

Original Article

ETHNOGRAPHIC STUDY OF TUBERCULOSIS TREATMENT SEEKER BEHAVIOR ON THE ISLAND OF BURU, MALUKU, INDONESIA

Rohmansyah Wahyu Nurindra<sup>1</sup> Usman<sup>2</sup> Firda Yanuar<sup>1</sup>

<sup>1</sup> Research Agency of The Ministry of Health Pangandaran

<sup>2</sup> Polytechnic of Bau Bau

Corresponding author : Firda Yanuar Pradani : fhierda@gmail.com

ABSTRACT

**Background:** Tuberculosis (TB) is reported as a world health problem, especially in developing countries. It is estimated that one third of the world's population has been infected by *Mycobacterium tuberculosis*. WHO has stated that tuberculosis has now become a global threat. Indonesia is one of the 27 countries in the world with MDR-TB cases.

**Methods:** A qualitative study with an ethnography design was conducted to determine and reveal the meaning of treatment-seeking behavior in "Batu Balender" or TB patients in Buru Island, Maluku, Indonesia. The research data was collected through interviews with 15 informants from all risk groups that are directly related to TB. Observations were made to ensure the validity of the data.

**Results:** This study revealed that from generation to generation, the Alifuru tribe believes that diseases are grouped into three categories: natural diseases, sick submissions, and ancestral curse. Indigenous people have believed that TB is an incurable ancestral curse disease. They know the "Kaygosa" who is believed to be the holder of natural medicinal plants to treat TB, such as leaves and bark.

**Conclusions:** Alifuru tribal people who access health services to obtain Directly Observed Treatment Short-Course (DOTS) have experienced failure in treatment due to local customary rules that prohibit taking medicine if a tribal community has died and believes that a community health center or hospital is "house died".

This study suggest that education and counseling for TB treatment should be optimized in efforts to improve the health of local tribal communities.

**Keywords** : *Batu Balender, Ethnography, Health Seeking Behavior, MDR-TB, Traditional Medicine*

INTRODUCTION

Pulmonary tuberculosis is an infectious disease that has become a global issue, caused by the bacterium *Mycobacterium tuberculosis*, with an estimated one-third of the population infected and 2.5 million people dying each year. Tuberculosis is a problem that requires government attention because the target crude mortality rate has not been achieved. This is due to the low number of pulmonary tuberculosis case findings, where patient detection and treatment of pulmonary tuberculosis is an important key in treating pulmonary tuberculosis.<sup>1,2</sup>

Every year, it is estimated that 3 million people with TB are undetected and/or remain unnotified to National TB Programs (NTPs) globally.<sup>1</sup> Lack of accessibility and availability of TB services are major drivers for this.<sup>3</sup> Those who are missed are often members of key/vulnerable populations (i.e., miners, prisoners, elderly, people living with human

immunodeficiency virus (HIV), or people in hard to reach areas).<sup>4,5</sup> The discovery of pulmonary tuberculosis patients in the DOTS strategy is carried out passively or known as passive case finding. Screening of pulmonary tuberculosis suspects is carried out only for patients who visit a community health center, so that patients who do not come to the community health center are still a potential source of transmission. The application of the passive case finding strategy is considered less optimal because tuberculosis cases tend to increase.<sup>6-11</sup>

In Indonesia, 569,899 new tuberculosis cases were reported during 2018 out of the estimated number of 842,000 cases (32% of cases were underreported). These cases included 60,676 cases of childhood tuberculosis and 10,174 tuberculosis with HIV. The number of successful treatment was 85% with 4,412 drug resistance cases. Based on the health profile of Maluku province in 2016, it was found that the number of new BTA positive cases (BTA +) was 1,508 cases and continued to increase when compared to new BTA + cases found in 2013, which was 1,508 cases. The success rate for treatment in Maluku Province continues to fluctuate, 66.58% in 2014, 78.9% in 2015, 58.6% in 2016, and 58.15% in 2017. Even though it has increased in 2017, the treatment success rate is still far from the 85% WHO standard.<sup>12,13</sup> Based of Maluku Provincial Health Profile (2015), the children of the Alifuru tribe who were HIV-positive for tuberculosis counted 150 people and the recovery rate after treatment is 55.22%, still far from the indicator of Maluku province, up to 85%. This means that achieving the cure rate for tuberculosis treatment in Buru Regency requires attention to achieve the goal.

Minority groups are more likely to live in overcrowded and poorly ventilated houses. The perceptions of health and illness in some ethnic minorities may also have a negative impact on treatment-seeking behaviors and a poor socioeconomic status and language barrier can also impact minorities' access to health services.<sup>14</sup> Seeking treatment is closely related to people's perception of health and pain. This public perception will determine the decision making in seeking treatment, especially regarding tuberculosis. It is necessary to conduct a study to determine public

perceptions and preferences for seeking treatment so that it can simultaneously evaluate the implementation of tuberculosis control that has been carried out in the regions, in this case on Buru Island, Maluku, Indonesia.

## **METHODS**

The research method used in this research is qualitative with ethnography design. This research was conducted for approximately 6 (months), from 11 January 2016 to 29 June 2016 in the working area of Waelo Health Center, Waelata District, Buru Regency. Primary data were collected by conducting in-depth interviews and observations. The informants who were successfully interviewed were 15 people consisting of TB patients, tribal heads, Kaygoza (smart people) and health workers who are in charge of the Waelo Puskesmas infectious disease control program. In addition, observations were also made to maintain the validity of the data. The data obtained were analyzed using content analysis presented in narrative form.

## **RESULTS**

Informants for this study were TB patients, Kaygoza, chiefs and health professionals involved in these at-risk groups. The number of informants who were successfully interviewed by the investigator was 15 people, including 8 TB patients, 2 Kaygoza, 2 chiefs and 3 health professionals. On the basis of gender, there were ten male informants and five female informants, ranging in age from 24 to 73 years. Depending on the profession, there are informants who work as infectious disease control employees, farmers and housewives.

The first action the informant took when he first fell ill and was not receiving treatment. For this reason, the researcher wanted to know informants' perceptions of the disease, how to get to know informants' tuberculosis early, the first symptoms associated with tuberculosis, the first thing to do when they felt pain, and when the informant had a underwent treatment.

The informants' perception of diseases varied. The informants understood that the perception of pain was a condition in which someone experienced disturbances in their body and there were symptoms such as fever, cold, cough, insomnia, vomiting and body

sweat. Apart from that, there were also informants who had the perception that a sick state is when someone cannot do anything and lies on bed.

*".....My body hurts when there is disturbance, as I feel it now. Finally I can still chew betel nut, now it's hard because of the nausea ...."*

(RI, 27 years old, housewife, 03 May 2016)

The informant when he first learned of his illness felt shock and stress. Informants cannot accept the reality with what happened to them. This is because the symptoms that he felt for so long are a prolonged cough. This informant performs treatment at the health center and performs sputum checks. Another informant felt stressed when he first found out that he had TB because he knew that TB was very easy to transmit, while he had a family who lived with him. The informant was afraid of transmitting the TB germs to his family.

*"...beta, I was surprised, zinc was received when the doctor Dani said positive ba .. Balender stone. From getting treatment at the puskesmas, because of coughs, night sweats, even though one house is cold. The officer took sputum and sent to Namlea Hospital for a photo of the lungs..."*

(XT, 33 years old, People's Miners, 12 January 2016).

The results of the interviews with the informants describe what they did for the first time when they ill. JF said he did nothing when he was sick. After he can no longer move and cannot do anything, he goes to the hospital.

*"...Well, be quiet for a moment. Later if I can't face it ... complaints of chills, then I go to the hospital ..."*

(JF, 35 years old, Entrepreneur, 13 January 2013)

The informant took medication when he experienced a disturbance in his body. MN, for example, stated that he did the examination after he felt there was a disturbance. As expressed by MN when interviewed. Likewise, another informant named ZA, a 35-year-old housewife stated that when she felt symptoms she immediately got checked out.

*"... when I know such symptoms, go straight to the place ..."*

(ZA, 35 years old).

Informants performed self-medication when they felt initial symptoms related to TB on their own initiative without interference and influence from others. The informant's self-medication to treat his illness was to buy medicine at a shop as stated by LO (35 years). LO did self-medication because he did not know what disease he was suffered.

There were also informants who performed traditional medicine by drinking biana leaf stew (coleus benth) which is believed to treat coughs. The informant with the initials HR got information about the leaf from his parents. Apart from HR, another informant has also used traditional medicine that he made himself in the form of real leaf decoction (*chromolaena odorata*), which is believed to treat internal diseases. However, the effort he made meant nothing. He said that his illness was getting worse.

*"Anyway, give me the leaves of this forest. If here, the things here, life grows normally in the forest, which is the responsibility of the village midwife. Leaves and roots ..... Our parents from the beginning knew what the mantri was like"*

(HR, 30 years old, Farmer, 13 January 2015)

The informant made efforts in traditional medicine to treat tuberculosis. This traditional medicine

has help or interference from other people. The informant performs traditional medicine by drinking water that has been given "talk" by "Kaygosa".

Coughing was the first symptom felt by the informant. There are smart people who say that the disease suffered by AF by talking (in the language of Buru) can be cured. Talking is direct communication with ancestors so that the disease suffered by AF can be cured immediately. The informant drank the water that had been spelled with a white plate.

*"...pray in front of the house facing the sunset, hold a white plate containing water and ask for prayers in the Alifuru language. ..."*

(Kaygoza 73 years old, 28 March 2016)

YS did different things from the previous informants. YS is the head of a family who works as a community mining worker who performs traditional medicine by drinking tree roots to treat his illness. He gets tree roots in the forest and he often finds it on his way to the forest to pick soklat (cocoa). However, after a while YS's cough did not go away.

The next finding relates to the informants' attempts to seek treatment at modern health services. The informants did modern medicine after alternative medicine did not cure the disease. However, a hereditary belief has said that the place of health care is "a house to die from." Until now, care and treatment at the health care center. They have requested and signed a forced return letter. Treatment is given at the community Health centers and regional public hospital "Namlea". For this reason, researchers identified the process leading to the informant's place of modern medicine, where modern medicine is used, when to use modern services, the health impacts they get and their greatest motivation to take medication.

IR was treated in a modern manner without his knowledge. IR was taken to the hospital on the initiative of his children when he was unconscious. This 52-year-old man was unconscious for three days, but after feeling

able to speak, IR insisted he had to go home because he did not feel well if he was in the hospital. This is because from generation to generation there is a belief that a hospital is a "house of the dead". Likewise, SR felt, he was referred to the hospital after his condition was very severe, this mother of six with an unconscious condition was referred from a community health center after experiencing a cough a year ago.

*"...if someone is sick, take him to the hospital or health center, if we see that our family is sick just a little we have to take it home, on a bed that is usually used, we must go home to obey the messages passed down from generation to generation..."*

(IK, 27 years old, IR's companion)

*"The hospital is the same as "house of death". Every time a family falls from a tree, the wound can be torn. if it hurts, it's not karma from the ancestors'. if you bring it to the hospital, you will definitely die, so you need to take it to the hospital if the mother says the mantri ordered it there "*

(IR, 52 years old)

Initially MY felt the side effects of the drug very hard. Nevertheless, gradually his condition got better. However, after 6 months of treatment (August 2015-February 2016), MY relapsed again even though he had finished his treatment and was diligently taking medicine. But after the researcher asked about his medical history, it turned out that MY underwent an incomplete DOTS period. He believed that a leader could not take medicine if his people died. Not only a village head or tribal head, but also local people do not take any medicine if they experience illness when a relative or resident in their village dies, as a form of respect for the local tribal community.

*"...back to a hereditary tradition, said our ancestors, our habit of taking medicine is still left over, which has become our tradition, in one pill there must be something left, not*

*finished, and if a family or village member dies, you can't take medicine..."*

(MY, 38 years old, village head, 13 January 2015)

Informants are highly supported by those around them. Apart from that, the informant had the enthusiasm for self-medication. For example, MN, his mother's support is very important when he is treated. MN always tries to feel comfortable. The same thing was expressed by JF regarding motivation. This 35-year-old informant stated that the motivation came from himself. Because the one who feels the pain is himself. JF thought that when he did not take medication, surely the disease would end up getting worse and more dangerous.

*"... I think the problem of motivation arises from myself. I was the one who was sick. If there was no treatment .... it would have been chaotic if I didn't get treatment ..."*

(JF, 35 years old, Entrepreneur, 13 January 2015)

Regarding how health workers treat HIV patients with TB co-infection, all informants stated that all health workers served well, and considered them like their own family. The results of the interview with JF said that the health workers treated him like a child. When JF came, he immediately took the medicine and then went home. Nothing was complicated and he received free medicine, free of charge.

## DISCUSSION

Informants' perceptions about illness varied. The informants understood that the perception of pain was a condition in which a person experienced a disturbance in his body and there were complaints such as fever, cold, cough, accidents, knife cuts, sleeplessness, vomiting, and body sweating. Apart from that, there were also informants who had the perception

that sickness is when someone is unable to do anything and is helpless. These perceptions affect the response of informants when experiencing illness.

The responses of the informants varied greatly when they first learned about the symptoms of TB disease they were suffering from, starting from being normal, stress, and shock. All informants felt the symptoms of TB disease, but had different complaints. Symptoms include coughing and bleeding, night sweats, nausea, vomiting, chest pain, chills, swelling of the neck and base of the armpits and spots all over the limbs. In line with research conducted by Puspitasari, cough is the most common symptom of pulmonary TB. Hemoptysis, coughing with blood, is rarely the main complaint, but usually this complaint is a further symptom that indicates the presence of active bacteria in tuberculosis sufferers.<sup>15</sup>

Informants' knowledge about TB symptoms also varied. Informants who know the early symptoms of TB will immediately take treatment action. Unlike the case with informants who do not know anything. This knowledge affects the response of informants when experiencing illness. Most of the informants, who did not know the symptoms of TB, did nothing until they were very sick. Meanwhile, when the informant did the treatment, he did not immediately apply modern medicine but tried self-medication or alternative medicine. Novita et al. (2017) also observed that understanding information and experiences with sufferers should be used to assess their condition (perception). In this study, low threat perception tends to cause people who interact directly with patients to not make early detection.<sup>16</sup> Informants who initially did nothing, take medication when their pain is so severe that they fall and cannot do anything about it. Some informants took medication when their illness was very serious. There were also informants who took medication when they first felt symptoms

The concept of Rosenstock's health belief model explained that if a person feels sure that he is not infected with a disease, even though he perceives the disease as having a serious impact, then he tends not to make efforts to reduce the risk of the effects of a disease and not have his health checked.<sup>17</sup> Self-medication was

the informant's first treatment when he was sick. The informant's first choice when experiencing TB symptoms for the first time was to buy medicine at a shop or pharmacy without instructions from a health worker. Symptoms that were treated by the informants with local drug stores were cough and fever. This action was carried out because they did not know that the symptoms they were experiencing were TB symptoms. After the treatment did not provide a healing effect on the symptoms, the informants in this study continued with modern medicine.

This study revealed that the informant self-medicated by consuming traditional ingredients that he prepared himself. The concoction is in the form of boiled miana leaves that they then drink. They concocted the potion themselves without involving other people. They believe the herb can treat coughs and clear the throat. The reason the informant chose the treatment related to the experience and information from his family. Previously, families who had used this herb felt the same symptoms. In traditional medicine, miana leaves are commonly used to treat intestinal worms and coughs. Regarding this, Rizal stated that miana leaves are used to treat coughs, as a therapy for heart disease, increase appetite, neutralize toxins, remove blood clots, and as a worm medicine.<sup>18</sup>

The traditional medicine performed by the informants in this study was drinking water that had been spelled by the shaman and drinking traditional herbal medicine purchased from a mobile herbalist. Informants believed that the treatment could treat the diseases they were suffering from. Apart from their own beliefs, informants also received information from their families. They visited the smart person who is their family and neighbor to get drinking water that has been given a spell. However, after the treatment did not make any difference, the informants then accessed medical services from community health centers and hospitals. It was revealed that there were informants who visited traditional healers for various reasons such as the proximity to the house, the affordable cost, and the benefits obtained by the informants including reducing the fever experienced by their children. Furthermore, if self-medication and traditional methods are

unsuccessful, they will visit health services for medical help.<sup>19</sup>

As has been researched by Masaru Emoto in Wardiani, et al. (2017), who succeeded in proving that water can respond to words, sounds, and even affects a person's health and makes the earth prosperous. The stronger the concentration of the message giver, the deeper the message printed on the water. Water can transfer the message through other water molecules. Therefore, water that is prayed for or given a spell will be able to heal the sick.<sup>20</sup> This study revealed that self-medication with herbs is a common practice among TB patients. As for those who practice traditional medicine by drinking herbal medicine purchased from mobile herbalists, they believe that this herbal medicine helps to relieve their throat like what they have ever tasted. Previous research found that there are two methods of administration of the herbal leaves. In several instances, the TB patients first make use of the herbs before seeking proper anti-TB treatment. Also, the patients and traditional healers alike accepted that the medicines provided by DOTS programme could cure the disease. As the herbal plants identified were well known medicinal plants in different parts of the world, their therapeutic value and efficacy should be further explored in the light of developing effective complementary medicines for TB.<sup>21-23</sup>

Theory plan behavior has explained that a person's actions are influenced by control beliefs in the form of experience. Actions are heavily influenced by one's past experiences. Likewise with treatment-seeking behavior in terms of traditional medicine. Based on the experience of the informants regarding the symptoms of pain suffered, they are treated with traditional medicine in the form of drinking herbal medicine. Then, when the same symptoms were felt, the informant took the same treatment.

Furthermore, related to how the informants received medical treatment services, including because their condition was severe and they could not do anything. In the end, the informant's family member then took him to the hospital for treatment because he was unconscious. Another informant stated that he did his own treatment at home by buying medicine at a shop

without any advice from a health worker. However, the treatment did not cure the disease, so the informant took medication at a modern health facility such as a community health center.

In this study, some informants visited a health facility when they experienced symptoms such as the flu, headaches, and minor aches and pains. There are also those who use the health facilities after experiencing the illness they are suffering from. Informants recognized the symptoms of the disease as coughing and sweating at night. All informants who were treated underwent extraordinary changes. As the tuberculosis treatment that was given passed the second month, it slowly changed for the better. Informants believe their lifespan will be longer after treatment. Earlier, this informant had nearly died from the tuberculosis germs that ate in his body. However, after the treatment his condition slowly improved. According to research conducted by Anusha et al, a person's medication is associated with who has the most role in a family to determine where to seek treatment when someone is sick.<sup>24</sup> Previous researches identified the relationship between knowledge, family support and social support and self-care behavior. Social support has a strong influence to the quality of life of TB patients. An influential source of social support to improve the quality of life of TB patients were family, friends and significant others. Family support provides the highest contribution with an OR of 19.7. An influential type of social support to improve the quality of life of TB patients were emotional, informational and companionship support. Emotional support provides the highest contribution with an OR of 7.4. Social support to TB patients given at the 5th month of treatment have a positive impact on the quality of life with PAR% was 70%.<sup>25,26</sup>

Self-motivation and family support / PMO for pulmonary TB patients is the key to the sustainability of pulmonary tuberculosis treatment until fully recovered. Education and counseling for pulmonary TB patients and their families / PMOs are absolutely necessary in Indonesia.<sup>27</sup> Furthermore, someone's medication is also related to the role of health workers & social support in motivating people to access services or treatment in

health care facilities. Social support affected individual behavior, such as decreased anxiety, helplessness and hopelessness, and therefore can improve a person's health status. Increasing health status means improving the quality of life for sufferers. Family support, community support, and support from health workers had an important role in improving medication adherence.<sup>28-30</sup> Siahaan et al (2020) stated community-based organizations are best placed for accessing and engaging hard to reach populations and providing integrated support which can have a large positive effect on TB notifications.<sup>31</sup>

## CONCLUSION AND RECOMMENDATION

This research has revealed several actions of the people on the island of Buru when experiencing symptoms related to tuberculosis. The no action stage was influenced by the informant's perception of illness. At this stage, the informants felt that the symptoms were not severe, so they decided not to do anything to treat it. The self-treatment stage experienced by the informants because they had not felt any severe symptoms, thus they believed that these symptoms could be cured with drugs purchased from a local shop and traditional medicine that they prepared themselves. Information from family and experiences of family members played a role in the informants' decision-making process regarding their treatment. The traditional medicine performed by the informant was based on norms or beliefs in the community that considered that the disease he was suffering from could be cured by visiting "kaygosa" to get a cure. Experience with the same symptoms of pain is also a consideration for those who choose traditional medicine. Professional treatment, in this case utilizing modern medical facilities, is carried out when previous treatments have not worked either self-medication or traditional medicine. The use of health facilities is also greatly influenced by those closest to the informant, such as friends, family and health workers.

Based on the results of this study, TB service providers need to improve information about the symptoms and treatment of tuberculosis, especially for patients with MDR-TB, so that an infected person is able to make the right decision to take treatment. This effort

will reduce other risks that could be harmful to TB patients and treat early before additional symptoms appear.

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