

How to Cite:

Bahari, B., Sutantri, S., & Huriah, T. (2022). Socio-cultural issues in leprosy control and management: Literature review. *International Journal of Health Sciences*, 6(S2), 3240–3249. <https://doi.org/10.53730/ijhs.v6nS2.5810>

Socio-cultural issues in leprosy control and management: Literature review

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Abstract--Background : Background: Leprosy is a tropical infectious disease that is neglected worldwide. The world's SDGs target in 2024-2030 requires efforts to reduce it from 0.05 per 10,000 population. The lack of maximum preventive actions and the high number of cases of leprosy can be caused by social and cultural factors; on the other hand, it also impacts social and cultural problems of society in general. Objective: To explore whether social, cultural, and disease control or management factors are related to the high incidence of leprosy based on the existing literature. Methods : Methods: A literature taken from databases included SCOPUS, PubMed, Ebsco, Proquest, Google Scholar. The periods are from November 1 to December 30, 2021. The databases included SCOPUS, PubMed, Ebsco, Proquest, Google Scholar. The literature obtained was six articles that met the inclusion criteria. By using the review protocol through the PRISMA checklist. Stages through screening inclusion and exclusion criteria, quality assessment and data extraction. The analysis was carried out for the key characteristics of each included study and summarized qualitatively. Results: Six articles showed: Family factors are critical partners in providing services for people who have had leprosy, Cultural and Social factors affect the effectiveness of leprosy management, Knowledge factors are more related to leprosy healing than social distance, Improving social and economic factors in people with leprosy can improve the social and

economic conditions of people with leprosy, Social and economic factors affect the management of people with leprosy, Conclusion : social, economic, cultural, and disease control or management factors are related to leprosy. Suggestion : Need efforts from various cross-sectors in increasing social, cultural and economic factors for people with leprosy.

Keywords---culture, leprosy, management, control, social-economic.

Introduction

Background behind

World Health Organization (WHO) 2018 states that leprosy is one of seventeen neglected tropical diseases and requires special attention from the world. Leprosy is also known as "The Great Imitator Disease" because its manifestations are similar to many other skin diseases such as fungal skin infections, so that a person is rarely aware that he or she has had leprosy (Student et all, 2020). Delay in diagnosis in people with leprosy can cause irreversible damage to the nervous system and can even cause permanent disability (Student et al., 2020).

The target of the Sustainable Development Goals (SDGs) is a 90% reduction in the number of people who need the best interventions for tropical diseases such as leprosy and filariasis. nationally to less than 0.05 per 10,000 population with the following details: a decrease of 90% of new leprosy patients requiring Multi Drug Therapy (MDT) treatment (the 2017 baseline was 16,000 new leprosy patients), no leprosy disability in children with leprosy) zero children with leprosy with disabilities among new leprosy sufferers), maintain the second level of leprosy disability rate of less than 1 per 10,000,000 population, and maintain the rate of leprosy patients completing treatment on time (RFT rate) of more than 90% (PMK RI No 11 of 2019).

This unresolved problem is a factor in the high prevalence of infectious diseases. One of the infectious diseases referred to is leprosy, where leprosy is part of the Neglected Tropical Disease (NTD) which refers to the fact that this tropical disease is not considered an important infectious disease. This group of diseases generally spreads among the poor and marginalized living in resource-limited environments. NTDs can result in attrition, decreased productivity, and social consequences .

The phenomenon causing the incidence of leprosy based on the results of research conducted by KerrPontes (2006) in Brazil found that significant variables that influence the incidence of leprosy are the low level of patient education, lack of food availability or social factors, client behavior such as contact between the client and other people when bathing in rivers, ponds, and lakes, and rarely changing bedding. Research in Indonesia by Yuniarasari (2013) & Muharry (2014) found that the factors that influence leprosy are the level of knowledge, sanitation, type of work, and socio-economic.

Method

Literature review of data bases retrieved November 1 - December 30, 2021: SCOPUS, PubMed, Ebsco, Proquest, Google Scholar . The literature obtained was 6 articles that met the inclusion criteria. By using the review protocol through the PRISMA checklist. Stages through screening inclusion and exclusion criteria, quality assessment and data extraction. Analysis was carried out for the key characteristics of each included study and summarized qualitatively. The inclusion criteria carried out in this study were: 1. The research was published from 2015 – 2021. 2. The manuscript was in English, 3 . Research manuscripts are written by researchers or research teams with backgrounds behind the nursing profession 4 . Research manuscript is a complete text or full text, 5 . Keywords from research article manuscripts include: Social, Cultural, Leprosy, control and Management, 6 . Research manuscripts are based on adequate references. 7. Type of publication of relevant international research results.

Table 1. Schematic / Tree Diagram (PRISMA)

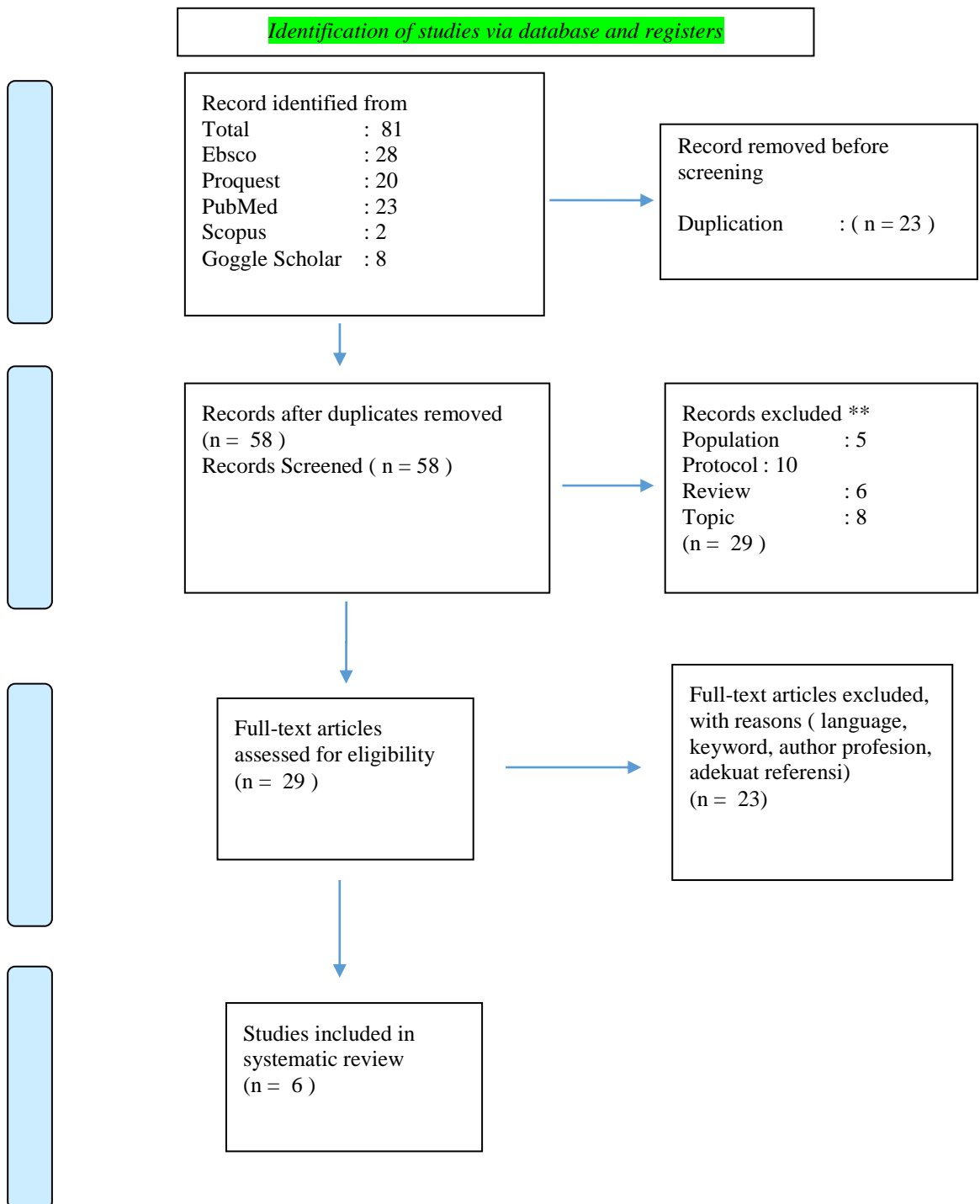


Table 2. Summary of All Articles

Table 2. Summary of All Articles No	Researcher name & year	Title	Settings	Method	Result	Themes
1.	Mavis Dako-Gyeke (2018)	Courtesy stigma: A concealed consternation among caregivers of people affected by leprosy	Accra Ghana West Africa	Qualitative research approach, twenty participants were selected purposively and in-depth interviews were conducted. Interviews were recorded, transcribed, and analyzed to identify emerging themes that address the study objectives.	Evidence shows that 1. The fear of contagion supports the caregiver's experience, especially in work and close relationships . 2. Participants adopt different strategies (ignorance, concealment, education, faith-based beliefs) to deal with stigma . 3. D psychosocial support and financial assistance to carers is a necessary consideration to achieve effective care for affected people by leprosy.	The family factor is a key partner in providing services for people who have had leprosy .
2.	Bani Bacan Hacantya Yudanagara (2020)	Psychosocial impact of discrimination on former sufferers leprosy	Surabaya Social Pondok Environment	Qualitative _ phenomenology	1. Participants have a stigma against themselves because leprosy, like a body that has been damaged and is frightening to others, although real discrimination is rarely encountered today. 2. The consequences of stigma and discrimination are: negative emotions such as sadness, anxiety about interacting with outsiders, fear of being shunned, and lack of confidence. 3. The social relations of the participants with fellow residents of the LIPONSOS Social Boarding School tend to be cohesive because they feel they share the same fate, but the relationship with family in their hometown and neighbors outside LIPONSOS is not very strong, in fact there is almost no deep interaction. 4. stigma on former lepers is still strong and their thoughts need to be changed so that they can live a better life.	Cultural, Social Factors affect the effectiveness of leprosy management

3	Anna T. van 't NoordendeID (2019)	The role of perceptions and knowledge of leprosy in the elimination of leprosy: A baseline study in Fatehpur district, northern India	Fatehpur district, northern India	This study uses a community-based cross-sectional design with mixed methods (mix methods) .	<ol style="list-style-type: none"> 1. A total of 446 participants were included in this study: 100 people affected by leprosy, 111 close contacts, 185 community members and 50 health workers. 2. 24 participants were interviewed in depth and 35 people were involved in focus group discussions. 3. As many as 12.5% of participants have sufficient knowledge about leprosy, while 22% have less knowledge. 4. Knowledge of the causes (answered correctly by 10% of participants), modes of transmission (5%) and symptoms of leprosy (16%) was very poor. 5. Better knowledge about leprosy is associated with lower levels of social distancing for people affected by leprosy. 	Knowledge factor is more related to leprosy healing than social distance
4	Dadun; Peters (2019)	Assessing the Impact of the Twin Track Socio-Economic Intervention on Reducing Leprosy-Related Stigma in Cirebon District, Indonesia	Cirebon District, Indonesia	RCT: SED intervention, in which a randomized cluster-controlled intervention study design was selected, and a mixed methods approach was used to measure the impact of the intervention on economic and social aspects such as stigma, participation and quality of life. The baseline survey was conducted in late 2011 and a final survey in early 2014, to assess the impact two years after the start of the intervention	<ol style="list-style-type: none"> 1. The profile shows a general improvement in the socioeconomic conditions of the participants' families and businesses. Forty-four (67%) have improved the family's economic condition since participating in SED (Social Economic Development) activities. They can, for example, buy more food. The profile also shows that the socioeconomic conditions of the families in 14 participants (22%) remained stable and seven (11%) decreased. Thirty-nine reported improvements since receiving microcredit in terms of more sales and more customers; 22 reported stable or no major changes in business conditions and four failed to establish or increase business due to illness, death, or having a baby. 2. Analysis of interviews and 	Increasing social and economic factors in leprosy patients can improve the social and economic conditions of leprosy sufferers.

					<p>FGDs showed that SED participants used their loans to start or strengthen their businesses thereby earning more money and reporting improved welfare. The data also show that many SED participants engage in savings activities related to microcredit schemes, increase their assets (eg TV, wardrobe) and property, and have more decision-making power in household matters.</p> <ol style="list-style-type: none"> 3. Changes in Welfare: The Impact of Socio-economic Development (SED) on Stigma, Stigma Effects and Quality of Life 4. Impact on Different Types of Stigma and Disclosure Concerns: Significantly higher reductions in domain disclosure and internalized stigma. 5. Feel more confident and able to socialize with others after the action is taken. 	
5	Bezerra; Barroso, Daniel Hollanda; et al. (July 2021)	The influence of leprosy-related clinical and epidemiological variables in the occurrence and severity of COVID-19: A prospective real-world cohort study	Brazil	Mixed Methods	<ol style="list-style-type: none"> 1. leprosy patients may be susceptible to COVID-19, although immunologic factors do not appear to be involved. Social and economic factors must always be considered for the prevention and adequate care of leprosy patients. 2. Public efforts, including vaccination, should be prioritized for vulnerable populations in leprosy endemic countries to reduce the impact of the pandemic on the management of leprosy. 	Social and economic factors play an important role in the healing of leprosy patients
6	Sekarningrum , Bintarsih (2017)	Social Exclusion and Impoverishment of Lepers	Sampang Regency, East Java Province	Qualitative : multi-method data collection, such as literature study, institutional survey, observation, and in-depth interviews with informants	<ol style="list-style-type: none"> 1. People with leprosy in Sampang Regency, East Java Province experience serious social exclusion and impoverishment; People with leprosy face barriers to economic access that lead to poverty. 2. The religious and cultural factors of the local community support the 	Social and economic factors influence the management of leprosy patients

					inhibition of economic access which is a determining factor for the development of social exclusion, resulting in the impoverishment of leprosy sufferers in Indonesia.	
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Discussion

Research from Mavis Dako -Gyeke (2018) shows that the fear of transmission supports the caregiver's experience, especially in work and close relationships, participants adopt different strategies (ignoring, concealment, education, faith-based beliefs) to deal with stigma , psychosocial support and financial assistance to carers is a necessary consideration to achieve effective care for affected people by leprosy. The results of this study require nurses to make maximum efforts based on the theory of the role of health workers according to Allender and Spradley (2018) which states that the role of health workers includes providing education, providing nursing or caring care, the role of counselor.

Bani Bacan Hacantya Yudanagara (2020) in his research explains that participants have a stigma against themselves because they leprosy, like a body that has been damaged and is scary to others, despite real discrimination are rarely encountered nowadays , the consequences of stigma and discrimination are: negative emotions such as sad, anxious interacting with outsiders, fear of being shunned, and not confident , Social relationships participants with fellow residents of the LIPONSOS Social Pondok Environment tend to be cohesive because they feel the same fate, but the relationship with family at home and neighbors outside LIPONSOS are not very strong, in fact there is almost no deep interaction . The stigma against former leprosy sufferers is still strong and their thinking needs to be changed so that they can live a better life . The results of this study emphasize the importance of cultural factors and social interactions that can affect the healing of leprosy patients. In accordance with the results of this study, the theory from Leininger, (2018) is very appropriate which states that culture refers to learning, sharing, and transmitting the values, beliefs, norms, and lives of certain individuals or groups that guide thoughts, decisions, actions, and ways of life. they are patterned, whereas cultural care refers to some aspect of culture that influences a person or group to improve the human condition or to deal with illness or death. The role of nursing in this cultural case is as a profession that studies and provides treatment based on existing phenomena.

From the research journal conducted by Anna T. van 't NoordendeID (2019) A total of 446 participants were involved in this study: 100 people affected by leprosy, 111 close contacts, 185 community members and 50 health workers. 24 participants were interviewed in depth and 35 people were involved in focus group discussions, 12.5% of participants had sufficient knowledge about leprosy, while 22% had less knowledge, knowledge of the causes (correctly answered by 10% of participants), modes of transmission (5%) and symptoms of leprosy (16%) are very poor. Better knowledge about leprosy is associated with lower levels of social distance for people affected by leprosy, these results are also in accordance with research conducted by Yuniarasari (2013) & Muharry (2014) which explains the

factors that influence leprosy are the level of knowledge, sanitation, type of work, and socio-economic. This is also in accordance with the results of research from LA EL HASSAN (2001) that social and cultural factors which include knowledge, attitudes and behavior factors affect the incidence of leprosy.

Research conducted by Dadun; Peters (2019) Shows a general improvement in the socioeconomic conditions of the families and businesses of sufferers, out of Forty-four participants (67%) have improved the economic conditions of their families since participating in SED (Social Economic Development) activities. They can, for example, buy more food. The profile also shows that the socioeconomic conditions of the families in 14 participants (22%) remained stable and seven (11%) decreased. Thirty-nine reported improvements since receiving microcredit in terms of more sales and more customers; 22 reported business conditions were stable or no major changes and four failed to set up or grow a business due to illness, death, or having a baby, Analysis of interviews and FGDs showed that SED participants used their loans to start or strengthen their businesses so as to make more money. and reported improvements in well-being. The data also show that many SED participants participate in saving activities related to microcredit schemes, increase their assets (eg, TV, wardrobe) and property, and have more decision-making power in household matters. (SED) on Stigma, Stigma Effects and Quality of Life, Impact on Different Types of Stigma and Disclosure Concerns: Much higher reduction in domain disclosure and internalized stigma, Feel more confident and able to socialize with others after the action is taken. The results of this study are also in accordance with what was explained by KerrPontes (2006) in Brazil who found that a significant variable that influenced the incidence of leprosy was the lack of food availability or social factors. On the other hand, the lack of social and economic impacts can cause disability in people with leprosy so that work productivity decreases. This is very influential on the decline in the quality of life of people with leprosy (Rahayuningsih, 2012).

In research conducted by Bezerra; Barroso, Daniel Hollanda; et al. (July 2021) suggests that leprosy patients may be susceptible to COVID-19, although immunological factors do not appear to be involved. Social and economic factors must always be considered for the prevention and adequate care of leprosy patients. Public efforts, including vaccination, should be prioritized for vulnerable populations in leprosy endemic countries to reduce the impact of the pandemic on leprosy management. Based on the results of this study, in the era of the COVID-19 pandemic, accuracy is also needed in diagnosing a symptom of the disease, because delays in diagnosis in leprosy patients can cause irreversible nervous system damage that can even cause permanent disability (Widodo, 2012). Leprosy is an infectious disease that can cause complex problems. The problems that arise are not only from the medical side, but also from the social, economic, and cultural aspects (Widoyono, 2008).

Conclusion

Based on the literature study that has been analyzed, it can be concluded that social factors (family and community support) , culture (perception, knowledge, belief) , and disease control or management (caregiver role, economic support and social support) are related to leprosy.

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