

Experience of Kaili Community in reducing pain and swelling because of filariasis disease

Experiencia de la comunidad de Kaili en la reducción del dolor y la inflamación a causa de la enfermedad de la filariasis

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SUMMARY

Introduction: *Filariasis has been common in Baluase area with complaints in the form of swelling in the legs. Patients who suffer from filariasis do not receive complete medication and often complain of swelling, pain, and disruption in their daily activities. In addition, they also often try traditional medication by applying decoction and buying drugs at the shop when they experience fever and pain in the legs. This study aimed to understand the culture of Kaili communities to reduce the symptoms of pain and swelling due to filariasis.*

Methods: *This study used a descriptive phenomenological qualitative design. Nine participants were recruited for the study using the purposive sampling technique. The data collection instruments employed included in-depth interviews. Interview guidelines were prepared based on the research objectives and were further translated into several*

questions to explore the patients' experiences. Data were obtained using in-depth interviews. The Colaizzi method was used for data analysis. All research processes utilized NVivo version 12.

Results: *The result characterized four themes: knowledge about filariasis, filariasis treatment that patients have obtained, physical changes related to filariasis, and Lero wood which is hard to find.*

Conclusion: *Based on the result of the research, Filariasis disease causes physical changes in the patient and causes discomfort in the Kaili community. However, Lero wood can reduce complaints of pain and swell due to filariasis, as experienced by the Kaili community.*

Keywords: *Filariasis, Kaili culture, pain, swelling*

RESUMEN

Introducción: *La filariasis ha sido común en el área de Baluase con quejas por hinchazón en las piernas. Los pacientes que padecen filariasis no reciben la medicación completa y, a menudo, se quejan de hinchazón, dolor e interrupción de sus actividades diarias. Además, también suelen probar la medicación tradicional aplicando decocciones y comprando drogas en la tienda cuando experimentan fiebre y dolor en las piernas. Este estudio tuvo como objetivo comprender la cultura de las comunidades de Kaili para reducir los síntomas de dolor e hinchazón debido a la filariasis.*

Métodos: *Este estudio utilizó un diseño cualitativo fenomenológico descriptivo. Nueve participantes fueron reclutados para el estudio utilizando la técnica de muestreo intencional. Los instrumentos de recolección de datos empleados incluyeron entrevistas*

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en profundidad. Las pautas de la entrevista se prepararon en base a los objetivos de la investigación y luego se tradujeron en varias preguntas para explorar las experiencias de los pacientes. Los datos se obtuvieron mediante entrevistas en profundidad. Se utilizó el método de Colaizzi para el análisis de datos. Todos los procesos de investigación utilizaron la versión 12 de Nvivo.

Resultados: *El resultado caracterizó cuatro temas: conocimiento sobre la filariasis, tratamiento de la filariasis que han obtenido los pacientes, cambios físicos relacionados con la filariasis y madera de Lero que es difícil de encontrar.*

Conclusión: *Con base en el resultado de la investigación, la enfermedad de filariasis provoca cambios físicos en el paciente y causa malestar en la comunidad de Kaili. Sin embargo, la madera de Lero puede reducir las quejas de dolor e hinchazón debido a la filariasis, como lo experimentó la comunidad de Kaili.*

Palabras Clave: *Filariasis, cultura Kaili, dolor, tumefacción.*

INTRODUCTION

863 million people in 47 countries worldwide remain threatened by lymphatic filariasis, and about 51 million people were infected in 2018, a 74 % decline since the WHO's Global Program to eliminate Lymphatic Filariasis in 2000 (1). Almost all regions of Indonesia are filariasis endemic areas, especially Eastern Indonesia, which has a higher prevalence of 14 000 cases spread over 401 regencies/cities (2). Data from Central Sulawesi, filariasis sufferers, were found in 172 cases, and nine regencies were considered endemic regions. Sigi Regency ranks second after Poso with 56 cases (3). Geographically, Sigi Regency has endemic areas suitable for breeding places for mosquitoes that transmit live lymphatic filariasis, namely swamp areas, dirty water, rice fields, and forests (4,5).

This disease is being ignored because there is no strategic interest from any party. This disease is associated with nutritional problems, environmental hygiene, and poverty. It causes socioeconomic losses and permanent disability, World Health Organization (WHO) set this disease to be eliminated worldwide (1,6,7). Filariasis remains one of the world's most

debilitating parasitic infections and is a significant contributor to poor health in many endemic countries, including Indonesia (8,9). Therefore, Indonesia also accelerated efforts to control filariasis. In 2000 WHO declared "The Global Goals of Elimination of Lymphatic Filariasis as a Public Health Problem by the Year 2020". In line with that, Indonesia has established the Filariasis Elimination Program as one of the national priorities for eradicating infectious diseases following the Presidential Regulation of the Republic of Indonesia number 7 of 2005 concerning the National Medium-Term Development Plan 2004-2009. Filariasis prevalence rate 19 %. This means that 40 million people could suffer from filariasis if mass drug administration, prevention of filariasis, and planned activities toward eliminating filariasis in Indonesia are not carried out by 2020 (4).

The Ministry of Health estimation result states that the annual economic loss of filariasis reaches 43 trillion rupiahs if the filariasis control program is not carried out. Therefore, effective intervention and efficient use of resources through systematic and strategic efforts will result in savings for the State. For this reason, a systematic plan at the national level is needed to overcome this problem, namely by establishing two pillars of activity to be taken: Breaking the chain of transmission by administering Mass Filariasis Prevention Drugs in endemic areas by using Diethylcarbamazine (DEC) 6 mg/kg body weight and combined with albendazole 400 mg once a year for a minimum of 5 years. Treatment of clinical cases of filariasis, both acute and chronic clinical cases. Mass preventive drug administration filariasis is implemented on a district/city basis (2).

Filariasis symptoms include lymphoedema, elephantiasis, and scrotal swelling, which occur later in life and can lead to permanent disability (1). In addition, body deformities often lead to social stigma and sub-optimal mental health, loss of income, earning opportunities, and increased medical expenses for patients and their families (2,10). Patients in acute conditions will have local inflammation involving the skin, lymph nodes, and lymphatic vessels, often accompanied by chronic lymphoedema, and even experience lymphatic system damage (10,11).

Based on the results of preliminary interviews with public health center officers, it was found that there were ten people with filariasis in the Baluse Health Center working area. The last new case was detected in 1997. The main treatment program provided to reduce the complaints of filariasis is by consuming drugs (12), and several patients even need chemotherapy (1). Another interview conducted with filariasis sufferers who have suffered from this disease since 1962 said that he always gets medicine from the public health center. Still, if the disease recurs, the pain and swelling in the leg area are disturbing. However, the patient does not go to the public health center to receive treatment since he prefers traditional medication. They are Kaili tribesmen who have a lot of “village medicine” to treat this disease, including using “Lero wood”, which has been scraped from the stem, added to salt, and then used to compress swollen or injured feet. The patient prefers traditional medication due to the side effects of drugs, such as fever, headache, muscle aches, nausea, and dizziness (13). The purpose of this study was to determine the habits of the Kaili tribe to deal with pain and swelling due to the symptoms of filariasis.

METHODS

Design and Population Study

This study was a descriptive qualitative approach with thematic analysis. Interviews were conducted using semi-structured interview guidelines and open-ended questions. Nine patients with filariasis, one community leader, a traditional healer, and a program holder at the public health center, in Sigi Regency, Indonesia, participated in this study by purposive sampling. Participants willing to participate in the study are 50-75 years old and in the acute filariasis phase (the legs are swollen and feel pain). The most informant said they had filariasis for about 35 years, one person was around 20 years old, and the longest was 60 years. All participants gave their informed consent to participate in the study approved by the ethics committee for Poltekkes Kemenkes Yogyakarta number LB.01.01/KE/XLIV/417/2016.

Data Collection

Data were collected through semi-structured in-depth-interview, and measure pain scales were performed on all subjects. First, researchers observed daily filariasis patients using videos, notes and observation sheets, interview guidelines, logbooks, and field notes. Next, a thematic analysis was used to identify the experiences and meanings of the views in each participant’s transcript. In the phenomenology approach, the meaning of a participant’s life experience comprises the key thematic points in the findings. The data analysis process employed in this study followed the steps described by Colaizzi (1978) using the Nvivo12 application. The intervention activities were carried out from 12 July to 03 August 2016 in 6 villages in Sigi Biromaru Regency.

RESULTS

The participants were twelve people as shown in Table 1. It consists of eight men and four women. Nine of them work as farmers in gardens or rice fields with two participants being retired teachers but also working as farmers daily. About five participants are only finished elementary school level. One participant did not attend school. The youngest participant was 48 years old, and the oldest was 75. Most of them

Table 1
Participants demographic data

Sex	Age (years)	Job	Education level
Male	48	Retired	Teacher/FarmerCollege
Female	59	Farmer	Primary school
Male	71	Farmer	Primary school
Female	57	Farmer	Senior high school
Male	75	Farmer	Not Attend School
Male	67	Farmer	Primary school
Male	68	Farmer	Primary school
Male	70	Retired	Teacher/FarmerCollege
Female	50	Farmer	Primary school
Female	50	Public figure	College
Male	52	Public figure	Senior high school
Male	55	Public figure	Senior high school

have had filariasis since before 1980, the longest being in the 1950s, around 60 years. Participant number 10th, 11th, and 12th was a public figure. There are four themes of this research in Table 2 and explained below:

Table 2
Summary of Themes

Themes
Theme 1: Knowledge related to filariasis
Theme 2: Filariasis treatment that patients have obtained
Theme 3: Physical changes related to filariasis
Theme 4: Lero wood which is hard to find.

Theme 1: Knowledge related to filariasis

There are two sub-themes related to the knowledge related to filariasis: having had filariasis for a long time and not knowing the cause of filariasis. Most of the participants said they had had filariasis for a long time. Before 1980, the average was in the 1970s, when they were still children. Even the longest was in the 1950s, as revealed by participant 5, who is a 75-year-old male. The same thing was also revealed by participant 7 that he experienced this in 1968 when he was in the 4th grade of elementary school (in the past, his name was SR). This means that most of them have had filariasis for more than 50 years. This was expressed by several participants as follows:

“It’s been a long time... it’s been a long time. ... I was in the school at that time was school since 1950 (P3)”.

For the second sub-theme, all participants said they did not know the cause was due to filarial worms. Some participants said they got sick because of paranormal activities. Such as the following:

“I brought to traditional healer... the nails were removed... there were needles... recently before this fast... not even nails... like the tailor’s needle (P1).”

Even the 9th participant, a woman, believed that she was being abused. She said this:

“I don’t know what the pain is. Because I used to take a bath in Kuala. Some parents broke through, they passed, and when they passed, Grandpa, I was surprised, I took a shower so that I couldn’t stand up. It hurts all my legs. I just lifted it there. I cry (Big) (P9).”

Theme 2: Filariasis treatment that patients have obtained

There were four sub-themes found related to the filariasis treatment theme undertaken. The four sub-themes are as follows 1) mass treatment carried out by the government in 1993; 2) self-medicating with over-the-counter drugs; 3) Try various kinds of traditional medicine; 4) Don’t use banana stems anymore. The description is as follows:

In 1993 in the working area of the Baluse Health Center, mass treatment of filarial was carried out. The program holder revealed this. All residents received filariasis drugs distributed by the government through the Health Service. Although some participants got the drug and took it, some did not take it for fear of getting sick. At that time, most residents were sick taking the medicine that was distributed. They wonder why taking medicine hurts. Participant 3, who is 71 years old, experienced symptoms of filariasis when he was in grade 3 SR and already had persistent symptoms where the participant’s right leg appeared swollen.

“Never-ever. There’s a drug... a combination... a medication. I have been given this drug. Everyone is sick, but I am not. Treatment is from health. there is that... I’m not all sick people. Usually, sick people, because it’s finished, please give me, I eat until I run out, nothing. There is a yellow, rather large he has seeds. Anyway, it’s been shared before. How many villages are, on average, not just Bulubete, Proud, Walatana, Bulubete? All of them are divided up there, everyone is sick, but I’m not sick.. ask people, but I’m not (P3).”

However, several participants had not received treatment, namely participants 4th, 5th, 6th, and 9th, because treatment was not in place as stated by the youngest participant, namely participant number 9th, a woman aged 50 years, as described below:

“I haven’t been here for treatment yet; still on the ground was waiting for some time (P9).”

This was confirmed by the program holder, Mrs. R, a nurse on duty at Baluse who has held this program since 1993. According to her, she had received mass treatment in 1993, as stated in her statement:

“Ai, it’s been a long time since.... 93. At that time, we came for treatment. All treatment. It was all sick

The interesting thing that was obtained from all the participants was that they did not believe they had filariasis because their peripheral blood examination results were negative. Even though they had persistent symptoms, they thought they only had malaria because the symptoms were almost the same, starting with chills and after taking the sold malaria medicine. Symptom-free disappears. Even most drink super tetra. Some participants come to health workers when sick, but most treat themselves, so this was appointed as the second sub-theme, self-medication. As stated by several participants:

“Just super tetras. So is amoxicillin. Only amoxicillin. Once I (P3)

Sub-theme 3 people try various kinds of traditional medicine. The local community has various conventional treatments, but the most common is using ground black rice as powder. Most participants said they had tried traditional medicine but felt tired after using it disappeared, but later, when not used, the symptoms reappeared. So, some of them feel tired of trying it. Below are the participants who said they used black rice as a powder:

“Usually use powder, jasmine flowers. Jasmine flower, rice, uh, what is it? (thinking) turmeric. Oh, turmeric. Uh, that’s a lot of mixed-up... uh aromatic ginger, jasmine, rice, what is it... pomegranate leaf. All pounded. What’s new?... feels good when given (P2)

Some use leaves:

“It could be such and such leaves, and we say that such and such leaves are Sirandi, perhaps what is the name of the leaf. It is ground, and then it is given like this (stuck to the leg) (P6).”

“Leaves. I also remember that the shaman said that the eggplant leaves were burned until they were black. If there is no change, you don’t have to use them. Burned until charred, drunk. There are changes. But it will come back again (P8).”

Others use salt to relieve itching

“I’m scratching like that. I take salt. Rub on the feet. If it itches, use it again (P5).”

In addition, some say his feet were buried:

“Many I have treatment, I give boiling water, then dig a hole. I planted it, as you said earlier. Close it. Then there is a small hole. I pour the hot water there. There is distance. So about 10 minutes, I gave it out. That’s a lot of water coming out (P8).”

The 4th sub-theme no longer uses banana stems. All participants said they did not use banana stems because after using their feet, there would still be a participant who said that he had used tofu and had used banana stems. Some participants said they did not use it because they heard information that caused itching, so they gave up. This was done by participant 6 with the following statements:

“It’s also normal to try that, and the banana stem is here. napopo banana stem, But I think it’s all itchy... If you give it a run (the banana). If you use it, itches again (P6).”

Theme 3: Physical changes related to filariasis

There are two sub-themes of this theme, namely 1) experiencing physical changes and 2) the disease often recurs. The explanation of sub-theme 1 is as follows:

All respondents said they experienced physical changes. Perceived changes vary. The observations of participants 1, 3, 5, and 6 observed persistent symptoms of enlarged legs and even P6, and both legs had enlarged. The participants who did not appear to be enlarged were 2, 4, 7, 8, and 9. However, all nine had clinical symptoms of filarial, although their examinations were

negative several times. Symptoms are felt. Some are swollen, painful, and itchy, and some are just itching and red. But everyone agrees that if you have a relapse, your feet will swell or be bigger than your usual size. Below is the statement of participant 1, who is a retired teacher:

“Pain, heat, pain, itching.. Nothing. Just like that. It’s just itching (P1).”

The second sub-theme is frequent relapse. Most participants said they would experience pain, swelling in their legs, and fever if they ate cooked but not cooked food. The most common are unripe corn, burnt bananas, undercooked bananas, and rice. Among them were revealed participants 3 and 7 when eating uncooked rice:

“If it’s just that there’s no pain, except if I eat half-cooked things, I get sick, like half-cooked rice, I’ll immediately get sick. one day I don’t keep going (P3).”

But some participants said the disease would be recurrent if they were too tired to work. Here’s his statement:

“Yeah... but it hasn’t been swollen for a long time. Let’s make it like this. If my work if I’m tired.. emmm.. (P4)

“.... I don’t know why. Tired..... eui is already destroyed (P9).”

The traditional healer also said the same thing: half-cooked food and long walks caused his illness to recur.

“That’s right, eating half-cooked food makes you sick, hot, swollen, it hurts (groins). What’s more, it’s far away.”

Theme 4: Lero wood Which is hard to find

All respondents said they had heard of using Lero wood to reduce pain and swelling, but not all had tried it. This is because Lero wood is hard to find. Following are the statements of participant 4, who have used Lero wood:

“It’s normal too. Then I used to use the Lero wood too.. I was given the skin and so and so, just pasted it on. Your Tina Roa uses Lero wood” (P4)

Some participants said that they had heard of Lero wood but did not use it because they were lazy or that it was difficult to find the Lero wood because of its location in the mountains.

“I don’t know which one. It is Lero wood. I’m old. But do not know me. Hard to find..(P8).”

In addition, the Lero wood should be used for 24 hours, and the following is the statement:

“If it’s already attached, it doesn’t run (fall) because it’s stuck to the leg. So, if you want it to be good, for example, this afternoon it’s pasted, then the next afternoon, it’s just taken off. That’s a good one. I have a cancer patient who is so trying this. 90 days at most. There is also a leg of this elephant named katum, so it doesn’t spread its roots.”

DISCUSSION

Based on the study, patients had filariasis for a long time and did not know about the cause of filariasis. Therefore, they did not realize that it was due to filarial worms. However, they have provided education several times to the patients. The nurses have also conducted home visits to explain the possible cause of their suffered filariasis. According to the researchers’ opinion, this might be caused by the respondents’ old age, which is in the range of 50 years old to 75 years old. In addition, the respondents also had low education levels, and only two had diplomas. In this case, they have been suffering from filariasis since 1980.

Furthermore, they also live in the village area, which is around 38.7 km from Palu City, and most work as farmers. Filariasis patients must know about the disease, signs, and symptoms to improve their efficacy in managing themselves by treating their disease and preventing it from reoccurring. The patient's learning needs are met by learning about their disease condition and treatment skill, complaint management, and medication (14). Therefore, health workers need to provide health education for the patients and family members (15) and involve the community in the Indonesian context to improve their life skills (16). Behavioral changes in a person can be known through perception. Health

perception is the experience of an individual about feeling sick, disease, health services, and health programs generated through the senses of sight, hearing, smell, and so on. Everyone has a different perception, even though the object is the same (17).

The behavior of participants in seeking treatment is very high. This can be seen from their experience of trying various kinds of treatment, be it traditional, or self-medicating with over-the-counter drugs. Some will go directly to health workers when they feel their illness begins to recur. Participants realized they were sick, but some did not believe they had filariasis. They always assume that they suffer from other illnesses such as malaria. Hence, they take malaria drugs and antibiotics that have long been withdrawn from the market, and some even combine super tetra and amoxicillin. Participants' behavior in seeking treatment is in line with the theory of health behavior, where behavior is something activity or activity that is organic and concerned that Everyone is different in responding. Therefore, influencing behavior in giving a response shared becomes an internal and external factor. Internal factors include knowledge, perception, emotional level, intelligence level, motivation, emotion, and so on, which function to process external influences. External factors include physical, social, cultural, economic, political, etc., which made the target realize the form of behavior (17).

Participants also used a lot of traditional medicines because they knew the customs, which are cultural treasures. It can be seen from their statement that the filariasis disease is called "arrival" shows that this disease is already known in the community and the treatment already exists. They trust traditional healers to treat their pain. It is shown by some of the participants claiming to have visited Traditional healers and followed the advice or suggestions given. But they were tired because conventional medicine was a bit of a hassle, so they used over-the-counter medicines from the public health center. Patient compliance with the treatment program that has been set is affected by their education level and the length of treatment they have received. The higher the education level they have and the longer the treatment they have received, then the higher the

patient compliance with the treatment that has been programmed (18).

The 9 participants involved in the study had a range of mild to moderate pain. After compressing the feet with filariasis using wood Lero, the patient's pain scale decreased by 1 point. Pain is felt sometimes. The researcher assumed that the decrease in the pain scale was due to the effect of the intervention given to the participants. Structurally, it can be seen that Lero wood is inherent to the feet and is a soft part, of course giving a comfortable feeling. This is supported by the opinion of a key figure who said that this Lero wood has a cooling effect, and when it is compressed on swollen feet, it will cause a cold and comfortable feeling. This wood sticks well and is strong on the feet, and it can even be used for walking because it will not fall. The efficacy of Lero wood itself is to reduce swelling or arrive. In addition, the feeling of comfort can be caused by a good perception or response from participants to the drugs used because they are tired of trying all the recommended treatments, be it traditional medicine using natural ingredients, such as powder or herbal leaves. In addition, they have also heard about the use of Lero wood, but most of them do not use it because they do not know where to get the wood and what it looks like. With the availability of Lero wood, they become more enthusiastic, which creates confidence in themselves. The decrease in the pain scale felt by the participants was different because it was influenced by the stimulus or their level of trust in traditional medicine. Perception is the experience of objects, events, or relationships obtained by inferring information and interpreting messages. Perception gives meaning to sensory stimuli (10,17).

An individual does not react or behave in a certain way but behaves according to what he sees or believes about certain situations. Traditional medicine is the ancient and culture-bound medical practice that existed in human societies before the application of modern science to health. The practice of traditional medicine varies widely, in keeping with the societal and cultural heritage of different countries. Every human community responds to the challenge of maintaining health and treating diseases by developing a medical system (19). The selection of traditional treatment

carried out by the patients is based on their beliefs and the culture of the local communities (20). Lero wood is hard to find. This follows the opinion of Ashari, the traditional healer. Therefore, the handling of elephantiasis in the community varies. It is narrated that the handling of elephantiasis, besides using Lero wood or rotten banana stems, also using large leaves, pemboka onions, turmeric, and bamboo. The way to treat it is by scallion mixed with pemboka leaves and turmeric. Then put into bamboo, then put into bamboo and then burned. After that, it is applied to the swollen feet.

Culture is a way of life that is shared by a group of people and passed down from generation to generation. Culture is a comprehensive way of life. Culture is complex, abstract, and broad. Many aspects of culture also determine communicative behavior. These socio-cultural elements include many human social activities (21). Culture comprises many complex elements, including religious and political systems, customs, languages, tools, clothing, buildings, and works of art. Language, like culture, is an inseparable part of human beings, so many people think of it as genetically inherited. However, when someone tries to communicate with people from different cultures and adjusts their differences, it proves that culture is learned (21). Traditional treatment can come from both animals and plants. However, it is sometimes difficult to find plants because they grow in the forest, so this kind of use of traditional knowledge should not be overlooked while framing the strategies of conservation and management of faunistic resources in the investigated area (20).

This study has several strengths; first, it describes the community experiences in depth through the interview that has been done. Second, it involves the public figure, the program holder, and clients so that complete experiences can be informed. Furthermore, the limitation of this research is that the participant used the local language, so the researcher needed a language expert to translate the interview transcription.

CONCLUSION

Based on the result of the research, Filariasis disease causes physical changes in the patient

and causes discomfort. The result characterized four themes: knowledge about filariasis, filariasis treatment that patients have obtained, physical changes related to filariasis, and Lero wood which is hard to find.

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