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Stigma in Leprosy Patients in the Community: A Systematic Review

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Abstract. *The increasing incidence of leprosy in the community causes individuals with leprosy to experience psychological stress. This pressure can come from the individual's internal perceptions such as feeling insecure, feeling embarrassed, and feeling afraid of being shunned. Apart from that, the psychological pressure experienced by individuals can originate from external factors such as discrimination from society, labeling, and isolation in social life. The method used in preparing this article is the PRISMA method with database searches including Google Scholar, Digital Reference Garba, and Science Direct. There are 15 articles selected based on the criteria, namely published in 2018-2023, can be accessed in full text, articles in Indonesian and English, and are qualitative research using the keywords stigma, leprosy sufferers, and community. The articles analyzed were selected according to criteria with results showing that the stigma experienced by leprosy sufferers in the community consisting of self-stigma and public stigma. These two stigmas cause psychological problems in leprosy sufferers.*

Keywords*: Stigma, Lepers, Community*

1. INTRODUCTION

Leprosy is part of a community-based infectious disease that can trigger problems in individuals such as permanent physical disability (Rismayanti et al., 2017), psychological problems due to failure to adapt to declining health conditions (Jatimi, Yusuf, et al., 2020) (Gunnara et al., 2020), changes in social life (Yudanagara, 2020) and economic problems (Siregar & Ratnawati, 2018). These problems are driven by negative perceptions from individuals and negative perceptions from the community around where leprosy sufferers live (Sodik, 2016).

The number of leprosy patients in the world has increased since 2020. In 2021, 135 WHO Member States shared information on leprosy, accounting for a prevalence of 133,781 registered cases and 140,546 new cases, of which 55,346 (39%) were women. Globally, 8,490 new cases with G2D were detected and 368 (4%) of them were children. Most countries with high rates of new case detection are in the WHO Africa and South-East Asia region. Brazil, India, and Indonesia continue to report the majority of new global leprosy cases (74%) in 2021 as the countries with the highest leprosy prevalence in the world (World Health Organization, 2022).

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The increasing incidence of leprosy can cause infected individuals to experience psychosocial problems such as anxiety with symptoms of excessive worry (Jatimi & Hidayat,2022) and self-concept disorders (Couto Dal Secco et al., 2017). Leprosy sufferers show maladaptive symptoms such as isolating themselves, feeling ashamed (Mahanani & Idris, 2020), feeling useless and lacking in self-confidence (Jufriyanto et al., 2020). This is conceptually related to the existence of problems in one of the points of mental assessment, namely self-concept (Yusuf et al., 2015).

Self-concept disorders in leprosy sufferers are influenced by negative self-perceptions (Utami et al., 2017) by labeling themselves with negative assumptions so that they fail to achieve self-acceptance (Govindharaj et al., 2018). In addition, leprosy sufferers also experience difficulties due to discriminatory treatment from society (Ministry of Health, 2022). The discrimination experienced is not only received by leprosy sufferers but also by their families and caregivers who care for leprosy sufferers (Putra & Tahlil, 2018).

Such discriminatory treatment often occurs in public places such as workplaces, places of worship and use of public transportation (Arisal et al., 2020). Discriminatory behavior shown to leprosy sufferers is influenced by community knowledge about leprosy (Ariani et al., 2019) as well as perceptions (Hidayat et al., 2020) and beliefs that develop in the community about leprosy sufferers (Sekarningrum & Yunita, 2017). From these problems, the author aims to compile this systematic review to find out about the stigma faced by leprosy sufferers in the community.

2. METHOD

The compiler of this systematic review uses the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analies) method (Efendi, 2019) from 15 articles selected based on criteria. The criteria applied by the author are articles published in 2018-2023, can be fully accessed, articles are qualitative research in Indonesian and English.

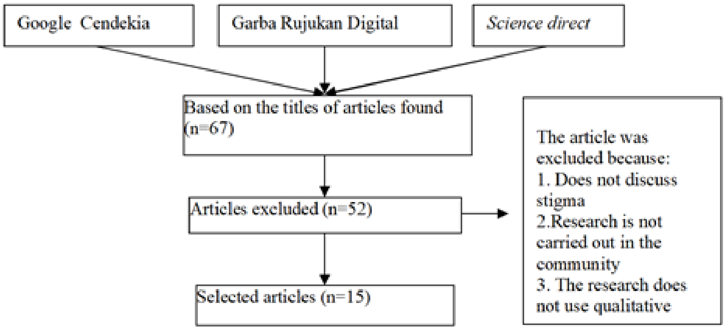

Figure 1. Flow diagram for article selection

The 5 articles were selected based on the results of a search on databases including Google Scholar, Garba Digital Reference and Science Direct using the keywords stigma, leprosy sufferers and community. Article searchstarting from April 7 to 8, 2023 according to the specified keywords. Articles that have been found from the search results are then selected based on the criteria. The selected articles are reviewed, data grouping is carried out based on the results of the review and described in a detailed discussion.

3. RESULTS AND DISCUSSION

The results of the article review found that the stigma faced by leprosy sufferers in the community is self-stigma such as negative perceptions of themselves, labeling themselves and discriminatory behavior carried out against themselves and public stigma that can come from family as the closest people or from society as listed in table 1. Self-Stigma against themselves experienced by leprosy sufferers is triggered by disturbances in the self-concept component (Mahanani & Idris, 2020). This is characterized by negative labeling regarding one's condition due to disability due to leprosy (Jatimi, Yusuf, et al., 2020) such as feeling unworthy of interacting with other people (Armaijn, 2019), being embarrassed to leave the house and choosing to lock themselves up (Muhammad Najmuddin, 2021) and individuals showing low self-esteem behavior such as not making eye contact with others and starting to move away (Jatimi & Hidayat, 2022). Self-stigma causes the social life conditions of individuals diagnosed with leprosy to decline and positions individuals as isolated and closes off interactions with other people in the surrounding environment (Govindharaj et al., 2018). This is done by individuals with leprosy because of feelings of insecurity, shame and the emergence of feelings.

Table 1. Article review

Title, author, year	Results
Phenomenological Study: Community Perception of Leprosy Patients in the Talango Health Center Work Area (Hidayat et al., 2020)	Concerns in society about leprosy sufferers are influenced by public knowledge about leprosy which can trigger perceptions and treatment. negative.
Psychosocial Problems in Leprosy Patients: A Qualitative Study (Jatimi & Hidayat, 2022)	Leprosy sufferers experience mental deterioration characterized by low self-esteem, anxiety and impaired social interaction.
Qualitative Study: Resilience of Leprosy Patients with Disabilities Due to Their Disease (Jatimi, Yusuf, et al., 2020)	Leprosy patients with disabilities experience self-stigma before achieving resilience.
Qualitative Study: Psychosocial experiences of former leprosy sufferers (Jufriyanto et al., 2020)	Leprosy sufferers experience social stigma and limitations in activities before achieving self-sufficiency. *acceptance*
Stigma Against Leprosy: A Review of Interpersonal Communication (Muhammad Najmuddin, 2021)	Self-concept in leprosy is influenced by negative self-perception and external perceptions.
Mental wellbeing among people affected by leprosy in the Terai region, Nepal(Van Netten et al., 2021)	The mental health of leprosy sufferers is influenced by various factors, one of which is the negative stigma from

	society.
Social Discrimination Against Former Leprosy Sufferers in the Community (Sa'diyah & Arsi, 2022)	Former leprosy sufferers and their families who care for them experience social stigma from society.
Qualitative Study of the Existence of Leprosy in Dendun Village, Mantang District, Bintan Regency (Gunnara et al., 2020)	The negative stigma received by leprosy sufferers shows that the existence of leprosy is considered bad.
Psychosocial Impacts of Discrimination On Former Leper Sufferer (Yudanagara, 2020)	Stigma experienced by sufferers leprosycausing negative emotions such as sadness, anxiety interacting with outsiders, fear of being shunned, and lack of self-confidence.
Community Stigma Towards Leprosy Sufferers in Batuputih District, Sumenep (Hannan et al., 2021)	Leprosy sufferers receive negative stigma from society.
Perception of Leprosy Sufferers Towards Leprosy Stigma in Ternate City (Armaijn, 2019)	Leprosy sufferers are ashamed of their condition, lack self-confidence and are afraid of being ostracized by society.
Qualitative Exploration of Experiences and Consequences of Health-related Stigma among Indonesians with HIV, Leprosy, Schizophrenia and Diabetes(Rai et al., 2020)	Individuals with HIV, leprosy, mental disorders and diabetes receive negative stigma from society in the community.
"If you will counsel properly with love, they will listen": A qualitative analysis of leprosy affected patients' educational needs and caregiver perceptions in Nepal(Correia et al., 2019)	Knowledge about leprosy in the community can influence perceptions and reduce negative stigma towards leprosy sufferers.
Psychosocial burden of neglected tropical diseases in eastern Colombia: an exploratory qualitative study in persons affected by leprosy, cutaneous leishmaniasis and Chagas disease(van Wijk et al., 2021)	People suffering from tropical diseases such as leprosy experience psychological burdens caused by social neglect.
The life experience of leprosy families in maintaining interaction patterns in the family to support healing in leprosy patients in Indonesian society. A phenomenological qualitative study(Nasir et al., 2022)	Leprosy patients with psychosocial problems such as stigma and impaired self-concept require support from their families.

Leprosy sufferers experience a grieving process with several stages that are difficult to go through, especially in the depression stage which shows maladaptive behavior towards oneself (Armaijn, 2019). Negative feelings that show symptoms of low self-esteem extend the time for individuals with leprosy while in the community to achieve self-acceptance (Jufriyanto et al., 2020). Leprosy sufferers in the community experience a decline in social skills triggered by physical problems such as disabilities, resulting in a lack of self-confidence when interacting with other people.

Public Stigma

Stigma from society encourages leprosy sufferers to isolate themselves due to rejection and discriminatory behavior in social life (Grzybowski et al., 2016). Negative perceptions given to leprosy sufferers are often carried out openly with labeling and neglect in every daily activity (Jatimi & Hidayat, 2022). In daily activities, individuals with leprosy experience limitations due to negative perceptions from society, such as not getting free space to participate in every activity while in the community (Sodik, 2016). In addition, society believes that leprosy sufferers are bad individuals and result in being infected with diseases that can cause permanent disability (Zamparoni, 2017).

Individuals with leprosy are socially burdened which has an impact on psychological conditions due to neglect by society with lack of knowledge about leprosy so that social discrimination continues to apply (Correia et al., 2019). Knowledge about leprosy in the community can be increased through education with the aim of reducing negative stigma towards individuals with leprosy living in the community (Hidayat et al., 2020) and by improving the coping mechanisms of leprosy sufferers to overcome psychological problems and problems originating from negative stigma in society (Jatimi, Nenobais, et al., 2020). Leprosy sufferers in the community experience discomfort in social life due to negative behavior from the community during interactions, which is indicated by forms of rejection and other negative behavior.

4. CONCLUSION

Leprosy not only affects individuals physically but also imposes profound psychological and social burdens due to self-stigma and public stigma. Self-stigma leads to low self-esteem, mental health challenges, and social withdrawal, while public stigma results in social exclusion, economic marginalization, and barriers to healthcare. Together, these forms of stigma create a vicious cycle of isolation and distress, deeply impacting the social lives and overall well-being of those affected. To mitigate these challenges, a comprehensive approach is essential. This includes providing psycho-social support to help individuals combat self-stigma, implementing public education campaigns to dispel myths and reduce societal discrimination, and enacting policies to protect the rights and dignity of leprosy sufferers. By addressing these interconnected issues, society can foster inclusion, promote mental well-being, and empower individuals with leprosy to lead fulfilling lives free from stigma and prejudice.

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