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Stigmatization of Leprosy Patients at the Primary Hospital in North Central Timor: a Qualitative Study

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ABSTRACT

Background: Leprosy is a chronic bacterial infection that affects the peripheral nervous system, skin, nose, and eyes and can cause disability. Clinical symptoms and disabilities can give leprosy patients a negative impression, known as stigma, which can affect their self-acceptance. **Purpose:** This study aims to analyze the perceptions of leprosy patients at the a primary hospital in North Central Timor regarding the stigma they experience. **Methods:** The study was a qualitative research, utilizing the in-depth interview method. The sampling technique used purposive sampling, applied maximum variation sampling, and involved 20 patients in the study.The interview results were transcribed and analyzed using the Open Code 4.03 program. The coding results were grouped into themes and subthemes that emerged. **Result:** This study found that internal and social stigma affected 80% of the 20 leprosy patients at a primary hospital. Misperceptions primarily cause internal stigma, which in turn triggers fear of infection and isolation from the community. Social stigma, also triggered by misperceptions, leprosy symptoms, and disability, leads to discrimination, and ostracism, even in family circles and places of worship. Patients experience negative impacts on their self-esteem, social life, and economy. **Conclusion:** Leprosy patients experience internal and social stigma, with 16 out of 20 patients affected. Misperceptions, symptoms, and disability due to leprosy are the leading causes. This stigma has far-reaching social, economic, and educational impacts. Support, education, and preventive measures are needed to overcome the stigma that worsens the condition of leprosy patients.

Keywords: stigma, leprosy patients, primary hospital, internal stigma, social stigma.

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BACKGROUND

Leprosy, also known as Hansen’s disease, is a bacterial infection that affects the nervous system, skin, nose, and eyes. It is caused by *Mycobacterium leprae* and can be transmitted through droplets from the respiratory tract, especially saliva or phlegm released during coughing or sneezing. However, leprosy transmission requires prolonged and repeated close contact with leprosy patients who do not receive adequate treatment.[1-2]

Data from the World Health Organization (WHO) shows a significant increase in new cases of leprosy globally, with Southeast Asia being the region with the highest number of new cases, particularly Indonesia, which ranks third in the world.[3] Despite leprosy elimination efforts in several provinces, East Nusa Tenggara (NTT) province, including Kupang City, still has many cases.[4]

Leprosy, as a chronic infection, can cause permanent disfigurement of the skin, feet, hands, and fingers. These progressive skin lesions create physical and psychological isolation in leprosy patients, which can last a lifetime and is known as stigma. This stigma, whether originating from the patients themselves (self-stigma) or society, can hinder patients from performing social roles and fulfilling family expectations, negatively impacting self-acceptance.[5]

Previous studies, such as those conducted by Dyah et al. and Susanto, show that more than 50% of leprosy patients experience social stigma, feel embarrassed, get negative views, and even feel hopeless about their physical condition. However, some patients, believing in the possibility of disease cure and a normal life, do not react negatively to stigma.[6]

The Primary Hospital in North Central Timor, NTT, was the location of this study. This hospital is the only facility in East Nusa Tenggara dedicated to patients with leprosy and leprosy-related disabilities that remains active to this day, focusing on providing care for leprosy patients from across the entire East Nusa Tenggara province. Data from the hospital also shows that stigma towards leprosy is still a serious issue, affecting patients' emotional well-being and causing anxiety or depression. Despite numerous studies on leprosy stigma in various countries, including Indonesia, East Nusa Tenggara, where the majority of the population is Christian, has seen a dearth of such studies.[7,8] Despite numerous studies on leprosy stigma in various countries, including Indonesia, East Nusa Tenggara, where the majority of the population is Christian, has seen a dearth of such studies.

METHODS

This qualitative study focuses on a holistic understanding of phenomena involving leprosy patients at the Primary Hospital in the North Central Timor district. The subjects in this study were leprosy patients at the Primary Hospital who met the inclusion and exclusion criteria. The inclusion criteria in this study were leprosy patients at the Primary Hospital who were willing to become research subjects by signing an informed consent form or giving oral consent if they could not sign it due to their disabilities. Meanwhile, the exclusion criteria in this study were leprosy patients with declining cognitive abilities or who could not speak Indonesian and were not present during the interview. Respondents were chosen using a purposive sampling approach with the maximum variation sampling method, considering the variables of gender, age, and the presence of disability.

In-depth interviews were used as a data collection technique to explore the feelings and perspectives of the subjects using an interview question guide created specifically for this study. Data will be grouped into themes and subthemes to provide an in-depth understanding of patients' perceptions of leprosy stigma. The data analysis involves data collection, data reduction by selection and abstracting, data presentation in the form of narrative text, and conclusion drawing and verification, which are carried out continuously.[9] This method can provide a comprehensive and in-depth picture of stigma, its causes, and its impact on leprosy patients. This research has received ethical approval from the Faculty of Medicine and Veterinary Medicine Ethics Commission, Universitas Nusa Cendana Kupang (42/UN15.16/KEPK/2023).

RESULT

This research was conducted at the Primary Hospital in North Central Timor in Naob Village, East Noemuti Subdistrict, North Central Timor District, East Nusa Tenggara Province. The Local Foundation established this hospital in 2007, providing health and social services. It is the only Catholic private hospital on Timor Island that specifically serves people with leprosy and disabilities through promotive, preventive, curative, and rehabilitative efforts. In addition to providing medical services, the hospital is also a place of community empowerment for general leprosy and disability sufferers from various regions in East Nusa Tenggara, especially from the Timor region.

Twenty out of the 41 leprosy patients at the Primary Hospital participated in the study. This research was conducted in July-August 2023. This study employed a qualitative method. The data was collected using the in-depth interview method. Researchers conducted face-to-face interviews with research subjects, adhering to previously compiled interview guidelines. The research subjects were determined based on maximum variation sampling with variables including gender, age, and whether they were disabled or not. The results of the interviews were transcribed and analyzed qualitatively with the help of the Open Code 4.03 application.

Based on the table above, of the 20 subjects who participated in this study, 17 subjects had disabilities related to leprosy. In contrast, the remaining three subjects were not affected by leprosy-related disabilities. Based on the table above, of the 20 subjects who participated in this study, 17 subjects had disabilities related to leprosy. In contrast, the remaining three subjects were not affected by leprosy-related disabilities. Based on gender distribution, most subjects were male (80%). We also found that more subjects (12 people) were in the adult age range than older people (6 people) and adolescents (2 people). Meanwhile, when viewed from the subject's leprosy type, the majority suffered from the multibacillary (MB) type of leprosy, as many as 17 people, while the other three people suffered from the paucibacillary (PB) type of leprosy.

Table 1. Sentence Case

No.	Characteristics	Total
1	Gender	
	- Male	16
	- Female	4
2	Age	
	- Adolescents (17-25 years old)	2
	- Adult (26-45 years old)	12
	- Elderly (46-65 years old)	6
3	With disability	
	- Yes	17
	- No	3
4	Leprosy type	
	- Paucibacillary	3
	- Multibacillary	17
5	Marriage status	
	- Married	8
	- Not married	12

The results of the interviews revealed that a variety of internal stigmas, as well as the causes and impacts of leprosy, arise within the subject. The internal stigma that arises varies, including "feeling afraid of not being accepted/shunned." As several subjects expressed, patients fear the acceptance of the surrounding community, which encourages individuals to avoid or isolate themselves from their social environment.

> *"I avoid them (family). Like, when I eat, I keep my plate separate because I don't want my family to be infected as well." (subject 3, female, 36 years old)*

> *". . . my wife eats separately from me. Sleeping is also separate. . .because I know this disease is not good (contagious). . .yes, I separate myself. . .just confined, in the village, I live in the kitchen. . . bathing in the kitchen, not in the bathroom." (subject 6, male, 48 years old)*

> *"Yes, I am afraid that they will not accept us (leprosy patients) . . . I did tell them that I was sick and paralyzed, but I didn't tell them that I had leprosy. I only told them that I was sick and paralyzed. . ." (subject 1, female, 27 years old)*

The stigma associated with leprosy affects not only patients' families and neighborhoods but also their work environment and places of worship. Some patients choose to stop working and avoid interactions at places of worship because they are worried that they could transmit the disease. These worries instil a fear of not receiving acceptance from others.

> *"I was accepted, but I left the job because this leprosy thing has come out to the surface. I do not want my illness spread to my friends, so I had to leave." (subject 17, male, 43 years old)*

> *". . .this disease makes me feel, like, if I'm in the village, I feel the most humiliated person. . . every time I go to church, I feel that I avoid many people because of my condition. I did that because I don't want my friends to have the same condition as me." (subject 17, male, 43 years old)*

Symptoms and disabilities caused by leprosy contribute to the stigma of "feeling afraid of not being accepted/shunned".

> *"Yes, I avoid people. . . I was ashamed because if I want to approach people, people will be disgusted because of my wounds." (subject 3, female, 36 years old).*

> *"My feet are about to sever, so when I go to school, I am afraid. . .because of the condition of my feet, I feel embarrassed to my friends, so I told my teacher I prefer online study more." (subject 5, male, 14 years old)*

Sufferers also face the internal stigma of "thinking it's a witchcraft disease." A minority of leprosy patients continue to hold the belief that witchcraft is the cause of the disease. The view is one form of misperception about leprosy that can encourage patients to seek alternative treatments other than medical ones.

> *"But I think like, maybe someone made me, people say someone made me, so. . . I didn't know this was leprosy; I came here and found out that someone made it, like black magic, that's how it is." (subject 3, female, 36 years old)*

Patients also experience internalized stigma, "feeling difficult to recover.". Misperceptions of patients who feel their disease is incurable lead to despair.

> *"I felt hopeless because I was afraid. Yes, I was afraid that I would not be able to recoverbecause I*

> *had never seen this (leprosy), I had never seen it in my family, so I was afraid." (subject 19, female, 38 years old)*

Additionally, patients experience internal stigma, "feeling abnormal/different," and believe that their bodies have changed and are no longer as regular as they once were. The symptoms of leprosy that manifest in the patient lead to feelings of inferiority and shame towards those around them.

> *"Yes, I feel inferior to other people because my face is damaged, this swelling is like this, my face is all damaged, so I feel inferior . . . I don't want talk to anyone." (subject 19, female, 38 years old)*

> *"I feel inferior because my face normally does not look like this. I look like an older adult even though I am still young, so I feel inferior. . . I have a face like an old lady, so I'd rather be insecure." (subject 1, female, 27 years old)*

Leprosy-induced disabilities also contribute to the stigma of "feeling abnormal/different." The disability causes patients to feel inferior and ashamed of their condition, leading them to quit their jobs.

> *"My face is swollen, just badly swollen. Legs and hands are too, so it can be seen as if they are bent. . . if we sit together, I feel like I am different. . . yes, ashamed, I live in the village, My body is different compared to everyone else" (subject 11, male, 27 years old).*

> *"Self-esteem is like, I used to be able to work, but now I can't. We feel inferior; sometimes, we feel like we are different from everyone else. We feel inferior; sometimes we feel like our face is blackened or something like that, we feel inferior. . . yes, shame because normally we do not look like this." (subject 9, male, 40 years old)*

> *"After it infected several fingers, it (leprosy) starts to spread, a big wound from here.*

> *. Yes (resigned), because the hotel needs normal people." (subject 10, male, 38 years old)*

In this study, some patients experienced internalized stigma, specifically "feeling talked about by others." Patients felt talked about, possibly because of their disability or because of the symptoms of leprosy itself.

> *"I was embarrassed when this disease infected me. When I just got it, I was embarrassed and felt inferior to my friends. Maybe people talk about me because my face is swollen. . ." (subject 1, female, 27 years old)*

Leprosy's internalized stigma, "feeling unlovable," also influences patients' perspectives on their future, especially marriage. Leprosy's internalized stigma, "feeling unlovable," also influences patients' perspectives on their future, especially marriage. Most of the unmarried patients revealed that they felt unworthy of love, which resulted in them losing motivation to get married and becoming inferior. This was due to their disabilities.

> *"It is automatic because only very few people might be attracted to (or like) someone like me. So it is indeed thought out. Can't say no. . . I think it will not be that easy (to get married)." (subject 10, male, 38 years old)*

> *"Me? Yes, I said that (it is difficult to get married) because I have this leprosy. People can't be attracted to me anymore." (subject 3, female, 36 years old)*

> *"It's even more desperate to get to know, like, women getting to know men is very difficult. Even to get to know is already difficult. . . because I am paralyzed, so I think that I will not recover from paralysis." (subject 1, female, 27 years old)*

The internalized stigma experienced by people with leprosy is very diverse and has various impacts on their condition. Stigma not only affects the way patients see themselves but also how they interact with their social environment.

This study revealed that the subjects experienced a variety of social stigmas from their social environment, including the causes and impacts associated with leprosy. The social stigma experienced by the research subjects included "being noticed or observed by others," more specifically, "being the subject of conversation," then "being shunned or avoided," and "being insulted." Disabilities or visible symptoms of leprosy, such as an old, swollen, and red face, trigger the stigma. In addition, social stigma also arises due to community misperceptions of leprosy. The misperceptions that occur in the community are that leprosy is contagious and should be avoided. This stigma can lead to feelings of shame, inferiority, avoidance, isolation from the social environment, depression, and even ostracizm by one's own family.

One of the social stigmas experienced by sufferers is "being noticed by others." The patient revealed that others overly noticed him because of the symptoms of leprosy on his face, which made him look older. As a result, the patient felt embarrassed and chose to avoid the social environment.

> *". . .people look at me like I am an old lady. . . this feeling that we are ashamed of other people because of the way people look at us, they look from head to toe. . . we keep our distance from other people so they don't ask us questions." (subject 18, female, 55 years old)*

In addition, some sufferers experience social stigma "becoming a topic of conversation." Patients become the subject of conversation or scorn from others because their faces are swollen and look old. The surrounding community also labels patients as virus carriers and shuns them.

> *" People also talk about me because my face is swollen. . . when I worked in Jakarta, my hair was blonde, so my face was red and my hair was red. So, when other people talk about me, I also feel insecure. " (subject 1, female, 27 years old)*

> *"People see me as an old lady. . . when people talk to my son, they say 'your mom is ugly', and I say 'yes, I am '. . . because of this disease, and he (the child) also accepts it, he said 'it's God's love, my mom didn't buy it'. . . " (subject 18, female, 55 years old)*

> *"Neighbors were even afraid to come. They even said, 'Don't go to his house.' My mom is MM, they said, 'Don't go to MM's family. A child is carrying a viral disease. You'll get it'. . ." (subject 9, male, 40 years old)*

Leprosy sufferers also experience social stigma, specifically being "shunned/avoided". People around patients shun or avoid them due to a variety of factors, including misunderstandings about leprosy in the community and the manifestation of leprosy symptoms in patients, such as a swollen face, an aged appearance, wounds, and unpleasant odours. The impact of this social stigma is that leprosy patients experience social isolation, not only from the general social environment, such as friends and neighbors but also from their own family environment.

> *" Embarrassed for sure. . . almost every day. . . we can tell from their actions, 'oh I am shunned, like this, like this'. . .sometimes these people influencing other people, they said he was like this, like this so don't get too close, be careful. yes, naturally we are already like this (leprosy), people must also be worried about being infected. . ." (subject 13, male, 37 years old)*

Another patient revealed that it was difficult for him to get direct access to water.

> *" When I was fetching water from the well, people said, stop fetching, you are not allowed to. . . your wife may fetch, and you can carry, but if you dip the dipper directly into the well, it's not allowed. . ." (subject 4, male, 49 years old)*

He also added that he lived in the forest because of other people's requests. He was told that he should not come close to people because of his illness.

> *". . . so I'm living in the forest, not living together with my wife, no . . .we can't be together, live together. . . already sick, so can't live in the village, I'm in the forest. . .can't be together with my wife . . . I can't even be with my friends" (subject 4, male, 49 years old).*

Social stigma does not only arise from the surrounding community but also from the families of leprosy patients. The patient disclosed that his own family shunned and even ostracized him due to their distaste for his leprosy symptoms.

> *" My feet are all blistered, when they blister, a lot of water will come out. That's where my family has started to be disgusted, my siblings too. . I was moved to sleep in the kitchen." (subject 9, male, 40 years old)*

Patients also face social stigma in the form of feeling humiliated. The subject revealed that the wounds that burst and smelled on his body became the subject of conversation by others. This made him feel embarrassed.

> *"My wound is broken and smelly. . .they used to tease me, some of them teased me. . .I was embarrassed " (subject 8, male, 27 years old)*

Another subject also revealed that he was scolded and labelled as "different' by his coworkers because of his crooked legs and hands. This made the subject feel ashamed and uncomfortable, leading him to isolate himself and work alone.

" My friends are angry because I have this disease, so they got on their nerves at us, we also feel uncomfortable. . . yes (embarrassed), so every day I work alone. . .they work in the back, I work in the front." (subject 11, male, 27 years old)

DISCUSSION

This study aimed to analyze the perceptions of leprosy patients at the Primary Hospital regarding the stigma they experience. Our findings show that stigma toward leprosy patients is very high, with 80% of the respondents experiencing it. We discussed the results based on the stigma conceptual model by Pryor and Reeder that stigmatization occurs on the societal, interpersonal, and individual levels and consists of four dynamically interrelated manifestations of stigma: public/social stigma, self/internal stigma, stigma by association, and structural stigma.[10]

Misperceptions, leprosy symptoms, and disabilities resulting from the disease trigger the dominant internal stigma that leprosy sufferers experience. Misperceptions are at the root of internal stigma, triggering fear of infection and concerns about social rejection. Sufferers tend to isolate themselves and keep their illness a secret, resulting in reduced quality of life and loss of social support.[11-12]

The findings of this study align with those of Pravangeesti Widya Aulia's research in Mojokerto Regency in 2019, which discovered that the most prevalent stigma among leprosy patients was the notion that the disease is highly contagious.[13] Research by Anna Tiny van't Noordende et al. in India and Indonesia (Pasuruan), in 2021, supports this, demonstrating that a lack of knowledge about the disease contributes to negative perceptions of leprosy.[11] Leprosy and the stigma it causes can affect the social relationships and social participation of leprosy sufferers. This can cause isolation, problems in social relationships, and a decrease in the sufferer's quality of life and self-esteem. Liasari Armaijn and Dewi Darmayanti conducted research in 2019 in Ternate City on leprosy sufferers through in-depth interviews, finding that all respondents were reluctant to disclose their leprosy to their distant family, neighbours, and co-workers. They were pretending to suffer from an allergic disease. They do this out of fear of social rejection and exclusion.[13]

Misperception also leads to the view that leprosy is a witchcraft disease, encouraging sufferers to seek alternative treatments that can delay the healing process. This view aligns with the findings of Anna Tiny van't Noordende et al. in 2021 in India and Indonesia, showing that belief in supernatural elements is still a factor inhibiting medical treatment.[11]

Internal stigma in leprosy sufferers also arises from the physical changes they experience, such as white spots, swollen faces, or an aged appearance, as well as disabilities due to leprosy. Sufferers feel afraid, ashamed, and low in self-esteem, and even quit their jobs voluntarily because they feel unable or unfit to work. This aligns with the findings of previous studies, including those conducted in Mojokerto Regency by Iqbal Al Bana and Siti Ina Savira in 2014 and in Indonesia by Sri Linuwih Menaldi et al. in 2022. These studies revealed that leprosy patients, fearing social disdain and experiencing social discrimination, tend to isolate themselves, struggle to secure employment, face rejection, and experience social dysfunction, among other issues.[14] Another research study conducted by Anna van't Noordende et al. in 2016 in Nepal revealed that leprosy sufferers did not want to get married because they were afraid and had difficulty finding a partner because of their disability.

In addition to internal stigma, societal stigma also arises from society's misunderstanding of leprosy and the constrained faced by those affected. Lack of understanding about the transmission, treatment, and prevention of leprosy causes public fear, which leads to isolation and discrimination against sufferers. Jufirzal and Nurhasanah's research in Tanah Pasir District, North Aceh Regency, in 2019, supports this finding, revealing that people's ignorance about the transmission, treatment, and prevention of leprosy leads to fear of infection and apprehension about approaching or engaging in activities with people affected with leprosy.[15]

The symptoms and disabilities experienced by people affected with leprosy also contribute to social stigma. This stigma makes them feel embarrassed and inferior. Some even choose to avoid and separate themselves from their social environment, making interacting or participating in social activities difficult. Sujan Babu Marahatta conducted research in Nepal in 2018 and found that the visible physical condition was the most significant factor contributing to social stigma in people affected with leprosy.[16]

Both internal and social stigma have a mutual impact on the condition of people affected with leprosy, influencing their economic, social and psychological aspects. Therefore, it is essential to implement community education programs and anti-stigma campaigns and build social support so that people affected with leprosy can overcome stigma and improve their quality of life. This support can come from family, friends, the community, and related parties in the health sector, especially the health workers with direct contact to the people affected with leprosy.

People affected with leprosy experienced internal and social stigmas. Out of the 20 patients, 16 of them experienced either internal and/or social stigma, and 12 of them experienced both internal and social stigmas. Our findings align with other leprosy studies that identify misperceptions, leprosy symptoms, and leprosy-related disabilities as the primary causes of this stigma. The stigma has a broad impact, covering various aspects of life, such as social, economic, and educational. Therefore, holistic treatment of people affected with leprosy is needed, including surgery for disability, efforts to increase public understanding of the disease, and psychological assistance for people affected with leprosy to reduce stigma and support better social reintegration.

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