

The Flow of Social Environmental Determinants of Disabilities on Lepers in Tuban City

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ABSTRACT

Background: Leprosy is a neglected tropical disease considered rare in most areas despite having a relatively high incidence in some countries. **Objective:** Analyze the flow of determinants of the social environment that can affect the occurrence of disability in lepers and their impacts. **Method:** Research using a qualitative approach. The research was conducted in Tuban Regency, East Java Province. The informant selection technique uses a purposeful sampling technique. Data analysis uses triangulation techniques. **Results:** The frequency of leprosy in Tuban Regency tended to decrease from 2014-2019. Leprosy distribution occurred in 18 sub-districts; Lepers were found every month in 2019 with various characteristics of lepers that cause the emergence of leprosy and disability in leprosy. The total number of informants in this study was seven informants. Determinants of disability in lepers include informant characteristics and social environment, including knowledge, contact history, family support, self-confidence, and impact. **Conclusion:** In this study, the social environment that most impacts the occurrence of disability in lepers is the informant knowledge factor. Informant knowledge is influenced by education, a large network of friends, and technological literacy. Education will show the type of informant work, and the type of work will determine the income of the informant; income determines economic status. Economic status contributes to food intake, medication seeking, and the home's physical condition. The duration of leprosy treatment will affect the worsening of the disability if good self-care is not carried out and always use PPE when doing activities.

Keywords: Disabilities, Environment, Knowledge, Leprosy, Social.

INTRODUCTION

Leprosy is a neglected tropical disease considered rare in most areas, although it has a relatively high incidence in some countries, (Jariyakulwong, Julanon and Saengboonmee, 2022). The emergence of leprosy is an interaction between various causative factors, namely individual factors (host), *Mycobacterium leprae* leprosy bacteria (agent), and the environment, through a process known as the chain of transmission which consists of 6 components, namely the cause, source of transmission, how to get out of the source

of transmission, how to enter the host and the host. By knowing the process of infection or the chain of disease transmission, appropriate interventions can be carried out to break the chain of transmission, (Kemenkes RI, 2019).

Poor management of leprosy cases can cause leprosy to become progressive, causing permanent damage to the skin, nerves, limbs, and eyes (Kemenkes RI, 2019). Leprosy is a public health concern related to disability, deformity, stigma, and discrimination of affected individuals, (Chokkakula *et al.*, 2020).

The presence of G2D at the time of diagnosis indirectly indicates delayed

detection, due perhaps to poor awareness in the community about the early signs of leprosy and the importance of seeking treatment, (World Health Organization (WHO), 2020). The distribution and spread of endemic leprosy are closely related to the social determinants of health that cause inequality, which include poor housing conditions, low education, low income, gender inequality and ethnic-racial inequality, (Ramos *et al.*, 2021).

There are 127 countries (out of 221 countries) that provided leprosy data to WHO in 2020. The registered leprosy prevalence (number of cases on treatment at the end of 2020) was 129,192, at a rate of 16.6 per billion population. Globally, 127,396 new cases were reported, for a case detection rate of 16.4 per million population. The highest proportion of both cases registered for treatment (61.1%), and new cases detected (66.6%) were in Southeast Asia. Brazil, India and Indonesia continue to report >10,000 new cases each, (WHO, 2021).

Throughout 2020, there were 8,629 new cases detected among children, equivalent to 6.8% of all new cases. Southeast Asia accounted for 62.3% of all new child cases, with India reporting 3,753 and Indonesia 1,126 new child cases. Of all new cases of G2D leprosy, 308 (4.3%) occurred in children. Another 68 countries reported 7,198 new cases of G2D. Over a third (37.7%) reported from Southeast Asia, 33.9% from Africa and 22.4% from America, (WHO, 2021).

There are 23 global priority countries for leprosy, accounting for 121,358 new cases or 95.3% of all new cases globally, corresponding to a rate of 40.3 per million population. India (65,147 new cases), Brazil (17,979 new cases), and Indonesia (11,173 new cases) accounted for 83.21% of new leprosy cases detected worldwide in 2020, (WHO, 2021).

In 2020 in Indonesia, there were 10,976 new cases of leprosy, with 4.03 per hundred thousand population and 12,254 registered cases of leprosy. There were 1,229 new leprosy cases in PB and 9,747 new leprosy in MB. There were 1,134 cases of leprosy in children <15 years (10.33%). There were 6,915 cases of male gender and 4,061 cases of female. The level of disability 0 is 9,176 cases (83.60%), and the level of disability 2 is

673 cases (6.13%). The level 2 disability rate per one million population is 2.47. There were 19 cases (1.68%) of leprosy in children <15 years with level 2 disability, (Kemenkes RI., 2022).

East Java contributed the highest number of new leprosy cases, with the main spread on Madura Island and the North Coast of Java. There were 1,696 cases with a new case finding rate of 4.22 per hundred thousand population. There were 90 new cases of PB-type leprosy and 578 new cases of MB-type leprosy. There were 1,280 (75.47%) for grade 0 disability and 164 cases (9.67%) for grade 2 disability, with a grade 2 disability rate per one million population of 4.08. There were 98 cases of leprosy in children <15 years (5.78%), and leprosy in children <15 years with level 2 disability, there were 5 cases (5.10%), (Kemenkes RI., 2022).

Tuban in 2020 was included in the top 10 regencies/cities in East Java with the highest cases of leprosy; there were 66 new cases of leprosy (8 of them were new cases of child leprosy), and 101 cases of leprosy were registered. There were 46 new cases of male leprosy and 20 new cases of female leprosy. There were four new cases of PB-type leprosy and 62 new cases of MB-type leprosy. New leprosy with grade 0 disability was 44 cases (66.7%), and grade 2 disability was 4 cases (6.1%). One new case of child leprosy <15 years old, (Dinas Kesehatan Provinsi Jawa Timur, 2022).

Several factors influence the implementation of leprosy management, which is not yet optimal, among others; the community has not fully received information about leprosy and has the assumption that leprosy cannot be cured because of the disability it causes; lack of ability of puskesmas staff in early detection and management of leprosy sufferers; inadequate MDT management; lack of cross-program and cross-sector involvement in leprosy management; stigma and discrimination are still high; and the magnitude of the problem of controlling other diseases such as tuberculosis and HIV. This affects the lack of attention to leprosy prevention, (Kemenkes RI, 2019). So do not be surprised if leprosy is one of 17 neglected tropical diseases (NTD). This requires world attention because the incidence rate is high, (WHO, 2016).

WHO treatment of leprosy (MDT) began in 1985 by recommending three-drug regimens, namely rifampicin, dapsone, and clofazimine, for all leprosy patients, with a treatment duration of 6 months for PB leprosy and 12 months for MB leprosy, (Jariyakulwong, Julanon and Saengboonmee, 2022). The National Leprosy Eradication Program (NLEP) conducts an active case detection campaign involving social health activists and other public health volunteers. In April 2016, WHO launched a global leprosy strategy which aims to further reduce the burden of leprosy at both global and local levels with the main targets: Zero G2D (Disability level 2) in children diagnosed with leprosy; reduce new leprosy cases with G2D to < 1 per million population; and zero countries with laws that allow discrimination due to leprosy, (Reddy *et al.*, 2022).

Many studies have shown that healthcare organizations are characterized by network decentralization, provision of additional screening, surveillance of contacts, health promotion measures, and active case tracing to be a determinant of diagnosis and, therefore, of increasing coefficients, at least in the short term. In the long term, a marked and sustainable reduction of endemic diseases is expected, (de Sousa *et al.*, 2020), (Sato *et al.*, 2021).

Given the above information, it is necessary to carry out further research to understand the occurrence of disabilities in leprosy patients in Tuban. The condition of leprosy sufferers who tend to close themselves to people they have never known is due to the psychological burden they experience, such as stigma against themselves and/or those around them, so the research approach used is qualitative. Through a personal approach and assistance from the officer in charge of the leprosy program at the health centers, it is expected to obtain an analysis of the path of social-environmental determinants that can affect the occurrence of disabilities in leprosy sufferers and their impacts. For this reason, it is necessary to conduct a study entitled **"Flow of Social Environmental Determinants of Disabilities on Lepers in Tuban Regency."**

METHODS

The research was conducted in 4 sub-districts (5 health centers) out of 20 (33 health centres) in Tuban Regency, East Java Province. The research subjects were leprosy cases of the MB type with disability levels 1 and 2, totalling 17 subjects.

Research informants were determined according to inclusion and exclusion criteria. Inclusion criteria included new treatment status, diagnosis with leprosy for more than five months, type of MB leprosy, level I and II disability, disability score of more than 1, aged more than 15-10 years, open to new people, and willing to become informants. Exclusion criteria include limitations such as being blind and deaf and living alone or neighbours who are next to/around the house are not relatives.

The condition of leprosy sufferers who tend to close themselves to people they have never known is due to the psychological burden they experience, such as stigma against themselves and/or those around them, so the research approach used is qualitative. Through a personal approach and assistance from the officer in charge of the leprosy program at the health centers, it is expected to obtain an analysis of the flow of social-environmental determinants that can affect the occurrence of disabilities in leprosy sufferers and their impacts; so that the informant selection technique used is the purposive sampling technique. Data collection methods were obtained through in-depth interviews with informants and research-supporting subjects. The research instrument was field notebook, camera, and a closed questionnaire using Indonesian about the characteristics of the informants and the social environment, including knowledge, contact history, family support, self-confidence, and impact. Data analysis uses triangulation techniques, and data presentation uses narrative text, image, and tables.

RESULTS AND DISCUSSION

The frequency of leprosy in Tuban

Regency tends to decrease from 2014- 2019. This trend is shown in Images 1:

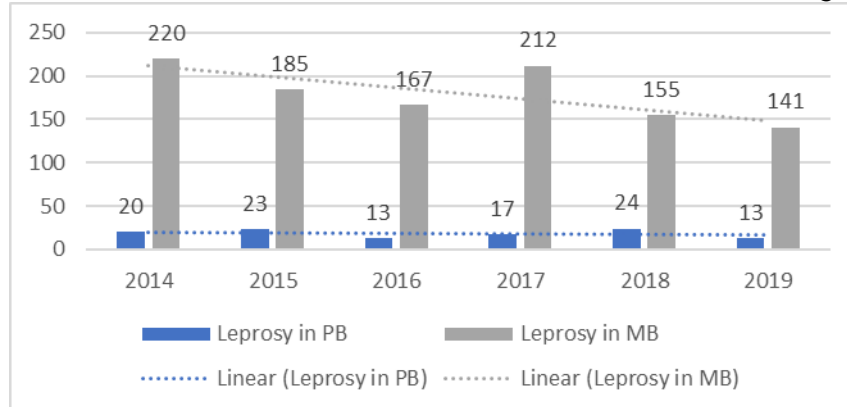


Figure 1. Bar chart of PB and MB leprosy distribution by year in Tuban Regency in 2014-2019. Source: Secondary Data from The Tuban Regency Health Office, 2019 processed.

The distribution of leprosy occurs in 18 districts (27 health centres) out of 20 districts (33 health centres) in Tuban Regency, East Java Province. Leprosy sufferers were found every month in 2019 with various characteristics of leprosy sufferers, which led to the emergence of leprosy and disabilities in leprosy sufferers. The determinants of disability in leprosy patients include the characteristics of the informants and the social environment, including knowledge, contact history, family support, self-confidence, and impact. The results of this study will be distributed in tabular form.

Table 1. Characteristics of research informants.

	Total (n=7)
Gender	
Man	6 (85.71%)
Woman	1 (14.28%)
Age	
10-19	2 (28.57%)
20-19	0
30-39	2 (28.57%)
40-49	0
50-59	2 (28.57%)
60-69	1 (14.28%)
Marital status	
Marry	4 (57.14%)
Single	3 (42.85%)
Education	
No school	2 (28.57%)
Didn't graduate from elementary school	1 (14.28%)
Elementay school	3 (42.85%)
Junior High School	1 (14.28%)
Income per month	
<UMK	6 (85.71%)

>UMK	1 (14.28%)
Number of occupants of the house	
One person	0
Two persons	1 (14.28%)
Three people	3 (42.85%)
Four people	1 (14.28%)
Five people	2 (28.57%)

Table 2. Access to the informant health centre. Total (n=7)

Distance from home to the health centre	
±3-5 km	2 (28.57%)
±6-10km	2 (28.57%)
±10-20 km	3 (42.85%)
Travelling time	
10-30 minutes	7 (100%)
Cost to the health centre	
Rp. 10,000.00	7 (100%)

The total number of informants in this study was seven informants. The sex of the informants was 6 (85.71%) male and 1 (14.28%) female. There were 2 (28.57%) informants aged 15 years, aged 36-38 years; there were 2 (28.57%) informants, and aged 59-60 years, there were 3 (42.85%) informants. In finding leprosy, there were 2 (28.57%) informants with active detection status and 5 (71.43%) informants with voluntary discovery status. Level 1 disability was 1 (14.28%) informant and 6 (85.71%) informants with level 2 disability. RFT treatment status there were 3 (42.85%) informants and 4 (57.14%) informants still undergoing MDT.

Informant educational status; There were 2 (28.57%) informants who did not go to school, 1 (14.28%) did not graduate from elementary school, 3 (42.85%) had

passed elementary school, and 1 (14.28%) graduated from junior high school. There was 1 (14.28%), informant who did not work, 1 (14.28%) housewife informant, 1 (14.28%) farmer informant, 1 (14.28%) factory worker, there was one student (14.28%) informant, and there was 1 (14.28%) informant who chose to drop out of school. There were 4 (57.14%) informants with married status and 3 (42.85%) with single status. All informants rode motorbikes to seek treatment at the puskesmas alone or accompanied by their children, 3 (42.85%) informants and 4 (57.14%) other informants accompanied by their wives, fathers/mothers and siblings.

Table 3. History of leprosy Informants.

	Total (n=7)
Discovery state	
Volunteer	5 (71.42%)
Active	2 (28.5%)
Been feeling sick for a long time	
<1 year	1 (14.28%)
>1 year	6 (85.71%)

Table 4. The informant's history of disability.

	Total (n=7)
Level disability	
1st-degree disability	1 (14.28%)
2nd-degree disability	6 (85.71%)
Treatment status	
RFTs	3 (42.85%)
Not RFT yet	4 (57.14%)
Disability conditions before MDT	
Ulcers all over the body	7 (100%)
The right/left hand is stiff and numb	5 (71.42%)
Fingers that are not straight	2 (28.5%)
Feet numb	2 (28.5%)
Disability conditions during MDT	
Ulcers all over the body	7 (100%)
The right/left hand is stiff and numb	5 (71.42%)
Fingers that are not straight	2 (28.5%)
Feet numb	2 (28.5%)

households, inequality, poor health care, and low education are leprosy risk markers, (Dwivedi *et al.*, 2019). There were 5 (71.42%) informants who did not correctly explain the meaning of leprosy, and 2 (28.57%) informants did not know the definition of leprosy even though all informants during their first visit to the health centre took part in the leprosy program had been explained by the person in charge of the leprosy program. There were 5 (71.42%) informants who did not know the causes of leprosy and 2 (28.57%) informants who knew the causes. There were 6 (85.71%) informants who did not know the signs and symptoms of leprosy, and 1 (14.28%) informant knew the signs and symptoms of leprosy.

Table 5. Knowledge of leprosy informants.

	Total (n=7)
Leprosy definition	
Not true	5 (71.42%)
Don't know	2 (28.5%)
Causes of leprosy	
Know	5 (71.42%)
Don't know	2 (28.5%)
Source of transmission of leprosy	
Don't know	7 (100%)
Methods of transmission of leprosy	
Don't know	7 (100%)
Signs and symptoms of leprosy	
Know	1 (14.28%)
Don't know	6 (85.71%)
Free leprosy drug knowledge	
Don't know	7 (100%)
The impact of breaking up leprosy drugs	
Don't know	7 (100%)

How they manage their lives depends on how they interpret their illness and give meaning to their existence, (Rahman *et al.*, 2022). Various studies across India have reported lower levels of knowledge and awareness among most people, (Reddy *et al.*, 2022). Follow-up efforts should be continued even after completing MDT. In addition, many are lost to follow-up because they stop being evaluated regularly by healthcare professionals. They are taught self-care and advised to return if their symptoms recur or worsen. Some individuals do not receive timely treatment or follow-up because of their age, lack of knowledge, poor perception of symptoms, stigma, or inability to go to

Research in Brazil, India, and Bangladesh reveals that age, poor sanitation, socioeconomic conditions, past food shortages, food insecurity, household contact, manual labour, crowded

a health centres due to distance and economic hardship. The deteriorating status of leprosy and physical disability is not managed because they are ostracized from their environment, (Rahman *et al.*, 2022)(Banna *et al.*, 2022).

Dysregulation of the immune system of leprosy sufferers is related to poor nutritional status, failure of health services to reduce the stigma of leprosy, low number of vaccinations, low nutritional status, inappropriate breastfeeding, and low environmental hygiene and sanitation, including clean water facilities, type of floor, humidity, intensity sunlight, ventilation, and residential aspects that can be found in several endemic areas, (Ramona *et al.*, 2021).

Informants' knowledge is influenced by education, the number of friendship networks, and technological literacy. Education will indicate the type of work of the informant, the type of work will determine the informant's income, and income will determine the economic status. Economic status contributes to food intake, treatment seeking, and physical housing conditions. The length of time seeking treatment for leprosy will affect the severity of the disability if good self-care is not carried out and always use PPE when doing activities.

Symptoms of leprosy may appear within a year, but for some people, symptoms may take 20 years or more to occur, (Farag *et al.*, 2022). House contacts with leprosy cases are at the highest risk, (Tió-Coma *et al.*, 2021). Households with greater population density facilitate transmission through close contact, (da Paz *et al.*, 2022).

Leprosy is associated with poverty, indicating that the comorbidities of poverty can promote leprosy transmission, (Dennison *et al.*, 2021). In this study, there were 2 (28.57%) informants who had a history of family contact, 1 (14.28%) of informants had a history of contact with neighbours, and 1 (14.28%) of informants had a history of contact with peers. Or colleagues, and 3 (42.85%) informants had no contact history with family or neighbours.

Table 6. Contact history of leprosy informants.

Total (n=7)	
Leprosy contact	
Family	2 (28.5%)

Neighbour	1 (14.28%)
Peers/Colleagues	1 (14.28%)
No contact	3 (42.85%)
Examination of contacts (suspect/BTA+ after the informant	
There are suspects after informants	1 (14.28%)
There are no suspects after the informants	6 (85.71%)

Many studies suggest that *Mycobacterium leprae* can be found in the environment and may have a role in continuing disease transmission. Cleanliness is always associated with disease because it drastically smoothes and prevents the risk of exposure, (Turankar *et al.*, 2019). Additional socioeconomic factors that reflect exposure to contact tangles and increased levels of deprivation, such as urbanization and household density, have also been associated with an increased risk of leprosy detection, (Pescarini *et al.*, 2020). Delays in diagnosing and treating leprosy and its complications can result in permanent deformities, (Ortuño-Gutiérrez *et al.*, 2021) and social exclusion (van Hooij *et al.*, 2021).

Post-exposure prophylaxis (PEP) with a single dose of rifampicin (SDR) reduces the risk of developing leprosy among contacts of leprosy patients (Barbieri *et al.*, 2022). Several villages in the working area of the health centers in Tuban Regency refused when the program officer in charge of the leprosy program carried out chemoprophylaxis activities; the residents claimed that they were healthy and did not feel sick, so they refused to be given and take a single dose of rifampicin. In several villages where the health centers work's, it receives and takes a single dose of rifampicin, which requires good cooperation between residents and staff.

Despite advances in treatment and political commitment at a global level with reductions in the worldwide leprosy burden, further reduction of the leprosy burden is met with enormous challenges. This challenge consists of three prongs, including further reductions in new cases, registered prevalence, and social stigma and exclusion through the prevention and management of disability. The full involvement of endemic communities and people with leprosy is fundamental in

reducing the burden of leprosy, (Tabah *et al.*, 2018).

The existence of contact before the informant determines the cause of the infection of the informant. Informants can become a new home transmission source to the family if they do not immediately carry out a leprosy MDT treatment program. The intense relationship with informants influences the occurrence of leprosy in new patients, the size of the house, the physical condition of the house, and food intake related to immunity.

The first person to know that an informant has leprosy is a family member; there are 6 (85.71%) informants and 1 (14.28%) informant whose neighbours know when the informant has signs and symptoms of leprosy. There were 3 (42.85%) informants for treatment accompanied by their children, 1 (14.28%) informant for treatment accompanied by his wife, 1 (14.28%) informant for treatment by his mother and sometimes his junior high school teacher, 1 (14.28%) the informant was seeking treatment accompanied by a sibling or brother-in-law. There was 1 (14.28%) the informant was seeking treatment accompanied by his father.

Table 7. Family support to informants

Total (n=7)	
The person who first knew the informant had signs and symptoms of leprosy	
Family	6 (85.71%)
Neighbour	1 (14.28%)
Family members accompanying treatment	
Child	3 (42.85%)
Wife	1 (14.28%)
Mother	1 (14.28%)
Father	1 (14.28%)
Siblings	1 (14.28%)

The existence of support from the family gives sufferers the hope of enthusiasm for recovery. The government's free medical treatment program for leprosy should not affect families providing moral, material and social support to sufferers. In this study, all lepers received full support from their families.

The demand for a speedy recovery became the motivation for the informants. Roles and responsibilities also

accompany the demands before being diagnosed with leprosy and after being diagnosed with leprosy. Most leprosy sufferers choose to rest completely or only when a reaction occurs. This resulted in changing roles and responsibilities, which were originally able to help the economy in the family by working after being diagnosed with leprosy to taking complete rest so that income was reduced, which impacted economic status. Furthermore, economic status affects the food consumed daily and the house's physical condition.

The existence of family support will bring hope to the spirit of recovery to the informants. Furthermore, demands, roles, and responsibilities are important in raising hopes for a speedy recovery. Roles and responsibilities before and after being diagnosed with leprosy can affect employment, income, and economic status.

Self-concept will affect the informant's self-confidence. Then, self-confidence will impact the informants' ability to interact well. The existence of social interaction is also influenced by ability. The length of friendship, experience, and age influence's ability.

Leprosy is a disease of public health concern associated with disability, deformity, stigma, and discrimination of affected individuals, (Chokkakula *et al.*, 2020). Stigma can be divided into applied stigma and perceived stigma. Prejudice and discrimination against patients by family members deprive them of emotional and material support, (Tembei *et al.*, 2022). Overcoming leprosy is how people manage stressful or traumatic situations to maintain their emotional well-being, (Rahman *et al.*, 2022).

There were 2 (28.57%) informants that their school-age children had no talent. Unlike the productive age informants, there were 5 (71.52%) of their informants who tended to be skilled and had many talents. This is because the informants of productive age have conditions that force them to be skilled in finding talent to work so that they can fulfil their daily needs independently. Psychological problems for lepers are a very serious threat because the consequences can go beyond the disease itself. Leprosy stress creates a psychological burden because it impacts physical, psychological and social

conditions, affecting all life processes, (Nasir *et al.*, 2022).

Table 8. Confidence of informants.

Total (n=7)	
Difficulty doing activities	
Have no difficulty doing activities	6 (85.71%)
Have difficulty exercising	1 (14.28%)
Social interaction	
Informant relationship with family, neighbours, friends peers, and good co-workers	7 (100%)
The views of family, neighbours, peers and co-workers on informants were favourable	7 (100%)
Self-description	
Just looking at him normally	6 (85.71%)
Seeing himself is different	1 (14.28%)
Role and responsibility before being diagnosed with leprosy	
Head of family and work	3 (42.85%)
Wife and work	1 (14.28%)
Child and work	1 (14.28%)
Children and students	2 (28.5%)

There were six informants (85.71%) who had no difficulties in their activities and 1 (14.28%) who sometimes still had difficulties. All informants did not limit their activities when the leprosy reaction did not recur. All views of family, neighbours, peers or co-workers tend to be normal and treat informants like other members, neighbours and friends. This is because they see that the informant can still carry out activities like a normal human being without any restrictions, and special treatment is required due to the illness they are experiencing.

There were 6 (85.71%) informants who saw themselves as normal by accepting the pain they were experiencing and 1 (14.28%) who saw themselves as different from the others. All informants did not have an unconscious attitude that could harm their physical and psychological condition of the informants and the conscious attitude carried out by all informants, namely obedient treatment and routine

self-care.

Self-care is important for individuals affected by leprosy to encourage them to change their behaviour to adapt to the permanent damage caused by the disease. Self-care in leprosy is a daily activity that requires the active involvement of individuals to care for themselves, reduce the number of ulcers, prevent further damage, improve their physical health and increase self-confidence and self-esteem, (Rahman *et al.*, 2022).

The results of this study indicate that all informants do not have certain demands in their lives. So that they lead a quiet life; according to the elderly informants, they are sufficient to make ends meet because their children are already married. The informants at school age did not have any specific demands because, at school, they chose to be ordinary students, such as not joining organizations and others.

The results of this study indicate that all informants have accepted the current conditions. This is shown by their motivation to recover by routinely checking and taking medicines at the puskesmas, doing good and proper self-care, and following the recommendations and prohibitions of the officer in charge of the leprosy program at the health centers.

Health services mainly focus on curative treatment and the biophysical impact of disease but less on psychosocial and economic aspects. Due to chronic leprosy, studying the life experiences of affected individuals will allow us to understand more deeply the effects of the disease, how they seek help and adhere to treatment, and cope with the disease, (Rahman *et al.*, 2022).

Impact on the body includes changes in urine colour and skin colour. Every drug must have side effects. Rifampicin rarely causes side effects because it is only given once a month. The appearance of symptoms is a change in the colour of the urine to yellow or even red. This is only temporary. Sufferers need to be notified so they are not surprised (Ministry of Health RI, 2019). The results of this study indicate that the side effect felt by all informants after taking the drug was that the urine turned yellow. Handling the side effect of changing urine colour after taking

rifampin, namely *reassurance* (soothing the patient with the correct explanation) and counselling, (Kemenkes RI, 2019).

Serious side effects when drinking lampren include skin and mucosal hyperpigmentation (skin changes to brown), dryness, ichthyosis, pruritus, acneiform eruptions, skin rashes, and photosensitivity reactions. Hyperpigmentation side effects will disappear 6-12 months after the lampren is stopped. The side effects of lampren can usually be tolerated so that treatment does not need to be stopped, (Kemenkes RI, 2019).

The side effects of rifampicin are flu-like symptoms (*flu-like-syndrome*), such as fever, chills, and bone pain which can be given symptomatic treatment, (Kemenkes RI, 2019). The results of this study indicate that the effect on the body after taking the drug by all informants is that all body skin turns black (hyperpigmentation) and often feels chills when there is a reaction to leprosy or exposure to the night wind. Handling the side effect of changing urine colour after taking rifampicin is *reassurance* (calming the sufferer with the correct explanation) counselling, (Kemenkes RI, 2019).

Psychosocial impacts occurred on school-age informants and productive-age informants. The results of this study indicated that there was 1 (14.28%) informant who felt scared, uneasy, and offended when at school; this is because the informant still remembers and always screams uneasy and is afraid to meet the teacher who reprimands him due to ignorance of changes in skin colour which are quite prominent among his friends due to the illness experienced by the informant. There was 1 (14.28%),

informant who felt embarrassed or uncomfortable going to school with his niece, so the informant was too lazy to go to school, resulting in him not wanting to go to school anymore and choosing to stop going to school. Self-acceptance from the social environment of the informant's current condition will lead to self-confidence. It is proven that 2 (28.57%) school-age informants have good social interactions with their peers outside the school environment.

The results of this study showed that there were 2 (28.57%) male informants of reproductive age who felt ashamed and tended to close themselves off from the social environment, such as neighbours, peers, and co-workers, before undergoing the leprosy MDT treatment program and began to be confident and open oneself with the social environment when the ulcers on the body begin to heal and finish the leprosy MDT treatment program (RFT). It is proven that when the ulcers began to heal, the informants began to open themselves to the social environment; however, the mental rehabilitation efforts of the officer in charge of the leprosy program would not be successful without emotional support from the family and social environment.

The social environment determinants that become the fundamental problem of disability in leprosy are the characteristics of the informants and the social environment, including knowledge, contact history, family support, self-confidence, and impact.

Analys flow of social environmental determinants of disabilities on lepers in Tuban Regency.

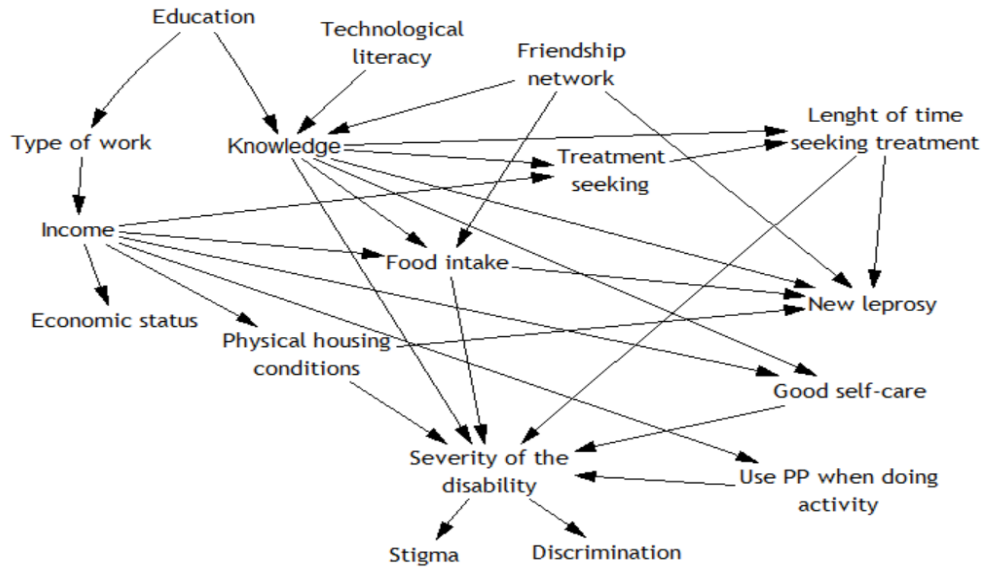


Figure 2. Flow of social environmental determinants of disabilities on lepers in Tuban Regency.

Informants' knowledge is influenced by education, the number of friendship networks, and technological literacy. Education will indicate the type of work of the informant, the type of work will determine the informant's income, and income will determine the economic status. Economic status contributes to food intake, treatment seeking, and physical housing conditions. The length of time seeking treatment for leprosy will affect the severity of the disability if good self-care is not carried out and always use PPE when doing activities.

Efforts that should be made so that global and national targets in preventing level 2 disability in leprosy include the following:

1. Government

a. Public Health Office

- 1) Providing facilities related to the needs of officers holding the leprosy program in handling BPJS or assistance with leprosy assessment results that require immediate surgery, self-care needs, and PPE for leprosy sufferers.
- 2) Establish cooperation in early detection and eradication of leprosy with Penta helix collaboration starting from the Social Service, sub-district government, village government, RW and RT.

b. Social services

- 1) Ensuring leprosy sufferers are included in poor community programs such as rice rations, BPJS, and other social assistance.
- 2) Helping to increase the economy of leprosy sufferers following the results of the assessment of the health office and puskesmas.

2. Health Center

- a. Improving nerve examinations in leprosy patients for preventive action on the occurrence of leprosy defects.
- b. Coordinate with the sub-district government, village government, RW and RT to detect and eradicate leprosy as early as possible.
- c. Increase outreach activities for new leprosy sufferers and their families and neighbours in the environment of leprosy sufferers during ICF and community activities.
- d. In puskesmas that have not yet formed KPD, it is hoped that they will form it soon to teach self-care to new leprosy sufferers.
- e. Submit as soon as possible to request a referral to the Sumberglagah Leprosy Hospital in Mojokerto Regency when sufferers need a referral.
- f. Form leprosy cadres of 4 people per health centre with a total of 132 people for cadre from the Health Office.

3. Public

- a. Eliminate stigma and discrimination against leprosy sufferers by having good social interactions with leprosy sufferers.
- b. Immediately check with the puskesmas when you find family members, neighbours, peers, and/or co-workers if you find signs and symptoms of leprosy.

The limitation of this study is that interviews with informants and supporting subjects were only conducted once. Observations were made to look at the conditions around the informant's house. The results of this study can only be used in other areas if some similar situations and conditions follow this research.

CONCLUSION

In this study, the social environment that had the most impact on the occurrence of disability in leprosy patients was the informant's knowledge factor. Informants' knowledge is influenced by education, the number of friendship networks, and technological literacy. Education will indicate the type of work of the informant, the type of work will determine the informant's income, and income will determine the economic status. Economic status contributes to food intake, treatment seeking, and physical housing conditions. The length of time seeking treatment for leprosy will affect the severity of the disability if you do not take good self-care and always use PPE when doing activities.

The existence of contact before the informant determines the cause of the infection of the informant. Informants can become a new home transmission source to the family if they do not immediately carry out a leprosy MDT treatment program. The intense relationship with informants influences the occurrence of leprosy in new patients, the size of the house, the physical condition of the house, and food intake related to immunity.

The existence of family support will bring hope to the spirit of recovery to the informants. Furthermore, demands, roles, and responsibilities are important in raising hopes for a speedy recovery. Roles and responsibilities before and after being diagnosed with leprosy can affect employment, income, and economic status.

Self-concept will affect the informant's self-confidence. Then, self-confidence will impact the informants' ability to interact well. The existence of social interaction is also influenced by ability. The length of friendship, experience, and age influence's ability.

Impact on the body; changes in urine and skin colour experienced by informants can be handled by counselling the officer in charge of the leprosy program. Impact on psychosocial; self-acceptance from the social environment to the informant's current condition will lead to self-confidence and good social interaction. The feeling of shame and the tendency to withdraw from the social environment is due to ulcers on the informant's body. It is proven that when the ulcers started to heal, the informants started to open up to the social environment.

REFERENCES

- Banna, M. H. Al *et al.* (2022) 'Knowledge and awareness about food safety, foodborne diseases, and microbial hazards: A cross-sectional study among Bangladeshi consumers of street-vended foods', *Food Control*, 134(November 2021), p. 108718. doi: 10.1016/j.foodcont.2021.108718.
- Chokkakula, S. *et al.* (2020) 'Genotyping of *Mycobacterium leprae* for understanding the distribution and transmission of leprosy in endemic provinces of China', *International Journal of Infectious Diseases*, 98(101), pp. 6-13. doi: 10.1016/j.ijid.2020.06.032.
- Dennison, C. L. *et al.* (2021) 'Mycobacterium leprae-helminth co-infections and vitamin D deficiency as potential risk factors for leprosy: A case-control study in south-eastern Brazil', *International Journal of Infectious Diseases*, 105, pp. 261-266. doi: 10.1016/j.ijid.2021.02.048.
- Dinas Kesehatan Provinsi Jawa Timur (2022) 'Profil Kesehatan Dinas Kesehatan Provinsi Jawa Timur 2021', *Dinas Kesehatan Provinsi Jawa Timur*, p. tabel 53.
- Dwivedi, V. P. *et al.* (2019) 'Diet and nutrition: An important risk factor in leprosy', *Microbial Pathogenesis*, 137(September), p. 103714. doi: 10.1016/j.micpath.2019.103714.
- Farag, A. G. A. *et al.* (2022) 'Interleukin-

- 17A in Egyptian leprosy patients: a clinical, genetic, and biochemical study', *Anais Brasileiros de Dermatologia*, 97(6), pp. 735-741. doi: 10.1016/j.abd.2021.09.016.
- van Hooij, A. *et al.* (2021) 'Prototype multi-biomarker test for point-of-care leprosy diagnostics', *iScience*, 24(1), p. 102006. doi: 10.1016/j.isci.2020.102006.
- Jariyakulwong, N., Julanon, N. and Saengboonmee, C. (2022) 'Lepromatous leprosy with a suspected 30-year incubation period: A case report of a practically eradicated area', *Journal of Taibah University Medical Sciences*, 17(4), pp. 602-605. doi: 10.1016/j.jtumed.2021.12.005.
- Kemkes RI. (2022) *Profil Kesehatan Indo-nesia, Pusdatin.Kemkes.Go.Id.*
- Kemkes RI (2019) *Peraturan Menteri Kesehatan Republik Indonesia nomor 11 tahun 2019 tentang penanggulangan kusta, Kemkes RI.*
- Nasir, A. *et al.* (2022) 'Relationship between resilience, coping resources, and psychological well-being with stress of leprosy as a predictor. A correlation study through the structural equation models', *Clinical Epidemiology and Global Health*, 17(October), p. 101151. doi: 10.1016/j.cegh.2022.101151.
- Ortuño-Gutiérrez, N. *et al.* (2021) 'Exploring clustering of leprosy in the Comoros and Madagascar: A geospatial analysis', *International Journal of Infectious Diseases*, 108, pp. 96-101. doi: 10.1016/j.ijid.2021.05.014.
- da Paz, W. S. *et al.* (2022) 'Impact of the COVID-19 pandemic on the diagnosis of leprosy in Brazil: An ecological and population-based study', *The Lancet Regional Health - Americas*, 9. doi: 10.1016/j.lana.2021.100181.
- Pescarini, J. M. *et al.* (2020) 'Effect of a conditional cash transfer programme on leprosy treatment adherence and cure in patients from the nationwide 100 Million Brazilian Cohort: a quasi-experimental study', *The Lancet Infectious Diseases*, 20(5), pp. 618-627. doi: 10.1016/S1473-3099(19)30624-3.
- Rahman, N. A. *et al.* (2022) *Experiences of living with leprosy: A systematic review and qualitative evidence synthesis*, *PLoS Neglected Tropical Diseases*. doi: 10.1371/journal.pntd.0010761.
- Ramona, F. *et al.* (2021) 'Faktor Lingkungan dan Kusta pada Ibu dan Anak : A Belajar di daerah endemik di Jawa Timur , Indonesia', 15(2).
- Ramos, A. C. V. *et al.* (2021) 'Social inequalities and their association with the leprosy burden in a Brazilian city of low endemicity: An ecological study', *Acta Tropica*, 218(December 2020). doi: 10.1016/j.actatropica.2021.105884.
- Reddy, N. V. *et al.* (2022) 'Awareness of Leprosy in an urban slum of Western Maharashtra Post 35 Years of the National Leprosy Eradication Program (NLEP)', *Medical Journal Armed Forces India*, 78(2), pp. 175-179. doi: 10.1016/j.mjafi.2020.11.009.
- Sato, C. M. *et al.* (2021) 'Social school contacts of multibacillary leprosy cases in children living in the hyperendemic region of the Midwest of Brazil', *Jornal de Pediatria*, 000(xxx). doi: 10.1016/j.jped.2021.11.009.
- de Sousa, D. B. *et al.* (2020) 'Hot spots of leprosy in the endemic area of São Luís, Maranhão State, Northeastern Brazil', *Journal of Infection and Public Health*, 13(2), pp. 228-234. doi: 10.1016/j.jiph.2019.08.006.
- Tabah, E. N. *et al.* (2018) 'Community knowledge, perceptions and attitudes regarding leprosy in rural Cameroon: The case of Ekondotiti and Mbonge health districts in the South-west Region', *PLoS Neglected Tropical Diseases*, 12(2), pp. 1-17. doi: 10.1371/journal.pntd.0006233.
- Tembei, A. M. *et al.* (2022) 'An analysis of social dimensions of podocniosis and leprosy on affected households in endemic health districts of the North West Region of Cameroon', *SSM - Population Health*, 19(July), p. 101187. doi: 10.1016/j.ssmph.2022.101187.
- Tió-Coma, M. *et al.* (2021) 'Blood RNA signature RISK4LEP predicts leprosy years before clinical onset', *EBioMedicine*, 68. doi: 10.1016/j.ebiom.2021.103379.
- Turankar, R. P. *et al.* (2019) 'Association of non-tuberculous mycobacteria with Mycobacterium leprae in environment of leprosy endemic regions in India', *Infection, Genetics and Evolution*, 72(November 2018), pp. 191-198. doi: 10.1016/j.meegid.2018.11.010.
- WHO (2016) *Global Leprosy Strategy 2016-2020: accelerating towards a leprosy-free world.*, *Weekly Epidemiological record*.
- WHO (2021) 'COVID-19 weekly epidemiological update', *World Health Organization*, (58), pp. 1-23.

World Health Organization (WHO) (2020)
'Global leprosy (Hansen disease) update,
2020: impact of COVID-19 on global

leprosy control', *Weekly epidemiological
record*, 96(36), pp. 421-444.