disease is quite slow. If the patients are not treated at the early stage of disease, it will cause nerve damage and may impair many organs such as eyes, hands and feet at later stage (Rajpracha Samasai Institute, 2007). This probably makes anybody who sees the patients on this stage afraid to be near them. Moreover, the disease can be spread to others from the infectious areas. Suffering from leprosy can also make both patients and families confront with social, economic and psychological problems due to the social stigmatisation. Many patients who are abandoned and hidden from society are afraid of going outside to get proper medical treatment. As time passes, the symptoms get worse and finally make them cannot live a normal life.

The leprosy situation in Thambol Landokmai of Muang District, Kamphaengphet in 2013 revealed that there were seven patients who were diagnosed with leprosy. The first patient, found in 1986, was a man around 50 years old who migrated from Pran Kratai District, Kamphaengphet Province. The second patient, aged 40 years, was the descendant of the first patient and lived in the same neighborhood. Both the patients were monitored and on intensive medication by the authorities of Ministry of Public Health until the symptoms were better and were under observation status. The third leprosy patient found in 2007 aged 50 years was the wife of the first patient. The fourth leprosy patient, found in 2008, was 30 years and was the son of the first and the third patient who unfortunately had already passed away. In 2009, the fifth leprosy patient was found. He was a boy under 15 years old. He was the son of the second leprosy patient, who was still under physician's observation. The sixth patient, a child under 15 years old, was the younger brother of the fifth leprosy patient. The seventh leprosy patient, a man

around 80 years old, was found in 2012 and was once under treatment but at that time, had stopped the medication and was later found some recurrent disabilities.

Currently at Thambol Landokmai, there are 6 people who were diagnosed with leprosy and need to remonitor the suspected symptoms of their household contacts and the patients who have already recovered from Leprosy by medication. (Thambol Thamaidaeng Health Promoting Hospital, 2013). Most patients were likely to be the relatives and neighborhood groups from three families. Among those patients, who were still under physician's observation, were from the group of new patients and recurrent patients. Besides, household contacts were probably considered to be at high-risk for disease emergence. Hence, according to the evidences and reasons mentioned above, this made the researchers interested in studying the self-care behavior, which consisted of knowledge and ways of behaving for those people who were at high-risk for leprosy in Thambol Landokmai.

In this study, the researchers applied the qualitative research methodology to find the conclusions by using the field survey which they took the PRECEDE framework of Green *et al.*, (1980) for data collection. They conducted in-depth interview with key informants who were both under observation patients and household contacts. The researchers expected that the results of the study would raise awareness about protective behaviors of the people at high-risk for leprosy, including preventing and controlling the spread of disease in a community. The objectives of this study were to study knowledge and perception of leprosy in the high-risk group of people, and to investigate the self-care behaviours of the people at high-risk for leprosy.

Material and Methods

The Sample Population

This qualitative research utilised case study research, multiple case study or collective case study, conducted with 12 participants who were related to leprosy in Thambol Landokmai, Muang District, Kamphaengphet Province, as follows:

Six who were diagnosed with leprosy and have recovered by the treatment and now are under observation status, in Thambol Landokmai, Muang District, Kamphaengphet Province.

Six who were the household contacts that lived together with the observation status patients and still had no symptoms of leprosy.

The research process

The data was sourced from:

- a) Secondary data from the study of document, journals, books, annual reports, registration report of Thambol Thamaidaeng health promoting hospital. This data helped the researchers to direct the way of research.
- b) Primary data from the in-depth interviews with key people. This data was considered to be very important. The qualified informants, specified by the researchers, were the people who were diagnosed with leprosy (now they are under observation status) and the people who were the household contacts.

The research tools

To collect the data for this research, the researchers conducted the interview using the PRECEDE Framework of Green, LW et al., (1980) as a main direction in the group of people at high-risk for leprosy. Several methods were applied, including interviews, observing the reallocation, photographing, and taking notes on necessary details regarding the following techniques and methods.

a) Interview

The researchers used the technique of informal interview to get the most comprehensive information which covered all objectives as much as possible through the in-depth interview with the key informants. The interview structures (unstructured interview) and interview questions were not fixed but only outlines that based on conceptual frameworks and the key factors to form the interview questions. The questions were not ranked in orders and tended to be open-ended. During the interview, if the researchers found special phenomena or any important

issues, they would take the special in-depth interview on that issue to get the most explicit answers. At the same time, they also recorded audio and took photos as necessary.

b) Observation

The researchers used the technique of direct observation, participant observation, and non-participant observation to obtain the most complete information for this study. In participant observation, the researchers got involved in personal self-care activities by joining with the informants in their daily lives. This made the researchers observed the informants' self-care behavior in various aspects and also had a chance to make informal conversations with them to get more other information. As for non-participant observation, the researchers secretly observed the informants all the time during the interview by focusing on their personal self-care behavior and other real conditions to make sure that all their interview data was correct.

c) Equipment for collecting data

The researchers collected data using tools as following:

- Field data collection forms: The data collection forms were prepared in advance to facilitate classification of the information and analysis. The data collection came from both interviews and observations.
- Audio Records: The audio records were used to record voice during the interview. The conversation was the key points of the informants. Before the interview, the researchers might need to ask for permission to record the conversation. This made the researchers get the most comprehensive information and helped them to be able to review the interviews' conversation afterwards.
- Notebooks and Stationery: Notebooks and stationery were used to record the interview and miscellaneous details during the conversations.
- Camera and Shooting Accessories: Camera and shooting accessories were used to take photos during the interview and conversation especially the photos of the phenomena in personal self-care behavior of the people at high risk for leprosy. These photos were the supportive evidence for the research. Kiatsuda,

Data Collection from the Interview

a) Planning and Preparation

- Defined the clear purposes of the interview
- Selected the representative samples of key informants who had risks for leprosy
- Contacted the interviewees to make an interview appointment
- Selected the Unstructured Interviews to allow the interviewees to express their opinions freely
- Prepared the interview questions, tools and other equipment for interviews

b) Interview

- Introduced the interviewers to the informants, informed the interviewees of the clear purposes and assured them that the interviews and results would be confidential and used for the research purpose only
- Informed the interviewees to know and asked for permission before taking notes or recording his/her voice
- Started the interviews by speaking of the general details such as their illness conditions, health problems. When both interviewers and interviewees started to feel more familiar to each other, interviewers started to ask the defined questions, for example, how they know about leprosy. Then, when the key informants started to talk about leprosy on the interesting issues, the interviewers began to ask for in-depth details on the specific matters

c) Recording the interview

- The researchers recorded the results of the interviews immediately, during or after the interviews
- The researchers accurately recorded the interview with no modification of the speech or the comments
- If the information could not answer the question. This researchers would change to record the reason why it was unanswerable and
- The researchers made a summary of the interviews

d) Closing the Interview

The interviews continued until the study was completed and comprehensive data was asked repeatedly until no new answers mentioned. The researchers ended the interview when there was no more useful information. The researchers thanked everyone for their cooperation which was the part of the success of this research Phitsinee and Pimtong,

Data collection by observation

Researchers collected the data about behaviours or phenomenon that happened in a high risk group for leprosy during the interviews. Observation method was used for data consideration. The observation consisted of Acts, Activities, Meaning, Relationship, Setting, and Field note.

Data collection

In this study, researchers collected various data from many sources. Data collection started by examining patient's registration of Thambol Thamaidang Health Promoting Hospital, then the researchers conducted the survey repeatedly in the community in order to get used to a high risk group for leprosy. Then, researchers collected the data from each individual of high risk people by interviewing together with observation and linked to main source by snowball technique. The data was collected many times to ensure that it was correct Phitsinee and Pimtong,

Data checkup

After studying literature review, the interview questionnaire was constructed for data collection. The questionnaire was sent to specialists for check and improvement. After field observation, researchers always recorded and checked the data to ensure that it was correct and complete with triangulation technique that included data triangulation and methodological triangulation.

Data analysis

The data from documents, field collection, and records were brought out and concluded based on the criteria. Data analysis was a process that was conducted along with the field data collection by observing and in-depth interviewing. Then researchers recorded the details in every aspect. Next, the data was classified into groups and rearranged in order to link all opinions. In addition, the data was also rechecked. If the data was not complete, then additional data collection had to

be conducted. All correct and complete data was analysed based on topics to interpret the meaning of variables that reflected self-care behavior of a high risk group for leprosy.

Results

Knowledge on leprosy among people who are susceptible to leprosy

a) The knowledge about leprosy

Most of the people who were susceptible to leprosy do not have the knowledge about leprosy, especially, the symptoms at the initial stage of the disease. They usually think that it is a skin disease such as ringworm. They knew about leprosy from the elderly and it became the song that is sung among the children but it is not called “leprosy” but it is known as “keetudkudtung”. They clearly knew about the leprosy when someone in the village has it. The people who are susceptible to leprosy have knowledge about symptoms of leprosy with the appearance of a patch of flat, pale-colored skin and fingers and toes fall off (Shaluay Sedkij *et al.*, 2009).

b) The general signs and symptoms of leprosy

The people who are susceptible to leprosy defined the sign and symptoms of leprosy that it has red rash with raised border around white patch, no itchy, no irritation, mostly found on parts of the body that cannot easily be seen such as on the back, and behind the knee. It can feel numb at the tips of hands and feet (Rajpracha Samasai Institute, 2007). The people who are susceptible to leprosy in Landokmai district call “Peuk”.

c) The neurological symptoms of leprosy

The people who are susceptible to leprosy are informed that the most severe signs and symptoms of leprosy are disability of hands and legs that can be noticed easily by other people. These symptoms affect lifestyle due to its disability but people still do not understand that leprosy can cause nerve infection and damage in fingertips and feet. The numbness in hands and feet was leading to loss of sensation and also injuries (such as burns or fractures). The injuries cause the secondary infections where fingers and toes

become shortened and deformed. Muscle weakness and mobility difficulties of hands and feet were also occurred. (Norina Benyapa, 2009)

Self-care behaviors of a high risk group of leprosy

a) Basic care of dermatophytosis

The high risk people for leprosy use their own way to treat general skin problems. They apply balm and herbs (leaves of ringworm bush) based on their traditional belief. In some instances, they scratch their skin before applying medicine because they believe that the medicine will absorb to the skin much better. If all methods are not effective, they will only go to see a doctor. Seeing the doctor is the last choice for them (Resume Chandawanich, 2009).

b) Basic method of body cleansing

The high risk people for leprosy have their own way of body cleansing by taking a bath called “Chu”. They take a bath twice a day using shampoo and soap. Sometimes if they are too tired from work, they will take a quick bath so that they can take a rest quicker (Apinya Kortem, 2009)

c) Basic method of laundry

The high risk people for leprosy always wash clothes together with their family members’. They do not separate their clothes from others. They wash the clothes separately only on particular purposes, such as working clothes, school uniforms and pajamas (Apinya Kortem, 2009)

d) Basic method of bed cleaning

The high risk people for leprosy clean their bed sheets and mattresses, by dusting off before they go to bed every day. Washing and putting bed mattresses in the sun is occasionally done because it is rather big. They sometimes open the window to ventilate and let sunlight shine into their bed rooms.

e) Periodic health examination

The high risk people for leprosy get their health examination only at Kamphaengphet hospital. High risk people do not like to see a doctor because it costs a lot of money and the hospital is quite far from their village. When the result of the examination is normal, they do not want to see a doctor for follow-up. This causes recurrence of leprosy in the community. People in this community do not like to get their periodic health examination, and prefer to treat by themselves at the first place. If their health problems do not get better, they will go to Thambol Thamaidaeng health promoting hospital. They go to Kamphaengphet hospital in case of severe neurological symptoms of leprosy.

f) Preventative behaviors resulting from the warmth and love of family

The high risk people for leprosy express their love and intimacy by kissing and hugging. These expressions are seldom done because of shyness. Kissing and hugging are the ways of disease transmission. This disease is transmitted via 2 ways: respiratory tract and skin (at area of skin eruption). Respiratory tract is the most common way of disease transmission (Department of Disease Control, 2003)

g) Self-examination of skin abnormality

Normally, the high risk people for leprosy cannot detect their skin abnormality. They only take a quick look when they take a bath. They start to pay attention when they have some symptoms such as itching.

Summary

There are six high risk people for leprosy in three families in Thambol Landokmai, Muang District, Kamphaengphet Province. A total number of 12 people consist of six patients after treatment and are still under observation status and six people of household contacts who are relatives or live near high risk people for leprosy. Our results showed high risk people for leprosy have little knowledge of leprosy, so the disease was spread from patients to others. High risk people for leprosy knew that the leprosy is a skin disease that is similar to dermatophytosis, but they were unable to distinguish between leprosy and dermatophytosis due to their similar

symptoms at the initial stage. At this stage, the muscular eruption and red bulge appeared on some parts of the body cannot be easily seen on skin, such as on the back and behind the knee. These symptoms do not irritate the individuals, and thus no attention was given. Unconsciously, the rapid progression of the symptoms of leprosy could lead to extremities, which cause disabled in those individuals of high risk group. Moreover, the vernacular name for leprosy known as 'hand-maimed disease' or 'keetudkudtung', also leads to confusion about the disease. In the process of leprosy treatment care, health promoting hospital staff should have knowledge about the vernacular name of this disease.

Leprosy can be infected via mucous and saliva from coughing and sneezing. Moreover, it can be infected by staying close to patient. The symptoms of leprosy patient explicitly showed in abnormality on skin and disabilities of hands and feet but the transmission through infected skin is relatively lower (about 0.2-0.8%) which was misunderstood by the patients. The most common way of infections is through the respiratory system. Controlling and protection of leprosy are very difficult because the high risk group for leprosy do not know that leprosy can be infected via respiratory system. The most common ways of leprosy transmission are olfactory neuron and broken skin.

Conventional medicine is the only way of leprosy treatment. There are two parts of medications. The first part of medications is the medicines that patient must take in front of medical staff. Another part is daily medicines. The treatment takes about two years. Due to the long period of treatment, most patients feel discouraged to continue the medications. Therefore, leprosy in Landokmai becomes an epidemic disease since 1986. In 2012, there were seven patients and, since 2013, six patients are still under supervision and 1 patient died. Patients with the maimed fingers likely have more motivation for treatment than patients with maimed hands. Landokmai proceeds treatment of leprosy by utilising Multi Drug Therapy (MDT), following the advice from the World Health Organization (WHO). The primary leprosy self-treatment in high risk group is similar to dermatophytosis. If it is not successful, they will go to see the medical staff at Thambol Thamaidang health promoting hospital. Kamphaengphet hospital is the patient's last choice because it is expensive and time-consuming. Leprosy patients do not clean their bodies properly because they are tired from work and they want to take a rest as fast as impossible. For

the laundry, they do not separate clothes of patients from normal people. The villagers in Landokmai seldom clean their beds by washing or putting mattress in the sun because of the big size. Due to the far distance, the patients tend to stop from visiting to the hospital when the outcome of the examination is seemed to be normal which could lead to recurrent of the disease. In case of general clinical examination such as blood pressure and blood sugar, high-risk people always check themselves at Thambol Thamaidang health promoting hospital because it is easier to get there. High risk people for leprosy always have self-treatment. If they do not get better, they will only go to the nearer hospital. If the symptoms get worse, they will go to Kamphaengphet hospital in order to see a doctor on the appointed date. This indicates that the doctor is the main influence for leprosy treatment. Kissing and hugging is the way of transmission of leprosy. Most of the high risk people for leprosy rarely give the information about this because they are shy. High risk people for leprosy do not pay attention about the abnormality on their skin until they feel irritated. These behaviors bring out the spread of leprosy, but the awareness of abnormality on body can lead to the prevention of the disease.

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References

- Rajprachasamasai Samasai Institute. (2007). *Guideline of the diagnosis and treatment of leprosy*. 6th ed., Bangkok: Karnsassana.publisher.
- Thambol Thamaidaeng Health Promoting Hospital. (2013). *Registered a case report Thamaidang Hospital Health Care: Thambol Thamaidaeng Health Promoting Hospital*. Kiatsuda Srisuk. *Research Methods*. Chiangmai : klongchang Printing.
- Phitsinee Choompookom, and Pimpong Sungsutthipong. . *Qualitative Research* Faculty of education. Chiangmai University.
- Green, L.W., Kreuter, M.W., Deeds, S.G., Partridge, K.B. and Bartlett, E. *Health education planning: A diagnostic approach*. California. Mayfield Publisher.
- Shaluay Sedkij, Sirimas Rodjan, Khanidtha Phathongrak, Pensri Kongsamrit, and Pradabporn. Duangaj-jana 2009. *Diagnostic Delay in Leprosy* Bangkok National Office of Buddhism Press.
- Norina Benyapa. 2009) *Knowledge and Practice of Leprosy Patients and Contacts in Thai-Muslim Community: Case Study in Rueso District, Narathiwat Province. Independent study*, Master of Public Health, Graduate Program, Chiangmai University.
- Resume Chandawanich. (2009). *Theoretical sociology*. Bangkok: Chulalongkorn University.
- Apinya Kortem 2009 : *Self care behaviors of leprosy patients in narathiwat province*. Thesis Committee: Thirapong Thiramanas, Dr.P.H. (Epidemiology),P rapha Nantaworasin, Ph.D. (Tropical Medicine), Siriporn Chanshai, Ph.D. (Tropical Medicine). Page 119.
- Department of Disease Control (2003). *Leprosy Health Development Plan No.7*. 3rd ed., Bangkok: National Agricultural Cooperative Printing.