



Lepers Living Experiences

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ABSTRACT

Leprosy is an infectious disease that causes problems from a medical perspective to social, economic, cultural, security and health problems. Leprosy is generally found in developing countries as a result of the country's limited ability to provide adequate services in the health sector. This study aims to explore the life experiences of leprosy sufferers on the island of Mahangetang by using a phenomenological approach. The data was collected using the purposive sampling technique, through field observations and in-depth interviews with 7 participants. Data analysis was carried out using thematic analysis methods. The results of the study found eight themes, namely, activities carried out by people with leprosy, economic conditions that occurred while suffering from leprosy, psychological burden while suffering from leprosy, behavior seeking treatment, the meaning of leprosy, social support and illness experienced as destiny that must be accepted. The conclusion of this study based on the results of interview analysis found 8 themes, 20 sub-themes and 41 categories. Although suffering from leprosy, all activities are still carried out, both work and religious activities, even though the psychological burden is directly experienced by leprosy sufferers, but with social support, it can strengthen the psychology of leprosy patients so that they remain patient in undergoing treatment.

Kata kunci:

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ABSTRAK

Penyakit kusta merupakan salah satu penyakit menular yang menimbulkan masalah dari segi medis sampai masalah sosial, ekonomi, budaya dan keamanan. Penyakit kusta pada umumnya terdapat di negara yang sedang berkembang sebagai akibat keterbatasan kemampuan negara tersebut dalam memberikan pelayanan yang memadai dalam bidang kesehatan. Penelitian ini bertujuan mengeksplorasi pengalaman hidup penderita kusta di pulau Mahangetang dengan menggunakan pendekatan fenomenologi. Pengumpulan data dilakukan dengan teknik Purposive Sampling, melalui observasi lapangan dan proses wawancara mendalam kepada 7 partisipan. Analisis data dilakukan menggunakan metode analisis tematik. Hasil penelitian menemukan delapan tema yaitu, kegiatan yang dilakukan penderita kusta, Kondisi ekonomi yang terjadi selama menderita kusta, Beban psikologi selama menderita kusta, perilaku mencari pengobatan, Makna penyakit kusta, Dukungan sosial dan Penyakit yang dialami sebagai takdir yang harus diterima. Kesimpulan dari penelitian ini berdasarkan hasil analisis wawancara menemukan 8 tema, 20 sub tema dan 41 ktaegori. Walaupun menderita kusta semua aktivitas tetap dijalani baik itu pekerjaan maupun kegiatan keagamaan, meskipun beban psikologi secara langsung dialami oleh penderita kusta, namun dengan adanya dukungan sosial dapat menguatkan psikologi penderita kusta sehingga tetap sabar dalam menjalani pengobatan.

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INTRODUCTION

Leprosy is one of the infectious diseases that causes many problems from medical, social, economics, cultural and safety perspective. Leprosy mostly found in developing countries, including Indonesia (Kementerian Kesehatan RI, 2012). In 2015, world leprosy prevalence were 210,758 cases and most cases were found in the Southeast Asia region (156,118 cases), followed by the America's (28,806 cases) and Africa's (20,004 cases), while the rest were found in other regions. There was an escalation of leprosy in 2016 until reached 217,971 cases, but fortunately in 2017 and 2018 it were decreasing to 211,182 and 208,641 cases respectively, according to official figures from 159 countries from 6 Regions, (WHO, 2019).

According to WHO report in 2012, Indonesia was considered as the country with high leprosy problems and has totally 18,994 cases. It was put Indonesia in third place of leprosy cases in the world, followed by India and Brazil. Fortunately starting in 2015, the leprosy's prevalence was decreased and reached 17,202 cases followed with 16,826 and 15,910 cases in 2016 and 2017, respectively (WHO, 2018).

Sangihe is one of the archipelago districts (kabupaten kepulauan) in North Sulawesi, a province is neighbouring to Philippines. This district has an area consisting of several islands including Mahengetang Island. This island have most leper and considered as a high endemic village of leprosy (BPS Kabupaten Kepulauan Sangihe, 2020). The leprosy's prevalence tend to increased and according to Kahakitang Health Center report, there were 12 and 22 leprosy cases in 2019 and 2020 respectively (Puskesmas Kahakitang, 2020).

People with leprosy often experience physical disabilities or significantly changes that affect their daily lives. (Nsagha et al., 2011). Severe of the disease, including permanent disability is influenced by many factors, inter alia are length of illness and disobedient in treatment (Siwi Sekar A, 2019). In other site, psychologically, leper usually are very burdened since the worst consequence of this illness is permanent disabilities, so it will affects the quality of life and cause lost of their self-confidence (Hidayati et al., 2019). Person maturity based on culture and living system community impacted on someone leprosy condition, and someone who has well life experience will tell every behavior during the treatment process that is being undertaken straightly (Abedi et al., 2013).

Providing treatment using MDT (Multi Drug Therapy) and educate the leper also surrounding community who live near them, could be done to break the chain of leprosy transmission (Kementerian Kesehatan RI, 2012). This study aims to explore the life experiences of leper which were : daily activities, impacts of leprosy, self recognition, and self-acceptance towards the illness. Based on the findings above, the researcher will conduct a research towards leper's life experiences on Mahengetang Island.

METHODS

This research approach is a qualitative with a phenomenological study. Data was collected using purposive sampling, through field observations and in-depth interviews using interview guidelines, voice recorders and field notes. There were seven participants that matched with the research inclusion criteria, those were : leper with > 6 months period, pastly had leprosy before, aged between 25-

55 years, not experiencing mental disorders, able to communicate well, domiciled on Mahangetang island and willing to be a participant. Data saturation occurred in the seventh participant, when the researcher did not get a new theme, sub-theme or category in the data analysis process, that was carried out using thematic analysis methods. In this study, the researcher used the triangulation method with the technique of checking the validity of the data using sources, and it was carried out from April 11 to May 8, 2021 on Mahengetang Island, Sangihe. This research has approved from the Ethics Commission of Health Research POLTEKKES Manado, with certificate number: KEPK. 01/03/048/21 on March 26, 2021.

RESEARCH AND DISCUSSION

This research resulted in 8 themes and those were : 1) Leper's activities; 2) Leper's economic conditions after disease 3) Leprosy's description; 4) Leper's psychological burden; 5) Treatment seeking behavior; 6) Leprosy Meaning; 7) Social support; 8) Leprosy is a Diseases that have to accept as a God Destiny . The explanation of each theme is as follows:

1. Leper's Activities

This theme is supported by two sub-themes, those were: Keep working and Keep carrying out religious activities. Below are participant expressions :

"...Sometimes it feel bothers when my body was in weak condition, and I just lie down at home a lot, contrary, when my body is on good circumstances I still go to sea" (P1).

"...I still go to church, I still attend household services" (P2).

Participants also stated that the daily carried out activities can also be hampered, when their body feel weak. A research from Amirudin (2012), revealed that a person with a heavy job with an unhealthy lifestyle can cause the decreasing of that person's immune system causing by acceleration of bacteria that cause leprosy growth. The activities carried out by people with leprosy are the same as before being sick, namely continuing to work and continuing to carry out their religious activities. This is in line with research conducted from Istiarti & Widagdo (2009), which explains that respondents feel very afraid and worried about leprosy, but to overcome this, most of the respondents respond by continuing to work, some are not caring about their environment and continue to follow activities in their village.

2. Leper's Economic Conditions After Disease

This theme is composed of two sub-themes, and those are : Profession of the participants and the income of the participants. Here are the participants' expressions:

"...I still work as a fisherman but sometimes sun exposure give me body ache so I decided get home earlier, and even though I haven't caught a lot of fish hehehe" (P5).

"... Well, as a fisherman, our daily income definitely depends on the selling fish result. But so far it is afford to provide our family daily needs like : eat and drink. But with this illness, when we are feel sick, the fishing activity will be disturbing, and sometimes we cannot doing the job "" (P1).

The participants profession are vary from fishermen, housewives and also village officials. Five participants revealed that the earned income, only sufficient for provide daily eatery and drinks. Along with this condition, there eas a tudy that stated thet those with low income, usually exist in lack nutrition, and dragging into a low immune system condition, and making them easy to be infected by germs. This condition will be worsen by low knowledge about health wherein will impact on their health status reduction as well (Soemirat, 2009). Adhikari et al., (2013) also stated that leprosy has placed as of low socioeconomic indicator, because often afflicts towards lower economic individual. Jariwala, et al., (2013) study found that leprosy was directly correlated with poverty and inversely corelate towards economic prosperity.

3. Leprosy Description

This theme describes leprosy description, and composed of 2 sub-themes. The first sub-theme: Signs of leprosy that appear on the skin for the first time. This is evidenced by the participants' expressions below:

"...Initially the skin on my right hand showed white markings resembling tinea versicolor (while pointing at his right hand)" (P1).

In addition to white marks that resemble tinea versicolor, there are also red marks that appear on the participants' skin. The following are the expressions of the participants:

"...At first, my body felt itchy and then my face turned red" (P4).

The second sub-theme: Leprosy patients examination. Here are the participants' expressions:

"...The examining methods done by using a cotton swab and then rubbing it on the white spots that appear on the skin" (P6)

"...After that the nurse put a needle in my ear to draw blood" (P4).

Early stages of leprosy development begins with the signs such as white patches that resemble tinea versicolor and signs such as redness on the skin, and this properties were revealed by the participants. This statement is supported by Bhat & Prakash, (2012) study, that has revealed that one of the most easily observed sign of leprosy is skin lesions manifestations, development of leprosy, also severity of the disease can be judged by the physical appearance of these lesions. A similar study by Wani et al., (2009), was also revealed that one of the signs that can be seen from leper's can be identified by the presence of lesions on the skin. Participants also revealed that when there were visible signs on the skin, the participants underwent a health examination, such as a physical examination using a cotton swab rubbed towards skin to held an examination from ear blood samples, to help ensure

the accuracy of the diagnosis. Sermrittirong & Van Brakel, (2014) study also suggests that leprosy suspected should be tested, and the diagnosis is done based on a physical examination of each patient and a careful study of their clinical history.

4. Leper's psychological burden

This theme explains the psychological burden of leper's and composed of 3 sub-themes, namely: fear, shame and despair. Below are the statements of the participants.

"...I am afraid of suffering from this disease because it can be transmitted to my wife and children, but the doctor said there is no need to be afraid because it will definitely get better if you take medicine regularly" (P1).

"...I feel ashamed to leave the house because my face is black, very black (both hands pointing at his face)" (P3)

"...At first I felt hopeless because this disease made me suffer and then I thought about dying" (P7)

This theme explains the participants' feelings when they suffer from leprosy, as participants say that they are afraid to transmit the disease towards family members who live in the same house. (Peters et al., (2013) stated that the decision to seek medical treatment is based on the awareness of contagious possibility to other family members. Participants also revealed they felt ashamed because the mark of the disease began to appear and could be seen by other people. Istiarti & Widagdo, (2009) explained that psychologically, spots and bumps forming on the skin also the loss of body parts will causes inferiority, also embarrassed and useless feel in the lepers. The participants also expressed despair about this disease. This statement is supported by research from Lusli, et al., (2016) which stated that individuals with leprosy will feel ashamed, worried, and even feel hopeless because of the lesions on their face and body.

5. Treatment Seeking Behavior

This theme is composed of 3 sub-themes as follows: Supporting Health Center, Village Hall and District Health Office. The following is the expression for the participation of each sub-theme:

"...I was told to take medicine for one year, after the medicine ran out, I took the medicine at midwife at the pustu" (P3).

"...I checked myself into the Village Hall (pointing to the village hall). At that time there were health workers from the District Health Office and from the District Health Center who came to conduct an examination at this place" (P1).

"...There is a relative of mine who usually takes medicine at the Health Office and then sends here by ship, when the supply of medicine at the Pustu runs out" (P5).

Right leprosy treatment is one way to break the chain of transmission of this disease. All treatment seeker often went to local health care facilities such as the Pustu, that seems to be the only health facility on the island. Singh, (2012) in his research suggests that respondents develop perceptions and

judgments about symptoms after experiencing physical discomfort. This discomfort is push them to seek appropriate actions, called health seeking behavior. The participants initiative to consulting about their discomfort at the puskesmas pushed by couple reasons, as : demands for health, signs and symptoms experienced such as injuries due to leprosy, as well as strong support from the family and health workers to seek treatment (Sandi, 2018). According to Ulfah, (2011) the patients that obedient in taking medicine, will become patients who finish their medicine according to the advice of health workers and come back to the puskesmas to take the next medicine according to the schedule determined by the health worker.

6. Leprosy meaning

This theme consists of two sub-themes, Those were: the first sub-theme is positive meaning. Five participants believed that their illness would be cured if they regularly took medicine and prayed for God's help. Following are participant statements below:

"...I believe that if God is pleased, then I am sure that he will healed me. So I routinely take medication within a year and never stop taking it" (P4).

Second sub theme: Negative meaning. Two participants believed that leprosy had existed since ancient times, and was even a disease of God's curse. Following are participant statements below:

"..Initially I thought this was an incurable disease because there was an old people dogma stated that the diseases was a curse from God. And because it has existed since ancient times also contagious, the patients have to live separately from other people, mas (looks at the researcher)" (P1).

Each participant has their own opinion about the disease experienced. Five participants interpret leprosy with a positive meaning. Participants' expressions are supported by research from Price, (2017) which states that compliance in treatment is required for preventive measures, eventough currently this disease can already cured easily through Multi Drug Therapy (MDT). This study results also found that two participants interpreted leprosy negatively. This participant's statement is reinforced by Charles-Damte, (2016) that stated leprosy is known to the community from cultural traditions so that leprosy is understood as a highly contagious and incurable disease, a disease as a God's curse.

7. Social Sevicees

This theme consists of 4 sub-themes, and those were : family, neighbors, village government and health workers. The following are excerpts from statements from participants:

"...Support from my family is always there, they always remind me not to forget to take my medicine, even accompany me to check my health and take medicine" (P6).

"...Neighbors always remind us to be diligent about taking medicine because it will definitely get better and they also say not to be ashamed to hang out" (P1).

"...Support from the village government is done by collecting data lepers to undergo examination" (P6).

"...Doctors from Tahuna and Manado came here to examine all residents who were registered as lepers. They were monitoring the patients progress, last year was the last time they came" (P4).

This study found that the social support received by the lepers mainly gain from family, neighbors, village government and health workers. The findings revealed that the seven participants received support from their families such as reminding them not to forget to take their medicine. Good family support will play an active role in leprosy patients cured, the given support like reminding the schedule for taking medication is very important (Zakiyyah et al., 2015). Family support will have a good affect towards leprosy patients health therefore the family as a providing support and also as a closest person will help lepers to seek health services and undergo treatment (Rahayu, 2017). Sholehuddin et al., (2019) stated that social support from the nearby environment has a major impact on people with leprosy, so they will be more enthusiastic and confident in carrying out their lives. The role of health workers also very important in dealing with diagnosis based on a physical examination of each patient and a careful study of their clinical history (Gosling et al., 2017).

8. Leprosy is a Diseases that have to accept as a God Destiny

This theme describes leprosy identification and composed of 2 sub-themes. The first sub-theme: early leprosy properties on the skin. The second one is about how to accept leprosy and patiently undergo treatment.

This is evidenced from the participants' statements and expression below:

"...I accept this disease even though it is very torturous but I still accept it sincerely, well consider this a life test hehehe" (P1).

"...How come this disease can be cured because there is a medicine, therefore you must be patient and take medicine regularly according to the prescription, moreover ask for God's help through prayer" (P6).

This research showed that all participants said they could accept leprosy suffering sincerely. This participant's expression is strengthened by Sandi (2018) which suggests that the encouragement in patients in the motivation form is presented by strengthening intentions, positive thoughts, efforts to comply the treatment and also showing an accepting attitude towards current situation in a resigned manner. The seven participants also revealed that they must continue to try to undergo treatment patiently while asking God's help so that they can recover from their illness. This phenomenon is supported by research conducted by Charles-Damte, (2016) which explains that the belief that participants have about the reason for the onset of disease comes from the Almighty with the aim of increasing the degree of participants if participants undergo and accept it patiently.

RESEARCH LIMITATION

Participants habitually were using local regional daily language and makes the participants have to translate into standard Indonesian so will easily understood by readers.

CONCLUSIONS AND SUGGESTIONS

Participants continued to carry out their daily activities, such as continuing to work according to their respective professions and their religious activities, although their physical impact of leprosy was seen clearly like : white marks on the skin resembling tinea versicolor and redness such as heat rash and even swelling of the face, feet and hands. This physical condition creates fear, shame and even despair, and underlies the participants to form seeking treatment behavior to nearby health care facilities also build an interpretation that leprosy can be cured. The support from family, neighbors, local government and even health workers, makes participants willing to accept the illness as a destiny, and this is a form a positive participants' self-acceptance. The local government needs to provide a special allocation from the APBD to control leprosy. This funding can be allocated to complete existing facilities and infrastructure lackness in the Puskesmas, in order to achieve leprosy elimination at the district/city target in 2024. This can support community nurses in carrying out their roles from the disease promotive and prevention through health promotion. This prevention approach will help patients to recognize the early signs and symptoms of leprosy and form personal early treatment behavior

ETHICAL CLEARANCE

This research has approved from the Ethics Commission of Health Research POLTEKKES Manado, with certificate number: KEPK. 01/03/048/21 on March 26, 2021.

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