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Community Stigma toward Leprosy Patients

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Abstract

Leprosy is a chronic disease that rarely causes death but often causes disability. This disability leads to different opinions in the community, which disrupts the social life of leprosy sufferers and the surrounding community. In this study, the researcher wanted to examine more deeply the opinions of people with leprosy. This research design uses qualitative research that focuses on a phenomenological approach. The participants taken in this study were 11 people who had criteria where the location of the participant's house was not more than 100 meters from the leprosy patient. Participants were selected through purposive sampling and data collection techniques using in-depth interviews with the main instrument, namely the researcher himself and assisted by other instruments in the form of field notes, interview guidelines and sound recording devices. The results of this study resulted in three themes: (1) Factors that influence stigma towards leprosy patients (2) Perceptions of Leprosy Patients (3) Forms of Stigma towards Leprosy Patients. Community stigma still occurs against leprosy patients, this is due to the low level of education and knowledge of the community about leprosy, so there needs to be intervention by health workers to increase community knowledge so that the stigma felt by leprosy patients can be reduced.

Keywords: Community Stigma; Perception; Leprosy**.**

Abstrak

Kusta merupakan penyakit kronis yang jarang menyebabkan kematian namun sering menimbulkan kecacatan. Kecacatan ini menimbulkan opini yang berbeda di masyarakat sehingga mengganggu kehidupan sosial penderita kusta dan masyarakat sekitar. Dalam penelitian ini, peneliti ingin mengkaji lebih dalam mengenai opini penderita kusta. Desain penelitian ini menggunakan penelitian kualitatif yang menitikberatkan pada pendekatan fenomenologi. Partisipan yang diambil dalam penelitian ini sebanyak 11 orang yang memiliki kriteria dimana lokasi rumah partisipan tidak lebih dari 100 meter dari penderita kusta. Partisipan dipilih melalui purposive sampling dan teknik pengumpulan data menggunakan wawancara mendalam dengan instrumen utama yaitu peneliti sendiri dan dibantu dengan instrumen lain berupa catatan lapangan, pedoman wawancara dan alat perekam suara. Hasil penelitian ini menghasilkan tiga tema yaitu: (1) Faktor-faktor yang mempengaruhi stigma terhadap pasien kusta (2) Persepsi Pasien Kusta (3) Bentuk-bentuk Stigma terhadap Pasien Kusta. Stigma masyarakat masih terjadi terhadap pasien kusta, hal ini disebabkan karena rendahnya tingkat pendidikan dan pengetahuan masyarakat tentang penyakit kusta, sehingga perlu adanya intervensi dari petugas kesehatan untuk meningkatkan pengetahuan masyarakat agar stigma yang dirasakan pasien kusta dapat berkurang.

Kata kunci: Stigma Masyarakat; Persepsi; Kusta.

1 Introduction

Leprosy (Lepra Morbus Hansen) is a chronic infectious disease caused by the bacteria Intracellular Obligate Organism Mycobacterium Leprae (Siswanto, 2020). People with leprosy who live in the community often experience difficulties in their daily activities (Couto Dal Secco et al., 2017). The psychological pressure that exists in leprosy patients causes negative reactions such as maladaptive behavior (Jatimi et al., 2020) due to negative social perceptions of society (Hidayat, 2020). Families who are stigmatized still consider accepting the presence of leprosy in their family (Nasir et al., 2022) Being able to communicate and accept the presence of leprosy so that it creates tension in the family is a very difficult challenge Because leprosy is still associated with stigma, the treatment process is difficult on family time, finances, and health, this is a burden on the family (Chang et al., 2023).

The discovery of leprosy cases in the world is still relatively high, in 2021. According to the World Health Organization (WHO), data on leprosy cases counted as registered prevalence of 133,781 cases and 140,546 patients as the latest case finding. Indonesia ranks third with 10,976 new cases after India and Brazil in the list of countries with the number of new cases (WHO, 2021). Data from the Central Statistics Agency (BPS) of Java Province. East Java Province itself recorded the latest leprosy case finding rate in 2022 at 22.27/100,000 population. (BPS East Java Province, 2022). Sumenep District is one of the districts in East Java Province with leprosy cases with the number of leprosy cases in 2022 in Sumenep District registered as many as 184 people with leprosy in the District (Ministry of Health of the Republic of Indonesia, 2022). Of the 30 health centers in the Sumenep district, Talango District is one of the leprosy contributors in the city ofumenep.

Based on an initial study conducted in February 2019 through face-to-face interviews with three residents in the Talango Health Center area, it was revealed that they did not understand about leprosy, and only knew that the disease was an infectious disease, a curse disease and a disease caused by a shaman commonly called santet or gunan guna so they were afraid to interact with leprosy patients, especially those who experienced disability. On the other hand, the researcher also interviewed one of the leprosy officers in the Talango puskesmas area, who found that the high number of leprosy cases was due to a lack of knowledge and poor environmental factors, this is in line with research (Romdhani & Sulistyorini, 2020) which says that one of the factors in the occurrence of leprosy is caused by environmental factors in the patient's home, which statistically proved to lack natural light and ventilation that did not meet the standards.

Hansen's disease is a chronic disease that rarely causes death but often causes disability. Lack of knowledge about leprosy and the high negative stigma in the community make patients reluctant to seek treatment and hide their disease (Aulia Rahma Noviastuti TUS., 2017). In connection with this, it is necessary to study in depth the stigma of the Talango community about people with leprosy.

2 Method

The research design used in this research is qualitative research that focuses on a phenomenological approach. The participants taken in this study amounted to 11 people who had criteria where the location of the participant's house was not more than 100 meters in leprosy patients in the Talango Village area.

Participants were selected through purposive sampling and data collection techniques using in-depth interviews with the main instrument, namely the researcher himself and assisted by other instruments in the form of field notes, interview guidelines and sound recording devices.

The duration of each interview had twenty-five minutes and was conducted in two meetings. The first meeting was an explanation of the research, obtaining informed consent from participants and interview statements. The steps taken were: 1) Describing the phenomenon under study; 2) Share a picture of the phenomenon using participants' opinions or statements; 3) Read the entire description of the phenomenon provided by all participants; 4) Reread the interview transcripts and quote relevant statements from all important statements; 6) Organize the continuous collection into thematic groups; 7) Write full descriptions; 8) meet with participants to confirm analyzed descriptions. During the interview, the researcher observed the attitudes, behaviors and facial expressions that emerged during the interview process and then recorded them as documentation of the interview results

3 Result

Participant characteristics include gender, education level, occupation, distance of residence.

Table 1. Participant characteristics of stigma towards leprosy in the Talango Health Center Working Area

Partisipan	Gender	Age	Work	Education	Home Distance
P1	F	43	Famer	Elementary School	±50m
P2	F	50	Famer	Elementary School	±70m
P3	M	39	Constructor	High School	±20m
P4	F	41	Teacher	Diploma 3	±35m
P5	F	37	Famer	Elementary School	±70m
P6	F	37	Famer	Elementary School	±35m
P7	M	48	Famer	Junior High School	±40m
P8	F	40	Merchant	High School	±100m
P9	M	53	Famer	Junior High School	±100m
P10	M	40	Famer	High School	±30m
P11	M	41	Famer	High School	±40m

Based on the table above, when viewed from the age of the participants at the time of the interview, we found that the majority of participants were aged 40-53 years with a total of 8 participants. The distribution of participants based on gender is dominated by women with 6 participants. Most of the participants' education level is 5 people with a high school education background, while the majority of participants' livelihood professions are farming as many as 6 people, traders 2 people, the rest are elementary and junior high school teachers. This research resulted in 3 themes, namely factors that influence stigma towards leprosy sufferers, perceptions of leprosy sufferers, and forms of stigma towards leprosy sufferers.

a) Factors affecting stigma towards leprosy patients

Factors that influence community stigma towards leprosy patients around the Talango area include the lack of public knowledge about leprosy and the low level of public education. The researcher identified the participants' basic knowledge about leprosy and found that leprosy is a hereditary disease, a curse, and a contagious disease (P1, P2, P3, P4, P5, Pl6, P7, P8, P9, P10, P11). Participants were able to recognize the signs and symptoms of leprosy, namely skin changes in lepers, weight loss and disability (P1, P2, P3, P4, P5, P6, P7, P8, P9, P10, P11).

Low education is also a factor in high stigma towards leprosy, where it was found that some participants had elementary school level education (P1, P2, P5, P6) junior high school (P7, P9), high school (P3, P8, P10, P11), D3 (P4).

The disability of people with leprosy is a factor that causes community stigma. Participants explained that people with leprosy experience disability in their hands and feet (P1, P3, P5, P7, P8, P9, P10, P11). Disability also occurs in the discoloration of the skin of people with leprosy (P2, P4, P6).

b) Community Perception of Leprosy

Participants' perceptions of patients with leprosy are caused by physical changes in patients, especially in the skin and disabilities experienced so that participants have a bad perception of leprosy patients which causes feelings of fear, disgust and worry of contracting if they interact with patients, especially patients whose conditions look dirty and disabled (P1, P2, P3, P4, P5, P6, P7, P8, P9, P10, P11).

c) Forms of Stigma towards Leprosy Patients

Forms of stigma towards leprosy patients were found in the form of discrimination in the form of expulsion (P1,P2,P3,P5,P6,P7) and labeling (P1,P2,P5,P6) by the community towards the leprosy patients. Forms of stigma in the form of distancing, reducing interaction with patients also occur (P1, P2, P3, P5, P6, P7, P8, P9, P10, P11).

4 Discussion

Factors influencing stigma towards people with leprosy

a) Knowledge

The dominant knowledge of the community is that leprosy is a curse from God. Knowledge about leprosy is very poorly understood by the community, although leprosy is increasing every year, it does not reduce the beliefs and misconceptions they have adopted so far, this has made this wrong knowledge a habit, so they are unable to identify the cause of leprosy itself (Rahman et al., 2022). The community's understanding of leprosy makes it difficult for leprosy sufferers to carry out their daily activities, even though they have been declared cured (Hannan Mujib et all, 2021).

This is in line with research (Jufriyanto et al., 2020) that erroneous knowledge in the community towards former leprosy is still high as evidenced by the high social stigma that exists in the community. Therefore, health promotion is needed to increase public knowledge about leprosy. Health education in health promotion is a form of communicating health messages or knowledge to communities, groups or individuals (Bintoro Widodo, 2014). On the other hand, not all officers conduct education to all levels of the general public but only to patients and their families.

The community stigma about leprosy patients is that leprosy is a curse and cannot be cured. The stigma that develops in the community is due to a lack of knowledge and understanding about leprosy. This lack of understanding is closely related to the role of health workers, to socialize the community about leprosy itself so that it can change the mindset of the community (Salamung et al., 2023).

The negative stigma and discriminatory treatment of leprosy sufferers is inseparable from the low level of knowledge that the community has about leprosy and the stigma attached to leprosy. Negative stigma about leprosy illustrates the community's low level of knowledge, which in turn leads to negative attitudes that take the form of discriminatory treatment of leprosy sufferers. The impact of low knowledge about leprosy and stigma on leprosy sufferers means that people tend to have incorrect feelings, prejudices and expectations of leprosy sufferers, which in turn can be manifested in negative attitudes and behaviors (Keswata, 2022).

b) Education

Low public education provides a low level of understanding of a disease. (Soekidjo Notoatmodjo, 2010) education can affect a person's knowledge, the higher a person's education, the easier it is for that person to receive information. Different levels of education between individuals can affect the level of knowledge and health services provided to patients. Research conducted by Kaehler on risk factors associated with stigma towards leprosy patients showed that a person who has a lower level of education is associated with a higher level of perceived stigma. Higher education can increase overall knowledge about the disease and an increased ability to counter negative stereotypes attached to leprosy (Kaehler et al., 2015).

The results showed a significant relationship between education and stigma towards leprosy patients. A total of 68.9% of respondents in this study had a high school education. Highly educated respondents have good information about leprosy and are exposed to information about leprosy. The higher the education, the lower the stigma towards leprosy sufferers (Carbani, et.al 2022). The results of another study explained that people with higher education such as undergraduate and postgraduate tend to maintain less social distance with leprosy patients and without formal education, people are more likely to maintain social distance with leprosy patients (Ibikunle & Nwokeji, 2017).

Stigma in leprosy patients shows that lower levels of education have higher levels of stigma awareness while higher education can increase general knowledge about leprosy and increase the ability to combat negative stereotypes attached to leprosy (Kaehler et al., 2015).

c) Disability

Disability in leprosy patients varies, with some experiencing first-degree disability with numbness in the feet and hands and a sense of weakness in the participant's muscles and joints. Level 2 disability is described as partial loss of fingers and hands (Rasyidi, et.al 2024).

People with leprosy face both physical and mental health challenges. Physical problems include peripheral nerve damage, leading to visible disabilities (Hambridge et al.,2021). Women with leprosy often experience subordination, stigmatization, and treatment delays, which negatively impact their quality of life and mental well-being. The psychological impact of leprosy can result in isolation, reluctance to leave the house, and withdrawal from social life (Van Dorst et al., 2020).

d) Community Perception of Leprosy

Lack of knowledge leads to misperceptions of leprosy itself. The misperceptions of the community are reflected in the results of interviews that convey feelings of disgust, anxiety and fear of infection due to the physical disability and dirtiness of leprosy patients. This reason is the trigger for stigma in the community. According to research (Irawan B, 2018) people are afraid of being infected, afraid of curses, believe lepers bring bad luck, or are afraid that if they come into contact with lepers they will get the same treatment. Public perceptions of leprosy vary, there are a small number of people who have a good perception of leprosy, but it is undeniable that the majority of people who are informants have the perception that leprosy is a frightening infectious disease and sufferers need to be kept away (Sodik, 2016).The views or perceptions of the community towards diseases and lepers are influenced by the understanding and phenomena that are rooted in the community environment (Hannan Mujib et all, 2021).

The research found that people's perceptions of lepers are disgust, anxiety, and fear. The form of public perception of people with leprosy shows that people feel disgusted when they see the disability (Hidayat, et.al 2020). This is in line with the results of research (Isnandi & Made 2020) which shows information from informants since the beginning of the existence of former lepers living in Sumberglagah Hamlet, the community has less respect and respect for former lepers, they keep their distance and often feel disgusted when close to former lepers.

The negative perceptions given to people with leprosy are often done overtly with labeling and neglect in every daily activity (Jatimi & Hidayat, 2022). In addition, people believe that leprosy sufferers are bad individuals and result in being infected with a disease that can cause permanent disability (Zamparoni, 2017). Leprosy sufferers in the community experience discomfort in social life due to negative behavior from the community during interaction, which is shown in the form of rejection behavior and other negative behaviors (Jatimi, et.al 2023).

e) Forms of Stigma towards Leprosy Patients

The form of stigma that is often carried out by the local community towards people with leprosy is in the form of verbal and non-verbal actions where verbal actions are carried out in the form of swearing or labeling and discrimination. While the expression of non-verbal forms of community stigma is shown by keeping a distance from leprosy sufferers and reducing interaction with sufferers due to fear of contracting leprosy. In research (Jufrizal & Nurhasanah, 2019) also shows that most of the negative impacts in terms of social aspects of leprosy sufferers are shunned, ostracized by the community as well as the emergence of acts of discrimination and sufferers find it difficult to get a job. The disability caused by leprosy creates a negative stigma from the community and discrimination for leprosy patients both newly infected and cured leprosy patients, discrimination against cured leprosy patients is based on public knowledge that cured leprosy patients still have leprosy that cannot disappear from the sufferer (Salamung et al., 2023).

Leprosy sufferers have been ridiculed and made fun of by their peers since childhood, which feels like a mental terror, making them feel inferior and inferior and increasing their sensitivity. Tend to be reactive in responding to situations around their environment, even though people who try to develop communication near them or simply greet and pay attention to them without any tendency to scoff, are often considered wrong (negative) by sufferers. It is not uncommon for the families of leprosy sufferers to also put leprosy sufferers in an unfavorable position because they feel ashamed to accept reality. The shame on the part of the family is justified, given the intense ridicule and mockery from neighbors and the community (Najmuddin, 2022).

Such bad behavior such as keeping a distance from leprosy sufferers, rarely communicating, often ostracizing leprosy sufferers and even carrying out activities that harm leprosy sufferers such as expulsion, This makes leprosy sufferers have difficulty in activities, especially getting a job which has an impact on the psychology of leprosy sufferers (Hidayat, 2020). Stigma given by informants from unpleasant treatment or hurtful words that make hurt feelings that physical condition, berating, not acceptin, acceptance of treatment, committing violence when medical staff are not biased justify the infusion, as well as those that are often often encountered in the form of infectious diseases but there are also medical personnel doing openly, namely the presence of writing on the wall of the puskesmas that leprosy is a disease curse of god (Aulia, 2019).

Social discrimination often occurs in various aspects, one of which is social discrimination in one's physical form (Wahyuni and Bayu, 2019). This social discrimination is also experienced by former leprosy sufferers due to the physical disability experienced due to leprosy. Leprosy sufferers receive various forms of discrimination from the time they are known to have leprosy, during the treatment process, and after being declared cured. Social discrimination is not only experienced by ex-lepers, but also by family members, such as being shunned by the community, insulted by the community, abandoned by spouses, and difficult to get a job (Sa'diyah & Arsi, 2022).

5 Conclusion

Factors affecting stigma towards leprosy patients include low levels of education and knowledge about leprosy, resulting in negative perceptions of leprosy patients and behavior away from leprosy patients to, labelling to discrimination. so the suggestion for further research is the need for intervention from health workers to increase public knowledge so that the stigma felt by leprosy patients can be reduced.

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