

## RESEARCH ARTICLE

## Personal Perceptions of Filariasis of Patients at Kodi Bolaghar Subdistrict, Southwest Sumba Regency, East Nusa Tenggara, Indonesia

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### Abstract

Perception is a mental process that occurs in humans that will show how we see, hear, feel, give, and feel around us. Patients' positive and negative self-perceptions are internal factors that significantly affect the healing process. Chronic filariasis patients experience a decline in physical condition, which becomes a mental burden for the patients and their families. Patients may experience negative stigma from their family and surrounding community. Some communities still believe in myths, supernatural powers, and magic, and patients suffer illness due to their evil deeds or that they have violated cultural norms that were passed down from generation to generation. How patients perceive themselves, their environment, and their families are rarely studied, though this information is essential to elucidate their needs. Kodi Balaghar subdistrict in the Southwest Sumba regency, East Nusa Tenggara, still has many filariasis cases. This study aimed to know the self-perception of filariasis patients in the Kodi Balaghar subdistrict, Southwest Sumba regency. We have selected ten patients to collect answers regarding self-perception from March to May 2021. The results of our study showed that respondents perceive themselves more negatively to both themselves and their families. We conclude that emotional and spiritual support from family, community, religious leaders, and medical personnel are critical to building self-confidence, life expectancy, enthusiasm, and fighting power to survive and undergo treatment for the disease.

**Keywords:** Family support, filariasis, self-perception

### Introduction

Health problems in Indonesia are complex conditions that are a combination of several issues, including environmental problems, both natural and man-made, socio-cultural, behavioral, genetics, and population.<sup>1</sup> Each person has a different perception of how to assess a complex problem. Perception will arise from each other as perception is an automatic process as a response to mental processes that occur in humans; it happens very quickly and sometimes unconsciously, where we can recognize the stimulus we receive from the senses. Perceptions that arise will affect our actions. Perception is also called a view, image, or assumption because there is a person's response to a thing or object in perception. Public perception of a disease occurrence that is contrary to health science is still there, can be passed down from one generation to the next, and can even expand.<sup>2-4</sup>

Lymphatic filariasis is an infectious disease that still causes health problems in the community.<sup>5,6</sup> Untreated filariasis patients, although the condition is not lethal, are very detrimental

because the sufferer will experience pain, physical disability, poverty, and even psychosocial problems in the community where the patient lives.<sup>7,8</sup> Disability due to filariasis experienced by the patients also causes dependence on others, so economically, it will be very detrimental to the sufferer's family and cause poverty.<sup>8,9</sup>

The World Health Organization (WHO) in 2000 declared "The global goal of elimination of lymphatic filariasis as a public health problem by the year 2020". The Indonesian government responded to this global agreement by launching the elimination of filariasis in 2002 in Musi Banyuasin regency and establishing the elimination of filariasis as one of the priority programs for eradicating infectious diseases in Indonesia.<sup>10-12</sup>

Filariasis occurs chronically, and this condition causes lymphedema or fluid build-up that causes swelling of the legs and arms. Accumulation of fluid and infections that occur due to weak immunity will eventually lead to damage and thickness of the skin layer. Accumulation of fluid can also occur in the abdominal cavity, testes in men, and breasts in women; this condition is

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known as elephantiasis.<sup>13</sup>

Chronic manifestations, caused by reduced lymphatic function, occur months to years from the acute episode. Clinical symptoms vary from mild to severe, followed by a regular course of obstructive disease. The main clinical signs were hydrocele, lymphedema, elephantiasis, and chyluria, which increase with age. Genital manifestations, in many areas, the chronic feature that occurs is hydrocele. In addition, chronic epididymitis, funiculitis, and edema due to thickening of the scrotal skin may be found, whereas, in women, vulvar lymphedema may be found. Lymphedema and elephantiasis of the extremities: episodes of lymphedema of the extremities will lead to elephantiasis in the area of the affected lymphatic ducts throughout years.<sup>14,15</sup>

Chronic conditions will have a psychological impact on filariasis patients; loss of self-confidence, psychiatric disorders, and long-term stress due to not being able to accept one's situation will become a problem in itself. People who are already disabled will usually feel inferior, ostracized, and embarrassed to meet other people, especially with the erroneous assumption from some people that this disease is disgusting. It is even believed that the disease is related to supernatural powers, magic, supernatural, curses/hereditary. The emergence of positive and negative self-perceptions will be one of the points/keys to give suggestions to sufferers to stay excited about life.<sup>16,17</sup>

The province of East Nusa Tenggara (*Nusa Tenggara Timur*, NTT) is the second largest contributor to filariasis cases after Papua 15,18. This case is spread in almost all cities/districts in NTT, including four districts on Sumba island. The number of reported cases was 311 from 3 regency, namely Central Sumba, Southwest Sumba, and West Sumba.<sup>19,20</sup> In 2011, 90 chronic cases were reported in Southwest Sumba regency, while the microfilariae (Mf) rate was >1%. The Mf rate was determined based on a finger blood smear sampling survey (*survei darah jari*, SDJ) conducted in Buru Kaghu and Mata Kapore villages in 2009.<sup>5</sup> Patanduk et al.<sup>21</sup> reported that the Kodi Balaghar subdistrict had a Mf rate of 4.2% based on the results of SDJ collection in 2012 with a total sample of 500 people.

This study aimed to know the self-perception of filariasis patients in the Kodi Balaghar subdistrict, Southwest Sumba regency. The healing process of chronic sufferers is not enough to rely on

medical treatment; emotional support is a critical need for sufferers. The research results are hoped to provide input to families, the general public, medical personnel, and community leaders in providing a support system for filariasis sufferers.

## Methods

This type of research is descriptive quantitative with a cross-sectional approach using questionnaires and interviews to collect answers from respondents. Its nature is to explore in-depth information from informants about self-perception of filariasis. As many as ten respondents from filariasis patients from the Kodi Bolaghar subdistrict, Southwest Sumba regency, East Nusa Tenggara, were willing to participate in the study by signing an informed concern. This research was carried out from March to May 2021 and registered with the Ministry of Health's Kupang Poltekkes Ethics Committee with registration number LB.02.03/I/0075/2020.

The determination of overall perception is stated in the score; perception is good if the score is >67.8, and perception is quite good if the score is <67.80. Respondents' answers to each question (43 numbers) were scored. From the data processing results, six respondents were in the sufficient category, and four were in the good category, with a median value of 65 and a mean of 67.8.

## Results

Respondents were interviewed to find the most appropriate answer; it was feared that if they filled it out on their own, it would result in a biased/inappropriate answer. The characteristics of the respondents are shown in Table.

Collecting answers from the questionnaires given, we classify them into four minor themes: positive perceptions of oneself with the environment and with family, as well as negative perceptions of oneself with the environment and with family.

Positive perception of self and environment as described in Figure 1. Of the ten respondents who answered the questionnaire, ten considered themselves honest people, would try to change if they realized what they were doing was wrong, and quickly adapt to other people. Nine of the respondents rated themselves as gregarious and easy to lose their minds; eight rated themselves

**Table Respondent Characteristics**

Characteristics	n=10
Age (years)	
40–50	2
51–60	4
61–70	–
71–80	4
Gender	
Female	9
Male	1
Marital status	
Married	10
Not married	–
Education	
Not in school	10
Elementary	–
Middle school	–
High school	–
Occupation	
Farmer	10
Civil servant	–
Self-employed/employee	–
Income (rupiah)	
<1,000,000	10
1,000,000–2,500,000	–
>2,500,000	–

as easy to adapt to circumstances and can accept mistakes without feeling hurt or angry; seven of the respondents think they can maintain body cleanliness and are religious in life; and only five who think they have a healthy body.

Positive perception of oneself and family as described in Figure 2. Respondents reside and live with their families during illness, so it is natural to have positive and negative perceptions

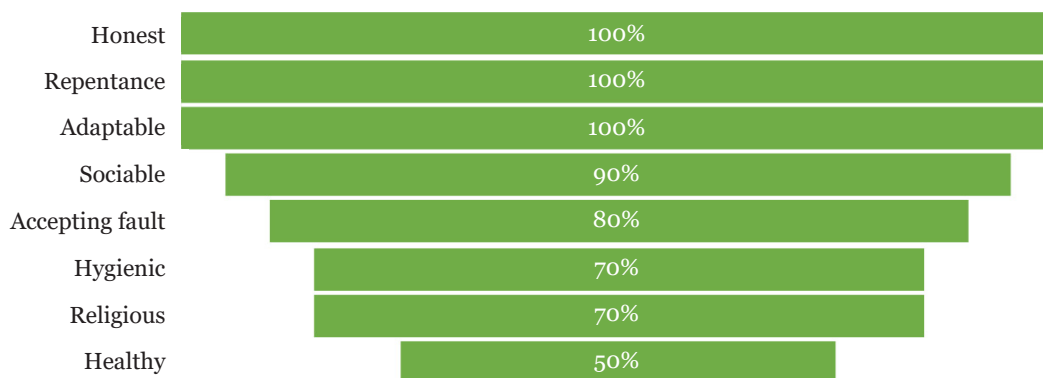
about their respective families. The results showed that ten respondents were satisfied with their relationship with their family and felt that the family cared about them. In addition, nine think that they are someone who means a lot to their family and consider themselves to be a happy family member.

Negative perception regarding self and the environment is described in Figure 2. Patients with filariasis tend to have unfavorable perceptions about themselves, severe physical conditions, and difficulty in accommodation and activities, which will lead to negative self-assessments. Ten respondents rated it negatively, saying they felt their physical appearance was not as expected, hoped not to give up as quickly as it is now, and should be more polite to others. Nine respondents want to improve some parts of their body. Eight feel they are not the person they want to be, feel sick, are too lazy to exercise, sometimes use dishonest ways to get ahead and find it difficult to be friendly to others; seven find it challenging to make friends; and five feel not a good person.

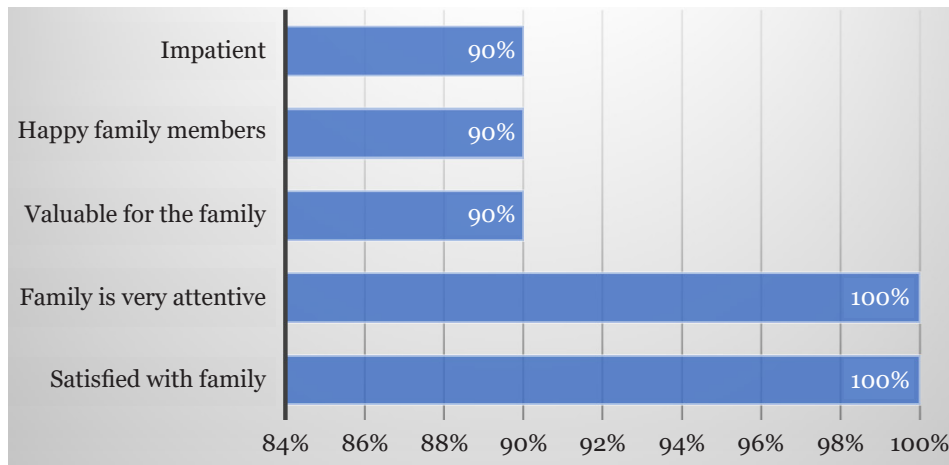
Togetherness with family also creates negative perceptions; nine respondents feel they should be able to trust their family more and try to be more honest with them, and eight feel that their family does not trust them in certain areas (Figure 4).

## Discussion

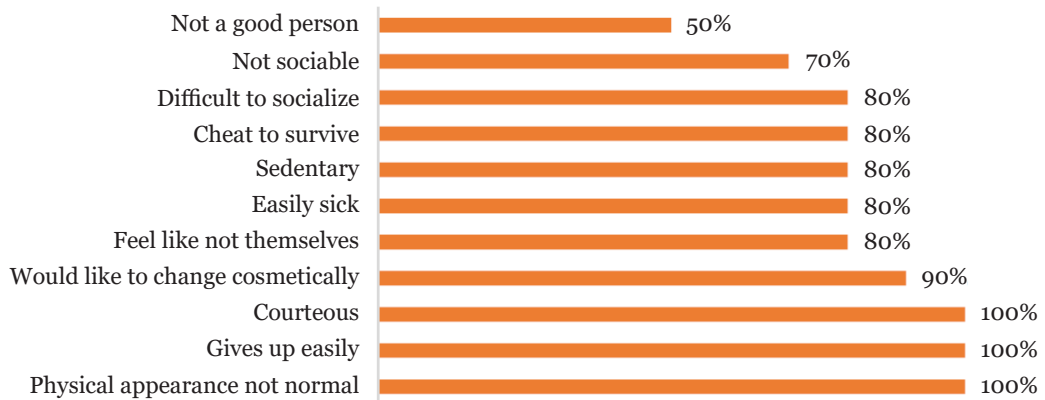
According to Mulyana,<sup>22</sup> perception is an internal process that allows us to select, organize, and interpret stimuli from our environment. These processes affect us so that perception determines us to choose messages and ignore other messages.<sup>23</sup> According to Walgito,<sup>24</sup> perception



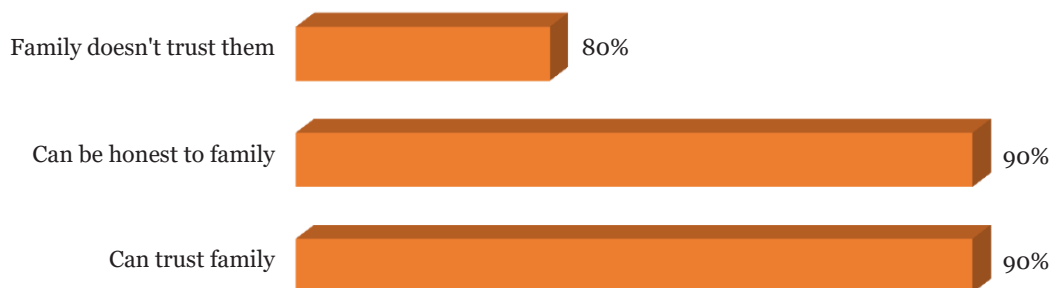
**Figure 1 Positive Perception regarding Self and Environment**



**Figure 2 Self-Perception with Family**



**Figure 3 Negative Perception regarding Self and Environment**



**Figure 4 Negative Perception regarding Families**

occurs because of a stimulus from within the individual, preceded by sensing. Sensing here is a process received from the stimulus by the individual through the receiver; the nerves transmit the stimulus to the brain as the center of the nervous system. The process is the perception

process. Perception is related to how to gain knowledge about objects or events at a particular time so that the perception of a person or group is different because they have other points of view.<sup>2,25</sup>

Perception includes interpreting objects, signs,

and people from the experience of a person or group. So self-perception is a view or assessment of oneself obtained from learning or experience that influences the individual to interact or behave with his surroundings. The theory of self-perception is a derivative of the theory of self-concept. Based on the research conducted, Daryl Benn stated that self-perception means that a person makes his conclusions according to his way of thinking and experience by observing the behavior of others.<sup>1,26</sup> With perception, an individual can be aware of and understand the state of the environment around him and the state of the individual concerned. Thus, the perception of the stimulus can come from outside the individual but can also come from within the individual concerned. Because perception is an integrated activity, all that is in the individual, such as experience, thinking ability, and other aspects that exist in the individual, will play a role in the perception.<sup>23,27</sup>

If what is perceived by oneself as the object of perception is called self-perception, then self-perception is a view or assessment of oneself that is obtained from the results of learning and experience that motivates the individual to interact or behave with the surroundings in the hope that it can be beneficial for the community.

How a person with filariasis makes the perception of himself becomes very important. Filariasis disease is chronic, and if it does not get treatment, it can cause permanent disability in the form of enlargement of the legs, arms, and genitals for both women and men. Chronic manifestations, caused by reduced lymphatic function, occur months to years from the acute episode. Symptoms of chronic filariasis include persistent enlargement (elephantiasis) of the legs, arms, breasts, and testicles (elephantiasis scroti) caused by adult worms in the lymphatic system.

Physical conditions like this will undoubtedly cause mental disorders in sufferers, loss of self-confidence, and difficulty doing anything independently. In general, many people with disabilities will feel inferior, abandoned by family and society, and not confident to meet other people. The belief that develops in the community is also a matter of psychological pressure for sufferers. Filariasis is considered a disgusting disease and is even believed to be related to supernatural powers, magic, supernatural, curses/hereditary. Complex problems cause psychological pressure

both from oneself and from outside. Patients will have their perception of their illness and how their families and society accept them. The emergence of positive and negative self-perceptions will be one of the points/keys to give suggestions to sufferers to stay excited about life.<sup>28</sup>

Our results show that filariasis sufferers have positive self-perceptions about themselves, their environment, and family. Positive self-perceptions that are built are self-acceptance as honest people, willing to change themselves if they make mistakes, like making friends, being able to accept their own mistakes, maintaining personal hygiene, and being religious. It was found that only five respondents took themselves as healthy people, and five respondents had self-perceptions as sick and unhealthy. On the other hand, respondents admitted that they were satisfied with their family relationships, their family cared about them very much, they were significant family members, and they were pleased. One interesting thing is that 50% of respondents admit it is easy to lose their minds. Perception of losing your mind quickly shows depressed mental conditions, stress, and even tends to be depressed. This can be caused by the inability to accept oneself with the condition of filariasis.<sup>29</sup>

A positive self-perception will have a long-term impact on healing, enthusiasm, and suggestions for patients to seek treatment and struggle to recover. Exceptional social support from the family is critical; when the patient is in a supportive family situation, it will indirectly impact healing.

We found more negative self-perceptions from respondents in this study due to the disfiguration of their physical appearance and found it difficult to socialize or blend in with society. Negative self-perception requires psychological therapy to build back self-confidence and the willpower to live. Patients should not be allowed to create perceptions that harm the healing process. On the other hand, respondents also negatively perceive their family, as some still do not trust their own family, are not honest with them and feel that their family does not trust them.

Munadhir<sup>3</sup> concluded that the negative public perception of filariasis patients was a critical factor in making them suffer and miserable, as well as psychological burdens such as feelings of shame, irritation, confusion, hurt, fear, and losing their source of income. The public's perception



of filariasis patients based on the socio-cultural values of the community still considers the disease to be a curse or a violation of the norms of society. Silalahi<sup>2</sup> concluded that knowledge, education, and access to health services influence people's perceptions of filariasis. They suggest health promotion efforts to change the public's negative perception of filariasis by increasing public knowledge and understanding so that they can adequately prevent filariasis. Lismayanti et al.,<sup>23</sup> in their study of life experiences of filariasis patients, reported that people infected with filariasis in Tasikmalaya city related to five themes, namely emotions, perceptions, clinical, economic, and social symptoms as well as experiences in accessing health services. The results of their research can be used as a reference for improving community nursing services, both physically, psychologically, socially, and economically. Prevention of filariasis is also essential to reduce the risk of transmission. Besides that, the rehabilitative process is also vital to minimize disability and assist the adaptation of sufferers in their lives biologically, psychologically, socially, and spiritually.

Based on the results of this study, we recommend that assistance from close family is very much needed, and community leaders and religious leaders are also expected to play a role. In particular, spiritual assistance/spiritual life to build life hope and the ability to accept one's situation. Medical treatment is considered insufficient to continue to provide enthusiasm and fighting power to patients with filariasis.

### Conclusions

Filariasis patients can build positive and negative perceptions of themselves, their environment, and their families. We found that negative self-perceptions dominated the respondents' answers, so support from families and communities was crucial during the treatment and healing.

### Conflict of Interest

All authors state whether there was a conflict of interest in this article or not.

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### References

1. Manurung S, Hutasoit MLC. Persepsi pasien terhadap perilaku caring perawat di ruang rawat inap rumah sakit. *Kesmas*. 2013;8(3):104–8.
2. Silalahi RH. Faktor-faktor yang memengaruhi persepsi masyarakat tentang filariasis di Desa Juma Teguh Kecamatan Siempat Nempu Kabupaten Dairi. *J Kesehat Bukit Barisan*. 2018;2(4):63.
3. Munadhir. Persepsi masyarakat terhadap penderita filariasis (studi kualitatif di wilayah kerja Puskesmas Maukaro Kecamatan Maukaro Kabupaten Ende Provinsi Nusa Tenggara Timur). *Media Komun Kesehat*. 2017;9(2):56–65.
4. Nadirawati. Hubungan dukungan kepala keluarga dengan partisipasi keluarga dalam program eliminasi (minum obat) filariasis di Majasetra Kabupaten Bandung. *JKS*. 2011;6(1):47–55.
5. Willa RW, Noshirma M. Permasalahan filariasis dan vektornya di Desa Soru Kecamatan Umbu Ratunggai Kabupaten Sumba Tengah Nusa Tenggara Timur. *Aspirator*. 2015;7(2):58–65.
6. Irfan I, Israfil I, Bai MKS. Evaluation of filariasis “MDP” implementation on changing aspects of knowledge, environment, and behavior of filariasis sufferers. *J Info Kesehat*. 2019;17(2):144–51.
7. Irfan I, Kambuno NT, Israfil I. Factors affecting the incidence of filariasis in Welamosa Village Ende District East Nusa Tenggara. *GMHC*. 2018;6(2):130–7.
8. Mutheneni SR, Upadhyayula SM, Kumaraswamy S, Kadiri MR, Nagalla B. Influence of socioeconomic aspects on lymphatic filariasis: a case-control study in Andhra Pradesh, India. *J Vector Borne Dis*. 2016;53(3):272–8.
9. Onggang FS. Evaluasi implementasi “POMP” filariasis dan faktor yang berhubungan dengan permasalahannya di Kabupaten Manggarai Timur tahun 2017. *J Info Kesehat*. 2017;15(1):45–69.

10. World Health Organization. Lymphatic filariasis: managing morbidity and preventing disability. Geneva: World Health Organization; 2013.
11. Purwastyastuti. Pemberian obat massal pencegahan (POMP) filariasis. *Bul Jendela Epidemiol.* 2010;1:15–9.
12. Arsin AA. *Epidemiologi filariasis di Indonesia.* Makassar: Masagena Press; 2016.
13. Irfan, Ora AP, Landi S, Patmawati TA, Kambuno NT, Poddar S. Lack of changes in community behavior and environmental factors after filariasis elimination program in Kodi Balaghar district, Southwest Sumba regency: a qualitative studies. *Mal J Med Health Sci.* 2021;17(Suppl 4):92–7.
14. Irfan, Ora AP, Landi S, Zubair. The use of mosquito nets and the habit of going out at night as risk factors for filariasis in Kodi Balaghar sub-district, Southwest Sumba district, East Nusa Tenggara, Indonesia; case control study. *Eur J Mol Clin Med.* 2020;7(10):2421–30.
15. Pusat Data dan Informasi, Kementerian Kesehatan Republik Indonesia. Situasi filariasis di Indonesia [Internet]. Jakarta: Kementerian Kesehatan Republik Indonesia; 2019 [cited 2022 May 21]. Available from: <https://pusdatin.kemkes.go.id/resources/download/pusdatin/infodatin/infodatin-filariasis.pdf>.
16. Yanuarini C, Aisah S, Maryam. Faktor-faktor yang berhubungan dengan kejadian filariasis di Puskesmas Tirto 1 Kabupaten Pekalongan. *Fikkes.* 2015;8(1):73–86.
17. Nawawi M, Puspawati, Arsyad M. Gambaran penularan filariasis pada keluarga pasien yang positif filariasis di Desa Hamaraung Kecamatan Juai Kabupaten Balangan periode Maret tahun 2017. *Ergasterio.* 2018;5(1):2–9.
18. Rahmawati E, Sadukh JJP, Sila O. Analisis spasial distribusi kasus filariasis di Provinsi Nusa Tenggara Timur tahun 2008-2012. *J Info Kesehat.* 2017;15(2):240–53.
19. Dinas Kesehatan Provinsi Nusa Tenggara Timur. *Profil kesehatan Provinsi Nusa Tenggara Timur.* Kupang: Dinas Kesehatan Provinsi Nusa Tenggara Timur; 2018.
20. Willa RW. Situasi filariasis di Kabupaten Sumba Tengah Propinsi Nusa Tenggara Timur tahun 2009. *Media Penelit Pengemb Kesehat.* 2012;22(1):45–50.
21. Patanduk Y, Yunarko R, Mading M. Penerimaan masyarakat dan cakupan pengobatan massal Filariasis di Kecamatan Kodi Balaghar, Kabupaten Sumba Barat Daya. *Bul Penelit Sist Kesehat.* 2016;19(2):157–63.
22. Mulyana D. *Ilmu komunikasi: suatu pengantar.* Ninth printing. Bandung: PT Remaja Rosdakarya; 2015.
23. Lismayanti L, Ibrahim K, Meilianingsih L. Pengalaman hidup orang terinfeksi filariasis. *JKP.* 2013;1(1):18–29.
24. Walgito B. *Pengantar psikologi umum.* Fifth printing. Yogyakarta: Andi Offset; 2010.
25. Sulistyaningsih N, Musthofa SB, Kusumawati A. Persepsi masyarakat terhadap program eliminasi filariasis melalui (POMP) sebagai upaya pencegahan filariasis di Kecamatan Bonang, Kabupaten Demak. *JKM.* 2018;6(1):780–90.
26. Agustiantiningsih D. *Praktik pencegahan filariasis.* Kemas. 2013;8(2):190–7.
27. Ibrahim N, Idrus NI. Ha'i Bou: perspektif lokal penyakit filariasis di Maukaro, Ende, Nusa Tenggara Timur. *Emik.* 2019;2(1):56–70.
28. Fitriasari E, Syahrul. Pengetahuan, sikap dan praktik pencegahan filariasis pada masyarakat di daerah endemik filariasis. *J Penelit Kesehat Suara Forikes.* 2019;10(3):227–30.
29. Siwiendrayanti A, Pawenang ET, Indarjo S, Windraswara R. Edukasi pencegahan filariasis dengan buku saku mandiri di wilayah endemis filariasis Kabupaten Demak. *J Abdimas.* 2019;23(2):107–11.