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Literature Review

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Overcoming Negative Stigma towards Leprosy Patients

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ABSTRACT

Background: Leprosy remains a public health problem, with various factors contributing to the transmission and progression of the disease. Stigma and discrimination towards leprosy patients have hindered the treatment and eradication of the disease. **Purpose:** To identify the related factors and strategies to overcome stigmas towards leprosy patients. **Review:** Leprosy is a chronic infectious disease that affects skin and nerve, and causes visible permanent impairment if the patients do not get adequate treatment. Therefore, visible clinical manifestations and cultural beliefs have created stigma towards leprosy patients, which negatively impacts their quality of life and their awareness of seeking health care. These factors may lead to patients avoiding diagnosis and treatment, which in turn increases number of G2D cases and transmission rate. Cultural and religious beliefs, low education level, and minimal information about leprosy have been known to contribute to the stigma. Several strategies can be considered to use to overcome stigma and discrimination towards leprosy patients. **Conclusions:** Understanding factors related to leprosy stigma and its effects on the progression of the disease will help determine the strategies to overcome stigma and discrimination.

Keywords : leprosy, stigma, disability.

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BACKGROUND

Leprosy is one of the neglected tropical diseases that produced problems in various aspects such as health, socioeconomics, and culture[1] According to the World Health Organization data for 2020, there were 177,175 registered cases of leprosy, with a prevalence rate 22.7 per million population. India, Brazil, and Indonesia are the three countries with the highest number of leprosy cases, accounting for 80% global leprosy cases.[2] In Indonesia, new leprosy cases reached 17,439 with 1,121 of them having grade-2 disability (G2D).[2] Leprosy causes skin and nerve impairment, as well visible complications such as disfunction, disability, and body deformation, which lead to negative stigma and discrimination against leprosy patients. Stigmas and discrimination are two of the problems that hinder the eradication programs of leprosy. Negative stigmas and discrimination affected the social-daily life and health of leprosy patients and their families[3]. This condition has negative psychological effects on leprosy patients, such as frustration or suicidal attempt.[4,5] In the health aspect, these negative stigmas hinder leprosy patients from seeking treatment, which in turn leads to a rise in the number of people with G2D.[6]

Numerous factors contribute to the proliferation of negative stigmas and discrimination against leprosy patients. This paper confirms to identify the related factors and strategies for overcoming stigmas.

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REVIEW

Leprosy or *Hansen's* disease, is a chronic infectious disease caused by *Mycobacterium leprae.*[1] Leprosy has become a public health concern due to permanent physical impairment caused by delayed diagnosis, improper treatment, and unavailability of interventions. World Health Organization (WHO) has classified leprosy-related disability into three grades : Grade 0, which involves no impairment, Grade 1, which involves loss of sensation in the extremities (hand or foot), and Grade 2, which involves visible impairment.[2] Disabilities and impairments that affect their ability to perform daily chores and jobs may compromise the quality of life for leprosy patients and their families, leading to a loss of family income.[7] Loss of family income leads to numerous issues, including the incapacity to provide nutritious food, education, and health care for the family. On top of the various problems, stigmatization and discrimination against leprosy patients and their families add another problem to the treatment of the disease.[8]

Perceived stigma refers to perceptions, fears, and subjective awareness that leprosy patients have about what society thinks or wants to do with them. The consequences of the perceived stigmas by leprosy patients lead to projects of what other people think and say about the patient, causing insecurity and lower self-esteem that can develop into an internalized stigma (self-stigma).[6]

Three levels of stigma exist around leprosy: self-perceived stigma, stigma from closest relatives, and community stigma.[9] Leprosy patients often experience restriction on physical, psychological, environmental, and social interactions that can reduce their quality of life. Quality of life refers to an individual's perception of their position in life, within the context of culture, and value system, in relation to their identity, life goals, expectations, and other related standards. World Health Organization (WHO) defines a measure of the quality of human life which includes physical, psychological, environmental, and social aspects, as stated in the World Health Organization Quality of Life-BREF (WHOQOL-BREF) questionnaire.[6]

Numerous factors contribute to the stigma of leprosy, such as the fear of transmission and contamination, the visible manifestations of deformity and disability in people, and the influence of religious and cultural beliefs, about the causes and treatment of leprosy. Adequate treatment at the early stage of exposure can manage leprosy and prevent impairment. However, despite these benefits, leprosy remains a disease misunderstood, feared, and subsequently stigmatized in society.[9]

People with leprosy suffer not only physically but also psychologically due to this stigma, as they often face neglect from family members and the surrounding community. According to the community-based survey, leprosy is considered a very contagious, incurable and frightening disease because it causes the fingers and toes to fall off. [10]

Stigma towards leprosy patients affects their daily lives such as restriction on social activities, rejection of job opportunities, difficulties in finding a marriage partner, or problems in marriage or divorce. Earlier studies showed 38% of people affected by the leprosy stigma were unmarried, separated, or divorced, and this correlates with a study in South Africa that stated one-third of leprosy patients were abandoned by their spouses[7,11]. In Indonesia, female leprosy cases predominate and have a greater impact on women due to the stigma and discrimination associated with the disease.[7] In addition, women in developing countries tend to be underdiagnosed and find it to access health treatment in health facility.[12,13] The dominant role of women in taking care of their family increases the risk of transmitting the disease, especially to their children. These conditions contribute to the relatively stable number of new leprosy cases, especially in children aged below 15 years old, which indicates the failure to stop the leprosy transmission, increased prevalence in general population, and poor monitoring programs.[14]

According to Noordendee *et* al.(2021*)*, the Indonesian people hold some of the following beliefs about leprosy: certain types of food or drink, such as seafood or unhealthy foods, can cause leprosy; dirty environment can cause leprosy; leprosy is a hereditary disease or curse; leprosy occurs due to supernatural phenomena by black magic; leprosy occurs when a man and a woman have sexual intercourse while the woman is menstruating, then bears a child that will be affected by leprosy; or leprosy is transmitted through touch and associates it with "untouchability" and sometimes becomes religiously unclean.[15]

Previous research also demonstrated a significant relationship between knowledge about leprosy and level of education with stigma and discrimination towards leprosy patients.[16–18] Other studies conducted by Oktaria et al. also reported higher education levels and their protective effects against leprosy.[19] Van Brakel et al. (2012) observed a higher, participation in restrictions among the Indonesian leprosy population compared to those in China and India. This study also showed higher education and economic status had a protective effect on stigma. Not only do leprosy patients themselves reject health treatments, but health workers outside leprosarium or leprosy centers also avoid treating leprosy patients.[8] Thus, stigmatization and discrimination in health services inhibit leprosy patients from getting proper examination and treatment.

DISCUSSION

In order to overcome stigma and discrimination and mitigate their negative effects, the benefits of communication, information, and education could be leveraged to enhance public awareness of leprosy. This initiative aims to reduce stigma and facilitate the treatment of leprosy patients prior to the onset of disability.[10] Different media could carry out a general introduction to leprosy and health information, conveying the message that leprosy is a normal disease that is curable and does not cause disability if treated early. A community-based survey informs the content of the introductory program, revealing leprosy-related knowledge, attitudes, and behaviors, while also examining public perceptions of the disease. The information obtained is used to develop the required materials for introductory programs.[10] The introductory programs should provide information on the initial symptom of leprosy, which typically manifests as painless hypopigmented patches (anesthetized macules), often accompanied by peripheral nerve enlargement, two of the three cardinal signs of the disease. Immediately refer leprosy patients with this condition to a dermatologist or other health care facilities.[20]

Promoting the importance of leprosy treatment may help to prevent stigma and discrimination against leprosy patients. If left untreated, leprosy may cause permanent visible impairment to the skin, nerves, limbs, and eyes. Therefore, promoting the importance of consuming multidrug therapy (MDT) completely could prevent the permanent visible impairment that could affect their ability and opportunities to perform important tasks in their daily activities.[20] Reassurance and supports from family and former leprosy patients who have completed their treatment can be used to educate people that leprosy patients can be readmitted by their families and the surrounding community.[9,21] Family support is the most important aspect of successful leprosy treatment. Patients' families should also receive information about leprosy and treatments, enabling them to complete the treatment.[12]

A rehabilitation program for leprosy patients is one of the strategies to reduce the stigma of leprosy by focusing on the rehabilitation process for patients with disabilities that involves community and government policies. Cross, Missions, and Way developed the Stigma Elimination Program (STEP), a program that emphasizes self-care for leprosy clients who have recovered or are currently undergoing treatment, with the aim of reducing disability. The STEP provides leprosy patients with skills training and aids in identifying leprosy cases in the community, with the aim of actively eradicating leprosy.[10] The East Java government's rehabilitation program, known as JELITA (*Jawa Timur Eliminasi Kusta 2017 Demi Indonesia di Mata Dunia*/ East Java Leprosy Elimination in 2017 for Indonesia in World's Perspectives) is implemented by SCORE (*Sosialisasi, Cari Pasien Kusta, Obati sesuai regimen sampai tuntas, Rehabilitasi dan Evaluasi*/ Find Leprosy Patients, Treat with Suitable Regimen Completely, Rehabilitate and Evaluate). These programs have had a significant impact on the lower prevalence rate of leprosy, which went from1,04/10.000 in 2016 to 0.93/10.000 at the end of 2017 and remain stable until September 2018.[22]

One strategy to eliminate the effect of stigma could be the Social Economic Rehabilitation (SER) program for leprosy patients. This is a program designed to eliminate barriers between leprosy patients and the community, promoting active client participation and empowering the client's abilities. This program might open opportunities and support for leprosy patients with disabilities by providing ongoing assistance, protection, and effective partnerships with other organizations that contribute to activities that benefit leprosy patients.[10] *Surya Mas Jelita (Sehat untuk berkarya, mandiri bersama kelompok jelang eliminasi kusta/* health to create, independent with groups towards leprosy elimination) is one of the SER program from Pasuruan District Government, East Java Province, Indonesia, to solve leprosy-related problems in Grati, one of the leprosy endemic area with *'Srupud'* approach. *The "Srupud"* approach (*Sosialisasi, Rembuk Kusta, Upaya Pembentukan Personal, Pembentukan Kelompok Perawatan Diri, Upaya Memberdayakan kelompok, Evaluasi/* socialization, leprosy discussion, health care groups, and empowering groups program, evaluation) is a modification of the JELITA program, aiming to decrease negative perception and discrimination.

Last but not least, various countries, including Japan, have changed the name of leprosy to Hansen's disease. In addition, the State of Brazil changed leprosy into "Hanseniasis". Changing the term hanseniasis can help reduce stigma and ensure that MDT treatment and management are successful.[10]

Stigmas and discrimination towards leprosy patients negatively impact their personal and family's quality of life. Rejection from daily activities and neglect from family, society, and health workers may contribute to the avoidance of seeking health treatment, which in turn can affect the disease's progression, increase the risk of transmission, and lead to an increase in the number of patients with leprosy complications. Understanding factors related to leprosy stigma and its effects on the disease's progression will assist in determining strategies to overcome stigma and discrimination.

CONFLICT OF INTEREST

The authors declare that they have no conflict of interest.

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