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RISK FACTORS FOR PSYCHOLOGICAL IMPACT AND STIGMA AMONG LEPROSY PATIENTS: A SYSTEMATIC REVIEW

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ABSTRACT

The bacterium Mycobacterium leprae causes leprosy, which causes peripheral neuropathy and prolonged disability that impacts a person's psychology, causing fear and anxiety. The aim of this review study was to find variables that impact on individuals' mental health and social stigma. Method: A systematic review searched for previous studies using cross-sectional or non-experimental designs published between 2019 and 2024 in five electronic databases (Scopus, Wos, Science Direct, and ProQuest). To transfer this view, the Center for Research and Dissemination and the Joanna Briggs Institute Guidelines were used to assess quality and the Prisma checklist. To assess research eligibility, titles, abstracts, full texts, and methodologies were evaluated. Data tabulation and narrative analysis of research results were conducted. Results: We found that seven journals met the requirements for inclusion in this observation. Any research on psychology and stigma addresses psychological impact and factors related to social stigma. Psychological impacts include knowledge, gender, culture, disability, economy, education, and lack of support systems, while stigma includes societal culture and the disability of leprosy. Conclusion: The results of this systematic review found many things that are risk factors for psychological disorders and stigma in leprosy patients including knowledge, gender, culture economy, education and lack of support system, disability which causes leprosy sufferers to experience discrimination, self-isolation, and misperceptions from society. Further research to understand this phenomenon is needed to reduce the global psychological impact and negative social stigma.

Keywords: leprosy; risk factors; psychological; stigma

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INTRODUCTION

Leprosy (Morbus Hansen) is a chronic infectious disease caused by Mycobacterium leprae. It is called the "great imitator disease" because its symptoms are similar to other fungal infections and skin diseases, so it is rare for someone to know that they have leprosy (Hidayat, 2020).The disease first attacks the skin and then progresses to a secondary stage, causing peripheral neuropathy that can lead to long-term disability and stigma. Most of the disease burden worldwide comes from leprosy patients (Chen et al., 2022)From 2020, the number of leprosy patients has increased worldwide. In 2021, 135 WHO member states shared information on leprosy. 133,781 leprosy cases and 140,546 new cases were recorded, with 55,346 female cases (39% of the total). Globally, 8,490 new cases were recorded, of which 368 (4%) were children. Most of the countries with high rates of new cases are in the WHO regions of Africa and Southeast Asia. As the countries with the most leprosy patients in the world, Brazil, India and Indonesia reported the majority of new leprosy cases (74%) in 2021 (World Health Organization, 2022). The Indonesian Ministry of Health reported that in January 2022 the number of leprosy sufferers was 13,487 people and the number of new infections in 2022 was 7,146 people. Up to 15.4 percent of leprosy patients experience disability due to delays in treatment (Wahyudi, 2023).

Psychological distress for people with the disease is increasing due to the rising incidence rate, Individuals may experience internal distress, such as insecurity, embarrassment, and fear of being shunned. In addition, the source of psychological distress may come from external sources, such as labeling, social isolation, and community discrimination(Jatimi, 2023). Behavioral stigma, such as labeling and discrimination, indicates the community's perception of people with leprosy (Hidayat, 2020). The community stigma against leprosy is still strong. They believe that leprosy is a hereditary disease, glaring, and not accepted (Hannan Mujib et all, 2021). The purpose of this study review is to find elements related to the psychological impact and social stigma in the community.

METHOD

To prepare for this study, a systematic observation technique was used. It includes the rationale and objectives of the study, the objectives and criteria for selecting articles for research, the sources of information used, the process of data collection and article selection, the results obtained, the method of assessing the risk of bias, and the results of data synthesis. PRISMA item reporting guidelines were applied in this study.

Search Strategy

Systematic research was conducted using five electronic databases: Ebsco, Proquest, Scopus, Sience direct and Wos. The search process began on February 18, 2024. After consulting with experts in systematic review strategies, the search methods for each database were refined. Four keyword groups based on Medical Subject Heading (MeSH) were used to conduct the literature research. These keyword groups were combined with the Boolean operators AND, OR, and NOT, and the search strategy was defined as follows: ("risk factor" OR factor OR cause*) AND (psycho* OR mental OR "mental health" OR "mental disorder" OR psychological phenomenon OR psychological stress) AND (stigma OR social stigma) OR (LEPROSY OR "MORBUS HANSEN") Journals had to be published in English or Indonesian during 2019-2024, but search results were not limited to cross-sectional, interventional, or qualitative studies. This time limit was set because researchers need recent studies to create theoretical models of freezing and health.

Eligibility criteria

Inclusion criteria based on population, intervention/issue of interest, comparison, outcome, and research design criteria (PICOS) were set in this study (Amir-Behghadami & Janati, 2020). The research questions were organized in the PICOS format (P = population, I = intervention, C = comparison, O = outcome, S = study type). Inclusion and exclusion criteria were made using the PICOS format to make the boundaries of the observation questions clear.

Study Selection

The number of journal publications found from the baseline search was 163; duplicated publications (n = 32) were excluded from the search results, resulting in a total of 131 records. The researchers assessed and separated the titles and abstracts (n = 106) of any publications that did not meet the inclusion criteria. We found seven full texts worthy of systematic scrutiny. During the literature screening process, the researchers defined common reasons for rejecting literature, including irrelevant study types and lack of a thorough explanation of the components that influence psychological disorders or stigma.

Risk of Bias

Each study was evaluated through the JBI Critical Appraisal for qualitative and cross-sectional research (n = 7). The checklist for the corresponding study had various assessment

criteria. Each criterion was scored as "yes", "no", "not applicable", or "unclear", and each point awarded for a "yes" criterion was added to the total score of the study. The researchers conducted a critical appraisal to assess eligible studies. Studies were included in the observations if they scored at least 70% during the critical appraisal-a threshold agreed upon by both researchers in advance. The researchers eliminated low-quality studies to avoid compromising on the validity of the results and suggestions from the review.

Extraction and Data Analysis

The data extraction process began with an initial observation of the various contexts. Then, the selected journals were compiled, which included author, country, year, background, theoretical framework, research objectives, conceptualization of cultural competence, educational content, research design, sample size, sampling method, description of participants, validity and reliability, measurement instruments, statistical analysis and techniques, and results related to cultural competence. The purpose of this stage was to synthesize related findings. The analysis was conducted independently by two reviewers. The final version of the script was approved by all authors.

RESULTS

Seven articles were eligible for inclusion (Figure 1). The included studies were related to the infectious disease leprosy. Five journals addressed the impact of risk factors on the psychology of leprosy patients and Two journals addressed the social stigma of risk factors. Each journal was cross-sectional and qualitative in design. The number of participants reached more than a thousand; in general, each study addressed psychological impact. Studies on psychological impact were of the highest quality, while studies on social stigma were of the lowest quality. Four studies that fit this systematic observation were conducted in Nepal, two in India and one in Brazil.The five journals found that the risk factors for psychological impact in people with leprosy were gender, knowledge, economy, education, disability, culture and support, while in the case of risk factors for social stigma with two journals, culture and disability were found.

Figure 1.

PRIMA flow diagram showing the screening and selection proses

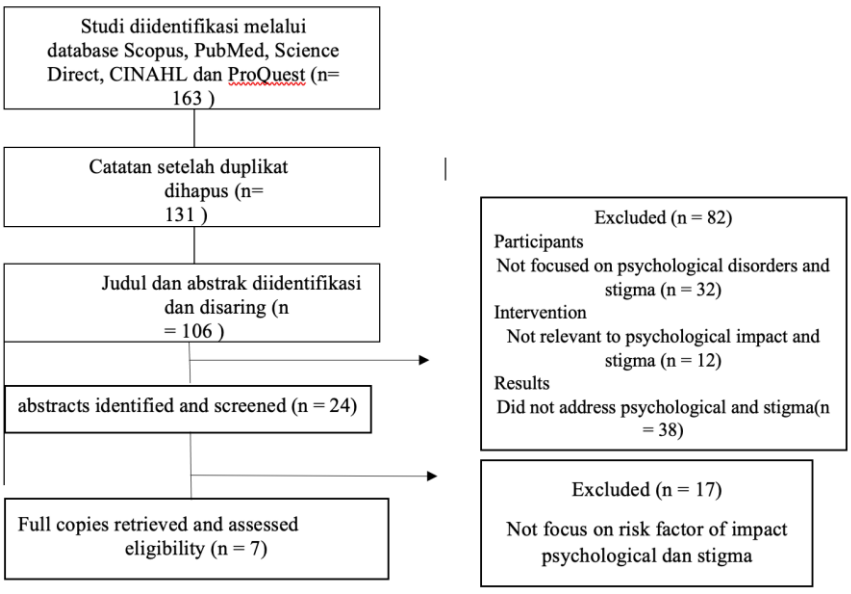

Table 1.
Included Study Characteristic

Judul, penulis, tahun	Metode	Hasil
” A life of disclosure: stigma, discrimination, and homelessness.” A case study of a factor that slowed (or contributed to the slowed) treatment-seeking behaviour of a leprosy patient in Nepal *et al.,2022)*	D: a case study S: 1 participant V: stigma, discrimination, and homelessness. I: interview, observation A: hermenuretik	Stigma factors that arise due to culture and lack of family and community support
Burden of depression and anxiety among leprosy affected and associated factors—A cross sectional study from India (Govindasamy et al., 2021).	D: cross sectional S: 220 patient V: Independent: Leprosy sufferers Dependent: burden of depression and anxiety I: depression questionnaire (PHQ-9), anxiety questionnaire (GAD-7) interview A: univariate analysis included in multi-variate linear regression model (bootstrap)	Female gender was most significant for the occurrence of anxiety and depression than male. Low education and level of disability affect the mental state of patients
Depression and mental wellbeing in affected by leprosy in southern Nepal (Dorst et al., 2020).	D: cross sectional S: 196 people 142 lepers with disability 54 leprosy surveys with stigma (6-15 years old, 66% male). V: Independent: Depression and mental wellbeing Dependent: leprosy I: Using Depression questionnaire (PHQ-9), Mental questionnaire (WEMWBS) Stigma questionnaire 5-QSI-AP) A: EpiInfo version 7.2 (CDC) and exported to SPSS (IBM SPSS Statistics 25), Student's t-test was applied for parametric data. For categorical variable analysis, Pearson's Chi-square test, Bootstrap univariate linear regression, multivariate linear regression were performed including all variables, Cronbach's alpha was calculated in SPSS for the categorical variables. memvalidasi skala stigma 5-QSI-AP.	Both mental well-being and depression are influenced by gender and levels of stigma. In addition, the level of depression is also associated with the level of disability of people with leprosy.
Depression and anxiety in people affected by leprosy: a cross sectional study in four States in India.(Lourmea et al., 2020).	D: cross sectional S: 2114 patient V: Independent: Depression and anxiety Dependent: leprosy. I: Using the Questionnaire A: Wald Chi-square test used through univariate logistic regression	Disability, female gender has the highest rates of depression and anxiety in leprosy patients
Factors influencing the mental wellbeing of persons affected by leprosy in Far-Western Nepal (Pierneef et al., 2022).	D: cross sectional qualitative approach S: A total of 38 people affected by leprosy were involved in this study: 25 people participated in the IDI and 13 people participated in the FGD. V: Factors influencing the mental wellbeing of persons affected by leprosy I: Semi-structured and in-depth interviews and group discussions A: Data analysis using Framework Analysis and Thematic Open Analysis.	leprosy-related stigma, physical discomfort (disability) social participation restrictions due to culture mental illness factors that occur due to the knowledge and culture of the community
Improving treatment outcomes for	D: qualitative	Personal factors, external

leprosy in Pernambuco, Brazil: a qualitative study exploring the experiences and perceptions of retreatment patients and their carers (Khanna et al. 2021)	S: 14 participants and 13 caregivers V: Improving treatment outcomes for leprosy in Pernambuco, Brazil: a qualitative study exploring the experiences and perceptions of retreatment patients and their carers I: Semi-structured interview A: Thematic data analysis.	factors, clinical factors and the nurse-patient relationship. Poor knowledge and lack of support cause patients to distrust treatment.
Mental wellbeing among people affected by leprosy in the Terai region, Nepal (Van Netten et al, 2021)	D: qualitative S: Fourteen people with varying degrees of leprosy disability and two health workers V: Mental wellbeing among people affected by leprosy in the Terai region, Nepal I: Semi-structured interview A: framework analysis method with characteristics Grounded Theory Approach	Respondents' mental well-being was negatively affected by the direct and indirect consequences of developing leprosy. Stigma, level of disability, family, community, work and culture are very important factors affecting mental well-being in the Terai region of Nepal.

DISCUSSION

Psychological problems and stigma are major factors in patients with leprosy. Factors that influence the psychological impact and stigma of the community consist of several things, including internal and external factors. Factors that influence psychological impact are gender, knowledge, culture, education, economy, disability and support system. All of these factors will influence each other and cause disruption to the psychological condition of the community. While the negative stigma that exists in the community is influenced by environmental factors (culture) and the disability itself. The female gender has an important role in causing depression and anxiety, this is evidenced by research that the female gender has a ratio of 8:1 with men in the status of leprosy patients who have depression and anxiety (Govindasamy et al., 2021). The psychological pressure that leprosy sufferers often feel is stress, depression and fear of disease (Somar et al., 2020) which limits their activities. On the other hand, leprosy sufferers often have a low level of welfare due to social stigma (Armaijn, 2019).

Physical problems experienced by leprosy sufferers include disorders such as damage to peripheral nerves, causing visible disabilities (Hambridge et al., 2021). People affected by leprosy with visible disabilities (grade 2 disability) have higher rates of depression and poorer mental well-being. This is in line with recent observations showing that women with leprosy are subordinated and often face stigmatization, silence, delayed treatment, difficulties in marriage, and social rejection, resulting in poorer quality of life and greater mental burden bearing (Van Dorst et al., 2020). This makes it difficult for leprosy sufferers to get activities, especially work, so it has an impact on the psychology of leprosy sufferers, such as becoming isolated, not wanting to leave the house, and withdrawing from social life (Muna, 2019). Discriminatory treatment of leprosy patients in society further worsens the patient's condition. (Ministry of Health of the Republic Indonesia, 2021)

One of the serious causes of leprosy is the lack of public knowledge about leprosy (Jufrizal and Nurhasanah, 2019). The stigma against leprosy sufferers of course affects the understanding of leprosy and self-acceptance of sufferers (Arianti Putri et al., 2016). Community knowledge about leprosy shows that the community considers leprosy to be contagious, hereditary and cursed. The community's lack of knowledge about leprosy is due to several factors, including internal factors within the community who are less enthusiastic to

accept or know the truth about leprosy, external factors from health workers who only provide counseling to sufferers, and uneven information in the community about leprosy (Hannan Mujib et all, 2021).Traditional beliefs - especially cultural beliefs that leprosy is a sin or a curse - have a negative impact on mental well-being. These beliefs are often associated with incorrect knowledge about leprosy. Beliefs cause participants to question themselves and cause mental distress. Belief that leprosy is caused by sin. Similar cultural beliefs were also found among leprosy communities in South Central Nepal, including the perception that leprosy comes from dirty blood, a curse, or from committing a sin (Pierneef et al., 2022)

Leprosy sufferers with low socio-economic status are also prone to poor mental health due to their disempowerment and the stigma attached to them, which makes it difficult for them to find work (van Dorst et al., 2020). However, a very big factor is the disability of leprosy sufferers, the visible disability makes them feel ashamed, afraid of the disease so that there is social discrimination that makes them have mental disorders (Van Netten et al., 2021b)The attitudes and behaviors of family and community members greatly affect the mental well-being of people with leprosy, and when asked to express their feelings, some of them included family and community in their answers. Respondents considered family and community to be an important part of their daily lives, even when asked to express their feelings, some of them included family and community in their answers. It seems that many respondents depend on the way others treat them, especially family and community members. One respondent refused to tell her family about her diagnosis for fear of additional effects (Van Netten et al., 2021b) The importance of motivation to fellow friends, family or community is to unite the community to be able to fight the social stigma that exists for people with leprosy, especially those with disabilities.

Stigma itself is formed from the social culture that has been embedded from a long time ago that is carried over to this day, where this is supported by the condition of sufferers who have a severe level of disability, giving rise to false social stigmas such as discrimination and labelling (Van Netten et al., 2021b). The experience of bad social stigma makes a burden for leprosy sufferers such as fear of judgment, shame, hesitation to participate in community activities which ultimately results in social isolation, depression, anxiety and then leads to concealment of disease status which has an impact on poor treatment adherence resulting in worsening disability (Surya et al., 2023).

CONCLUSION

Factors that contribute to social stigma include disability and societal culture, as well as gender, knowledge, culture, education, economy, disability and sources of support. On the other hand, factors contributing to psychological impact include disability and societal culture, which cause sufferers to experience discrimination, self-isolation, and negative perceptions from society. Further research to understand this phenomenon is needed to reduce the global psychological impact and negative social stigma.

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