

## Indigenous Perspective of Lymphatic Filariasis in Endemic Region Indonesia

### Perspektif Lokal Filariasis Limfatik di Wilayah Endemis Indonesia

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#### ABSTRAK

Filariasis limfatik mempengaruhi penderita baik secara sosial dan ekonomi. Perilaku pencarian pengobatan terkait erat dengan perspektif masyarakat lokal yang bervariasi. Penelitian ini diperlukan untuk menggali luasan variasi perspektif lokal sebagai masukan dalam strategi intervensi program pengobatan. Penelitian ini dilaksanakan secara cross sectional dengan menggunakan metode kualitatif. Pendekatan health belief model dipergunakan untuk melakukan penilaian pengetahuan masyarakat tentang filariasis dan upaya perawatan serta pengobatannya. Lokasi penelitian dilakukan di 12 Kabupaten di Indonesia yaitu Kabupaten Pidie, Aceh Utara, Aceh Jaya, Pasaman Barat, Pesisir Selatan, Subang, Tangerang, Kota Waringin Barat, Hulu Sungai Utara, donggala, Bombana dan Asmat. Terdapat 9 dari 12 Kabupaten yang memiliki nama lokal mengenai filariasis limfatik. Sebagian besar informan memiliki kepercayaan bahwa filariasis limfatik muncul sebagai akibat kutukan leluhur atau kutukan karena mendatangi tempat tertentu, atau kutukan penyebab lain yang bersifat gaib atau di luar kekuasaan manusia (suku Asmat, suku Aceh, suku Kaili, suku Banjar, suku Dayak). Informan memilih ke pengobatan tradisional apabila pengobatan sendiri tidak berhasil. Ada kecenderungan yang erat antara pengetahuan dengan upaya eliminasi penyakit filariasis. Untuk itu perlu direkomendasikan upaya pemahaman yang lebih baik terhadap pengetahuan lokal tentang filariasis.

**Kata kunci:** filariasis limfatik, indigenous, perspektif, suku, Indonesia

#### ABSTRACT

Lymphatic filariasis disease impacts the patients both socially and economically. Health seeking behavior was related to the variation of local perceived. This research is required to explore the wide variety of local perspectives as input into treatment program intervention strategies. The study was conducted in 12 districts in Indonesia, namely Pidie, North Aceh, Aceh Jaya, West Pasaman, South Pesisir, Subang, Tangerang, West Kota Waringin, North Hulu Sungai, Donggala, Bombana, and Asmat. Qualitative methods with the health belief model approach were used to assess the community's knowledge about lymphatic filariasis disease and its treatments. This study used 24 informants consisting of 14 men and 10 women. Results showed there were 9 out of 12 regions that have a localized concept of lymphatic filariasis disease. Most informants believe that the disease occurred as a result of the curse of the ancestor or the curse of visiting a certain place, or supernatural power. Most informants stated that seeking indigenous healers was carried out if the informant felt that self-treatment did not produce the result as expected. There was a tendency between knowledge and elimination

efforts of lymphatic filariasis disease. Therefore, it is recommended to provide a better understanding of local knowledge about lymphatic filariasis.

**Keywords:** lymphatic filariasis, indigenous, perspective, tribe, Indonesia

## INTRODUCTION

Lymphatic filariasis (LF) is a chronic infectious disease caused by *Wucheria bancrofti*, *Brugia malayi*, and *B. timori* filarial worms.<sup>1</sup> The disease is a major health issue in the world, mainly affecting susceptible people of all ages and genders, especially in the intropical and subtropical countries.<sup>2</sup>

In 2000, the World Health Organization launched Global Program to Eliminate Lymphatic Filariasis (GPELF) aiming to eliminate LF as public health problem in 2020. This program comprises two strategies: first, a once-annually mass drug administration (MDA) of single doses of diethylcarbamazine and albendazole for at least 5 years, and secondly, a morbidity management and disability prevention by providing access to health care facility to every clinically infected people in endemic areas.<sup>3</sup> Chronic patients of LF is a significant cause of poverty because of the loss of productivity, which ultimately becomes a family and community economic burden.<sup>4</sup> It is estimated in India lost 3.8-8 percent of the potential production of male labor because of chronic LF morbidity.<sup>5</sup> The impact of LF chronic patients was both economic and socially. The social stigma for the patients and their family come when it has caused swelling of the hands, feet, mammary glands, and scrotum. This produces both the patients and their family physical burden and psychosocial stigma. Among the symptoms of LF patients are distressing feelings, embarrassment, guilt, behavioral avoidance and self-isolation; Which affects the quality of life of patients.<sup>6</sup>

Until 2019, LF was endemic in 236 out of 514 districts across Indonesia. Yet, only 118 districts had implemented MDA-LF. There were 118 districts have completed the MDA-LF for 5 consecutive years, but only 88

districts had passed post-MDA survey (Transmission Assessment Survey/TAS) and 36 districts passed the evaluation phase, and received Free LF certification.<sup>7</sup> Information and perspectives on health-seeking behaviors and self-care practices of LF in Indonesia remain inadequate. The objective of this paper is to explore specific of health beliefs, health-seeking behavior and self-care practices of indigenous people with LF. This study analyzed a subset of the data from multicenter research to describe the community's knowledge of lymphatic filariasis and its treatment.<sup>8</sup> Disease control programs in developing countries are often unsuccessful or unsustainable because the strategies implemented are not compatible with traditional perceptions of etiology, prevention and control. Treatment interventions to prevent lymphatic filariasis require a broad understanding of traditional perceptions of the disease, its causes, its consequences, and its prevention.<sup>9</sup>

## METHODS

This was a qualitative study to assess the community's knowledge of lymphatic filariasis and its treatment.<sup>10</sup> Perspective understanding of local people, particularly for belief, is important as the basis for the formulation of prevention and treatment of a disease.<sup>11,12</sup>

The study was conducted in August to October 2017. The study area was selected based on the presence of active or chronic LF. There were 12 districts in Indonesia including Pidie, North Aceh, Aceh Jaya, Pasaman Barat, Pesisir Selatan, Subang, Tangerang, West Kotawaringin, North Hulu Sungai, Donggala, Bombana dan Asmat. Meanwhile, there were 9 tribes (Aceh, Minang, Caniago, Banten, Sunda, Kaili, Banjar, Dayak

and Asmat) spread across 12 districts. Data obtained through indepth interview techniques using interview guidelines. Informant purposively selected based on their understanding and experience of local knowledge. Informants consisted of community leaders, chronic patients and their families. There were 24 informants interviewed in this study, consisting of 14 males and 10 females. Qualitative data analysis is based on comparative method and thematic analysis, where coding was initially decided to construct themes based on local concept categories of lymphatic filariasis disease, the causes of lymphatic filariasis and the way to care, the treatment method and the pattern of treatment-seeking behavior from the basic data. Results were consistent with the researchers and assistants who worked independently to codify each message in the form of a matrix.<sup>13,14</sup>

## RESULTS

### Indigenous Concept and Perceptions of Causation

In relation with the concepts, not all indigenous in 12 regions could correctly answer about lymphatic filariasis. Informants in the three regions (Tangerang, Pasaman

Barat, Donggala) stated that lymphatic filariasis is caused by mosquito bites. However, they could not elaborate further information on the lymphatic filariasis disease. There was only one informant who can explain better.

“...bahwa penyakit itu tidak bisa disembuhkan, cacat pasti, kalau cacingnya bisa dibunuh”

“...that the disease can not be cured, the defect is certain, if the worm can be killed,” (Chronic LF in Tangerang)

The results of in-depth interviews showed that most informants have local names for lymphatic filariasis or elephantiasis. There were 9 out of 12 regions that have a localized concept of lymphatic filariasis. Asmat tribe in Asmat district called it as a *curly leg*, Bombana tribe in Bombana district called it as *kamba*, acehnese tribe in Aceh Jaya district called it as a *clash* or *barah*, *kamba*, minang tribe in West Pasaman district called it as *gadang legs*, Kaili tribe in Donggala called it as *tiba* or *natiba*, Banjar tribe in North Hulu Sungai district called it as *a hunt*, and Dayak tribe in West Kota Waringin district called lymphatic filariasis as *betubab*, and acehnese in Pidie district recognized it as a *saket*.

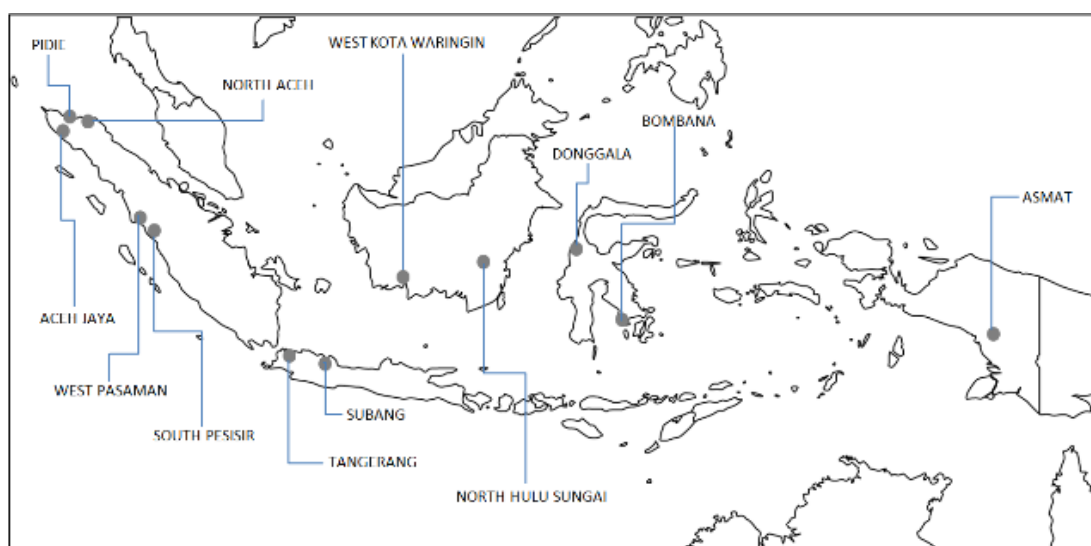


Figure 1. Distribution of Research Areas  
Source: Researcher visualization

In additions indigenous people had had their own beliefs about the causes of the disease. Most informants believe that a disease arises as a result of an ancestral curse or a curse for visiting a particular place, or the curse of another causes that is unseen or beyond human power (Asmat, Aceh, Kaili, Banjar, Dayak Tribes). Some informants called lymphatic filariasis as a hereditary disease (Minang and Caniago tribes). Some other informants mentioned the disease is caused by poor environmental factors (Aceh tribe in Pidie district, Kaili tribe in Donggala district).

### Healthcare-Seeking Behaviors

Informants were asked what kind of services they had taken for the treatment of Lymphoedema. Most of the informants said that they used traditional and home-based care in the first episodes of Lymphoedema. A man who had sought care from traditional healers said,

*“ketika gejala awal muncul berupa demam, orang tua penderita membawa anaknya ke dukun untuk ditiup-tiup karena anggapan orang tua anaknya keteguran (kesurupan), dibarengi, dengan pemberian obat yang dibeli sendiri di warung berupa obat penurun panas seperti parasetamol. Setelah tidak ada perubahan baru kemudian di bawa ke sarana pelayanan kesehatan terdekat”*

*“when the early symptoms appear in the form of fever, sufferer parents bring their children to shamans for the inflatable with the assumption that their children get possess, combined with the provision of self-purchased drugs in stalls such as paracetamol etc. If there are no new changes, the sufferer is then brought to the nearest health care facility.”* (Chronic LF in Bombana)

Most informants revealed that they do self-treatment before seeking help from others. Self-treatment is done when the disease is felt already, yet no dangerous, or other reasons like they can still walk. If the self-treatment does not show any improvement, they start looking for other treatments. Usually, they used to seek indigenous healers before they finally went to physicians.

Another interesting phenomenon is some informants claimed not to do any treatment. This is due to information obtained that the disease cannot be cured. Another reason was made because they did not feel any pain, despite swelling is seen in their body.

### Self-Treatment

Self-treatment is often done by informants with topical technique. Topical ingredients are formulated with various types.

*“berusaha diobati sendiri, Dibalur pakai parutan lengkuas. Kalau tidak bisa berjalan baru ke tenaga kesehatan”*

*“trying self-treatment. It can be swabbed with ginger (alpinia galangal. If they cannot walk, go to a health worker.”* (Patients in Kotawaringin Barat, Centre of Kalimantan)

*“itu daun tembakau dirajang halus, dibalur dibagian bengkak, kemudian diikat kuat-kuat dengan karet ban sampai keluar cairan seperti lender...”* (Penderita di Aceh Jaya)

*“... the tobacco leaves are finely chopped, it is then swabbed in swollen body parts, then tied firmly with tire rubber until mucus-like liquid comes out...”* (Patients in Aceh Jaya)

Another formula done by Kaili tribe in Donggala is using *marandini/siranindi*/miracle leaf (local term: *Kalanchoe mortagei*). This technique is done by attaching water-filled leaves to the swollen legs. By doing this technique, informants claimed to have a cool sensation that made them feel more comfortable.

Furthermore, another type of topical ingredient is grated pella fruit or known as papaya fruit (*Carica papaya*). This type of topical drug was reported by informants from the Banjar tribe. They claimed that this recipe has become a tradition that has been inherited from ancestors since antiquity. Another tradition was reported by informants from West Kotawaringin district in the form of grated red ginger (*Zingiber officinale var*

*Rubrum rhizoma*) recipe. As a healer indigenous said, “*Bebura...restricted receive food or guests...ingest our herbs...secret recipe, it is rooted from the forest...*” (Indigenous Healer in Kotawaringin Barat)

*“pengobatan sendiri dengan cara menusuk-nusuk kaki yang bengkak dengan jarum peniti. Dilakukan sampai cairannya keluar, setelah diikat kain sebelumnya. Perawatan ini terasa lebih nyaman setelah ditusuk-tusuk, dan kaki yang bengkak sedikit mengempes dan menjadi agak ringan”*

*“Other self-treatment variations were performed by informants by stabbing the swollen feet with needles. This is done until the liquid comes out, after previously tied with cloth. This treatment is done by the informant because they feel more comfortable after being stabbed, and the swollen feet become slightly lesser and lighter...”*

### **Seeking Healthcare from Indigenous Healers**

Seeking an indigenous healer is the second step. This step is done if the informant feels self-treatment does not cured the result as expected. A patient from Donggala Centre of Sulawesi Province said that “*treated by himself, legs are tied and stabbed with a needle until the liquid comes out...and then compressed the swollen legs using maranin leaves that feels cold...but if fever appear then parents bring their children to an indigenous healer, and health services is the last option...*”(Patients in Donggala District)

*“Dukun Kampoeng memberi campuran sadah dan asam ...kapur sirih dan air perasan jeruk nipis...untuk dibedakkan ...Kemudian memberi campuran telur angsa dan buah sauh ...sawo yang dikocok untuk diminum...”*

*“the traditional healer gives a mixture of sage and tamarind...whiting and lime juice to be smeared on the swollen body part, then gives the mixture of goose and sapodilla fruit to be shaken for beverage”*(Patients in Pasaman Barat)

A Similar type of treatment was performed by the indigenous healer of Aceh tribe in Pidie district. Lymphatic filariasis

patients are given a potion to drink and the ingredients to be smeared. Informants claimed they do not know the composition of the ingredients of the said potion. Meanwhile, informants reported that material to be smeared is chili pepper (*Capsicum annum* l.). Chili powder is smeared on the swollen part, and then wrapped in a nipa leaf (*Nypa fruticans*).

Information about the ingredient composition, whether oral or smeared, from the indigenous healer is often unknown. This is due to the secret of the healer. This ‘secret’ is a positioning part of the indigenous healer in which the practice of indigenous healer treatment is related to their ability in treating diseases caused by mystical things. A man with severe filarial lymphoedema in legs said,

*“peringatan dari kekuatan gaib disebabkan memasuki daerah terlarang”*(Penderita di Kabupaten Donggala)

*“warning from supernatural caused by entering forbidden area”* (Patient in Donggala)

### **Seeking Healthcare from the Health Worker**

Commonly at the first time, informants often do not know that the disease they suffer is lymphatic filariasis. This situation forces them to seek healthcare to the indigenous healer. Furthermore, this condition causes the delay of healthcare and treatment of the disease.

The lack of doctors also contributes to the public’s access to information about lymphatic filariasis. Almost all informants said that they were treated by midwives and nurses when dealing with health institutions. This was also exacerbated by the lack of knowledge of the health workers in the health sector in recognizing lymphatic filariasis.

*“ ...Pak TM ini awalnya sudah berobat ke tenaga kesehatan, tapi tidak juga sembuh, setelah dikonsultasikan ke Dinas Kesehatan Kabupaten baru diketahui kalau menderita filariasis dan menjadi salah satu pasien pertama yang diketahui menderita filariasis di Kabupaten Pesisir Selatan.”*

“... Mr. Tm was initially treated by health personnel, but he did not recover, after being consulted to the district health office, it was known that he had lymphatic filariasis and even became one of the first patients known to have lymphatic filariasis in Pesisir Selatan district.” (community figure in Pesisir Selatan)

## DISCUSSION

Previous studies have shown in preventive health behaviors that perceived susceptibility, benefits and barriers have been consistently associated with the desired health behavior.<sup>15</sup> The use of HBM to define group viewed concerning to MDA was based on the fact that a decision about preventive intervention is based on the opinion of people regarding disease and well-being.<sup>16</sup>

Due to the cause and treatment of lymphatic filariasis disease have not been properly socialized in the local community. The results showed that the informants named the lymphatic filariasis disease according to the visible physical condition. The same thing in Nepal who calls it as “*Hattipaile*,” literally meaning Elephantiasis. This term is used to describe someone with swollen legs that resemble an elephant’s legs. Meanwhile, in East Nusa Tenggara, Indonesia LF is locally divided into two characteristics, namely *ha’i bou fai* (female elephantiasis disease) and *ha’i bou aki* (male elephantiasis disease). elephantiasis disease).<sup>17,18</sup>

Similarly, the elephantiasis on the arm is called *jitintim* or *jipimpim* where *ji* refers to the arm, while elephantiasis on the breast is known as *yilpimpim* (*kassim*) or *bitintin* (*nankani*). The term for Acute Adeno-Lymphangitis (ADL) on the feet is *nasaana* (*kassim*) and *nasaare* (*nankani*). *Saana* or *saare* is a special term to indicate sore, swelling and pain.<sup>9,19</sup>

Research in Ghana showed that there is no single term for lymphatic filariasis. However, there are well-known terms, those are *kassim* and *nankani* for various forms of the disease. The term for elephantiasis on the leg is *natintim* (*kassim*) and *napimpim*

(*nankani*), *na* means the legs and *tintim/pimpim* means heavy or large. *Tintim/pimpim* draws and the sounds made when the person is running. Similarly, the elephantiasis of the arm is called *jitintim* or *jipimpim* where *ji* refers to the arms, elephantiasis on the breast is known as *yilpimpim* (*kassim*) or *bitintin* (*nankani*). The word for Acute Adeno-Lymphangitis (ADL) acute from *kaki* is *nasaana* (*kassim*) and *nasaare* (*nankani*). *Saana* or *saare* is a special term for heat, swelling, and pain.<sup>9,19</sup>

In local communities, the presence of local names for a disease often indicates a certain belief about the disease. This relates to the causes associated with the disease, which are often beyond the reach of traditional community thoughts.<sup>20,21</sup> The emic concept of indigenous Indonesians about lymphatic filariasis caused by a curse, hereditary or supernatural is due to the limited information they receive from modern medical practitioners. This condition is exacerbated by the geographical area of Indonesia with the unequal distribution of health workers.<sup>22,23,24</sup>

Lymphatic filariasis patients living in the community with the emic concept of supernatural increasingly burdened by the change in physical condition with enlarged several body parts. The lack of knowledge and these physical changes cause stigma itself in lymphatic filariasis patients. Lymphatic filariasis patients often have to change jobs, or even stop working altogether.<sup>25,26,27</sup> Disability of such lymphatic filariasis patients will further increase the economic impact.<sup>28</sup>

This research has shown that, according to several local illness concepts, the disease is unrelated to the mosquito and the different manifestations are seen as different disease entities. Treatment is mainly by self-medication or by consulting a traditional healer. The importance of the above findings regarding medical anthropology is concerned with how people in different cultures and social groups explain the causes of ill health, the types of treatment they believe in and to whom they turn if they get ill. It is also the

study of how these beliefs and practices relate to biological, psychological and social changes in the human organization in both health and disease.<sup>29</sup>

The health system is not a static phenomenon, yet a process of continuous change with good pressure from both within and outside the system. Every society has a diversity of health systems that can be called medical pluralism. The term is usually associated with the presence of different cultural or ethnic groups within a community, each following its own medical tradition.<sup>9,30</sup>

A study in Nepal found that a treatment-seeking pattern for the majority of lymphoedema patients was the traditional providers of health care as the first contact of healthcare. Only a few patients have practiced standard foot care and home care.<sup>17</sup> Research in Ghana on the socio-cultural aspects of lymphatic filariasis according to the concept of local disease showed that the disease is not related to the mosquito and the manifestation is seen as a different disease entity. Treatment is primarily done by self-treatment or in consultation with traditional healers.<sup>9,19</sup>

Low levels of community knowledge about lymphatic filariasis are at the root of this disease treatment program. Treatment patterns that place access to health workers as the last option cause considerable losses. The condition of the disease becomes severer, and the degree of dependence of the patient becomes greater<sup>31</sup>, and the larger cost.<sup>4</sup>

Disease control programs in developing countries are often unsuccessful or unsustainable because of poorly pursued strategies for the community or incompatible with traditional perceptions of etiology, prevention and control.<sup>32</sup> Proper interventions to treat and prevent lymphatic filariasis disease will require a broad understanding of the traditional perceptions of the disease, its causes, and its consequences, and its prevention. Due to the perception of varied diseases from place to place, it is necessary to conduct an in-depth study of the social,

cultural, and economic aspects of the disease before initiating control measures.<sup>25,31,33</sup>

This study had shown a wide range of indigenous perspectives from several tribes in Indonesia regarding-lymphatic filariasis, of which only a few had informants could get involved with this research. This may partly be due to limited of time to explore. These findings of this hence may not represent the general conditions of indigenous perspective areas where lymphatic filariasis is also endemic.

## **CONCLUSION**

During this study, important issues have been reported regarding knowledge gaps including perceptions of the causation, treatment, prevention, and the LF elimination program. We identified there was an interrelation between knowledge and elimination efforts of lymphatic filariasis disease.

## **RECOMMENDATION**

An effective educational intervention program is needed with a focus on the transmission and prevention of LF. The critical need for community engagement in the creation of an educational approach that represents local understanding and perception of the disease must not be ignored. Health workers could be held an internship activity for traditional healers regarding LF elimination program.

## **AUTHOR CONTRIBUTION**

The contributor in this article are MI and ADL as primary contributor, conceived of carried out the field study, conceptualization, methodology, writing draft original preparation, validation, supervision. EPA, BI, TW, Y, NR, MAN, NR and RY as Co-contributors carried out the field study, data analysis and writing- reviewing and editing.

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