Journal of Pakistan Association of Dermatologists. 2021;**31(2)**:250-261.

Review Article

Stigma towards leprosy: A systematic review

Ihsan Fachry Arba, Afif Nurul Hidayati, Soetjipto*, Damayanti

Department of Dermatology & Venereology, Faculty of Medicine, Universitas Airlangga/ Dr. Soetomo General Hospital, Surabaya, Indonesia.
* Department of Psychiatry, Faculty of Medicine, Universitas Airlangga/ Dr. Soetomo General Hospital, Surabaya, Indonesia.

Abstract

Background One of the many problems that hinder leprosy prevention efforts is the stigma attached to leprosy, people affected by leprosy, and even their families. Stigma against leprosy can lead to discrimination, which will cause leprosy patients to be reluctant to seek treatment. To date, there are still no reviews that discuss the overall picture of the causes, manifestations, and the impact of stigma related to leprosy. This systematic review aims to know the leading causes, manifestations, and the impact of stigma related to leprosy.

Methods Search for inclusion studies was carried out through the PubMed and ScienceDirect databases, resulting in 13 studies included. Six studies used an individual perspective in their research, three studies had a community perspective, and four studies with a combined perspective of individuals and communities.

Results The studies in this review consists of eight cross-sectional studies, two RCT studies, one grounded theory study, one exploratory study, and one study with an unspecified design. A total of 2,636 participants were included in all the studies. The analysis results of all of the included studies indicated that for the factors that cause stigma, eight studies discussed the fear of contracting the disease, 10 studies discussed the external manifestations of the disease and three studies discussed burden on the family. Seven studies discussed cultural and community misconceptions. All studies discussed manifestations of stigma, 10 studies discussed about anticipated stigma, and 11 studies discussed internalized stigma. All studies discussed the social and psychological impacts of stigma related to leprosy, and only 3 studies discussed health impacts.

Conclusion The stigma towards leprosy is mainly caused by external manifestations of the people affected by leprosy, with the main manifestations of avoidance, social exclusion and concealment of the disease, and the main impact of social isolation from the community, reduced employment opportunities, and feeling of shame.

Key words
Leprosy, Morbus Hansen, Hansen's Disease, Stigma, Discrimination, Social exclusion.

Introduction

Leprosy

Leprosy is a chronic infectious disease caused by an acid-fast bacillus called *Mycobacterium leprae*, that multiplies slowly, with the average incubation period of 5 years. The disease primarily affects the skin, peripheral nerves, the upper respiratory tract mucosa, and the eyes.[1,2,4] Leprosy has been classified into two main types, paucibacillary (PB) which show negative bacteria smear results and multibacillary (MB) which show positive smear results, and is more infectious than the former. Untreated leprosy can cause progressive damage to the skin, limbs, and

Address for correspondence
Dr. Afif Nurul Hidayati,
Department of Dermatology & Venereology,
Faculty of Medicine, Universitas Airlangga/
Dr. Soetomo General Hospital, Surabaya,
Indonesia 60286.
Email: afif_nurulhidayati@fk.unair.ac.id

nerves, causing permanent disability, deformity, or both.[1,3] However, WHO has provided multidrug therapy (MDT) as the primary treatment for leprosy, which managed to significantly reduce the prevalence of less than 1 case per 10,000 global population in 2000.[1,5]

To date, leprosy still deemed as one of the leading global health problems, with over 16 million people infected in total, and over 200,000 new cases reported spreading across 159 countries in 2019. To achieve better control and significant reduction of leprosy cases, WHO instigated its annually updated "Global Leprosy Strategy" since 2016 with one of its main focus that is to stop discrimination and promote inclusion of people affected by leprosy and their families.[1,6-8]

Stigma

Because of its clinical manifestations (hypopigmented skin macules and nerve damages that leads to physical deformity), the misconception of the disease and cultural misbeliefs, people affected by leprosy and their families often are subject to social discrimination and stigmatization.[3,9,10] Over the last few decades, stigma has been related with general health matter and defined as a process of harmful discrimination towards people with uncommon physical features, behavior, and social aspect, indicated by rejection, exclusion, blame, and humiliation.[11-13] With the immensely stigmatized diseases, the impact of the disease-related stigmatization may be equivalent, if not more severe than the actual disease symptoms itself.[12]

There are three types of stigma: enacted, anticipated, and internalized.[13-15,17] Enacted stigma is a form of negative, condescending attitude or social prejudice done by the community towards people affected by the stigmatized disease.[13] Currently, literature that studies stigma also considers the social and demographical context.[16] Anticipated stigma is the individual perception that 'anticipates' the possibility of stigmatization to happen,[13] whereas internalized stigma is the self-constructed negative attitudes and stereotypes of their own disease, causing them to feel more ashamed of their condition.[17]

Problem statement

In spite of the extensive ongoing effort of eradicating leprosy-related discrimination, this disease is still widely misunderstood and stigmatized.[18] The emotional effects of stigmatization and social exclusion could contribute to the difficulty of new case detection, delayed health-seeking behavior, and reduced quality of life, leading to the worsening of the disease symptoms.[3,18-20] Moreover, as stated above, the clinical manifestations of chronic leprosy are among the major cause of the stigma attached to the disease, thus creating the vicious cycle of leprosy stigmatization. The available literature about stigmatization related to leprosy usually focused on a single variable of the causes, manifestations, or impact. Reviewing into the combined and broader aspect of leprosy-related stigma in terms of the correlations and differences of the causes, manifestations, and impact among different time and demographical settings could give a better general understanding of the current condition and more efficient plan of intervention; thus, reducing the stigma related to leprosy. Therefore, this study's research objective is to explicate the current state of stigma related to leprosy, with a combined focus to its leading causes, manifestations, and impacts.

Methods

Included studies were chosen based on inclusion

Leprosy OR 'Hansen disease' OR 'Hansen's disease' AND (stigma OR stigmatization OR prejudice OR discrimination OR stereotype OR 'social exclusion' OR (negative AND attitude*).

Figure 1 Search terms used in this review.

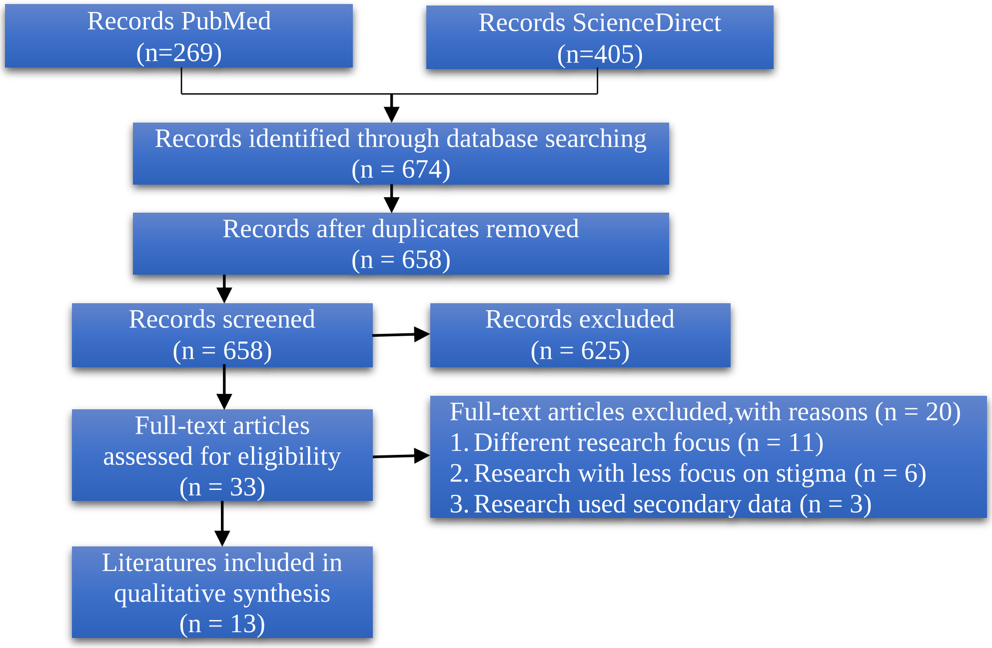

Figure 2 PRISMA flow diagram describing the systematic search process.

criteria: studies focusing on stigma related to leprosy that were published within 2010 and 2020 in the English language of which a full-text version of the studies was available. Studies with less than 10 participants and based on secondary data were excluded.

Studies were identified by carrying out a search through two electronic databases, *PubMed* and *ScienceDirect* throughout May to July 2020, following the (PRISMA) guidelines. Search terms used in the databases involved the main study subject, leprosy, and the main study interest, stigma, with its synonyms **(Figure 1)** for the search terms used in this study. Duplicates were removed after the initial search. The inclusion and exclusion criteria were used to base the titles and abstracts' screening process. Furthermore, the screened full-text were assessed to determine the studies to be reviewed further **(Figure 2)**.

The data extraction from included studies consisted as follows: the causes of stigma, the manifestations, and the impact of the stigma related to leprosy. The causes of stigma in this study were distinguished based on the most common stigmas related to leprosy: fear of transmission, external manifestations of the disease, being a burden on family or community, cultural and community misconceptions of the disease.[16] Manifestations of the stigma were differentiated to enacted, anticipated, and internalized stigma and the impact were distinguished as social, psychological, and health impacts. To obtain more context regarding the included studies, the variables regarding study characteristics were also added: publication year, study location, study design, sample size, type of study, sample characteristics and study perspective. The results were then compared to assess the current state of stigma related to leprosy, while also considering the time and demographical settings of each study

Results

Search results

The systematic search identified 674 studies. 16 duplicates were removed, and 625 studies were excluded based on the titles and abstracts, and 20 more were excluded after the full-text assessments, resulted in the remaining 13 studies that were included in this systematic review.

Studies description

The 13 studies included in this systematic review were published between 2012 and 2020. There were various study designs included, such as cross-sectional, randomized controlled trials, grounded theory, survey, and exploratory. The studies sites were located mostly in the Asia continent (8), followed by Africa (3) and South America (2). Most of the study type used was qualitative (8); five studies used mixed methods, and one study used a quantitative method. An interview is the most used instrument among the studies (8). The sample size among the studies varies from 10 to 1.339 people. Samples included were people affected by leprosy, patients' families and caregivers, healthcare workers, and community members. There were six individual perspective studies, four combined studies, and three community perspective studies (see **Table 1** for more explanation of the reviewed studies).

Table 1 Characteristics of the included studies.

Study author (year)	*Country*	*Study design*	*Study perspective*
Adhikari *et al.* [2014]	Nepal	Mixed methods cross-sectional study	Individual – People affected by leprosy
Dako-Gyeke *et al*. [2017]	Ghana	Design not stated; qualitative	Individual – People affected by leprosy
Dako-Gyeke [2018]	Ghana	Exploratory qualitative cross-sectional study	Community – People affected by leprosy
Garbin *et al*. [2015]	Brazil	Quantitative cross-sectional study	Individual – People affected by leprosy
Goncalves *et al*. [2017]	Brazil	Exploratory qualitative cross-sectional study	Individual – People affected by leprosy
Jung *et al*. [2020]	India	Qualitative grounded theory design	Individual – People affected by leprosy; Community – Healthcare workers
Lusli *et al*. [2015]	Indonesia	Qualitative exploratory study	Individual – People affected by leprosy
Lusti *et al*. [2016]	Indonesia	Mixed methods cluster-randomized controlled trials (RCT)	Individual – People affected by leprosy
Marahatta *et al*. [2018]	Nepal	Qualitative cross-sectional study	Community – Healthcare workers
Noordende *et al*. [2019]	India	Mixed methods cross-sectional study	Individual – People affected by leprosy; Community – Community members, healthcare workers, and family
Noordende *et al*. [2020]	Ethiopia	Qualitative cross-sectional study	Individual – People affected by leprosy; Community – Family
Peters *et al*. [2015]	Indonesia	Mixed methods cluster-randomized controlled trials (RCT)	Community – Community members
van Brakel *et al*. [2012]	Indonesia	Mixed methods cross-sectional study	Individual – People affected by leprosy Community – Community member

Stigma towards leprosy

Causes of stigma

Among all the studies, a minimum of one cause to most of three causes was mentioned in one study (see **Table 2** for an in-depth spread of causes mentioned in the studies). Eight studies mentioned fear of transmission as the cause of stigma related to leprosy. As stated by five studies located in four different countries, community tended to avoid close contacts and were unwilling to touch the affected parts of leprosy patients' bodies.[21-25] People affected by leprosy also had a decreased self-esteem, presumed that their disease is dangerous, and chose to hide their diagnosis due to the community' fear of transmission.[26,27]

External manifestations of the disease were the most stated causing factor in this review, which mentioned by 10 studies. The more visible deformities, skin ulcers, and disabilities people with leprosy have, the stigma inflicted would be more severe.[27] People affected by leprosy often get cast out from public places or public transportations, and even from their neighborhood after people saw their deformities.[22,28] Four studies reported that many community members scorned, felt disgusted, and avoided going near the leprosy patients' house mainly because of the external manifestations that the patients have.[23,25,26,28] The disabilities and deformities caused by leprosy could contribute to financial difficulty for people with leprosy and their families because of the difficulty finding jobs and prolonged special needs. It could also instill the thought of their families that they are a disgrace to the family, which led to people with leprosy internalize the thought of being a burden on their family.[26,28,29] There were seven studies that mentioned negative stereotypes and cultural misbeliefs as the causing factor of stigma related to leprosy. Many people across different regions still believed that leprosy could not be cured[28] and caused by a supernatural occurrence,[21] curses and 'evil spirit',[23,28] wrath of God and hereditary factor,[24] resulted in social exclusion and difficulty having interaction.[21,25]

Table 2 Causes of the stigma towards leprosy.

Literatur (Tahun)	*Causes of stigma**			
	Fear of transmission	*External manifestations*	*Burden on family*	*Community misconceptions*
Adhikari *et al*. [2014]	O	O	X	O
Dako-Gyeke *et al*. [2017]	X	O	O	O
Dako-Gyeke [2018]	O	O	X	O
Garbin *et al*. [2015]	X	O	X	X
Goncalves *et al*. [2017]	X	X	O	X
Jung *et al*. [2020]	O	O	X	X
Lusli *et al*. [2015]	X	O	O	O
Lusti *et al*. [2016]	O	O	X	X
Marahatta *et al*. [2018]	O	O	X	O
Noordende *et al*. [2019]	O	X	X	X
Noordende *et al*. [2020]	O	X	X	O
Peters *et al*. [2015]	O	O	X	O
van Brakel *et al*. [2012]	X	O	X	X
Total	8	10	3	7

*O = Mentioned in the study; X = Not mentioned in the study.

Table 3 Manifestations of the stigma towards leprosy.

Literatur (Tahun)	*Manifestations of stigma**		
	Enacted stigma	*Anticipated stigma*	*Internalized stigma*
Adhikari *et al*. [2014]	O	O	O
Dako-Gyeke *et al*. [2017]	O	O	O
Dako-Gyeke [2018]	O	O	O
Garbin *et al*. [2015]	O	O	O
Goncalves *et al*. [2017]	O	O	O
Jung *et al*. [2020]	O	X	O
Lusli *et al*. [2015]	O	O	O
Lusti *et al*. [2016]	O	O	O
Marahatta *et al*. [2018]	O	O	X
Noordende *et al*. [2019]	O	O	O
Noordende *et al*. [2020]	O	X	O
Peters *et al*. [2015]	O	X	X
van Brakel *et al*. [2012]	O	O	O
Total	13	10	11

*O = Mentioned in the study; X = Not mentioned in the study.

Manifestations of stigma

Almost all studies reported no less than two forms of stigma manifestations, with only one study reported one type **(Table 3)**. Enacted stigma was mentioned among all 13 studies included in this review, stated that people with leprosy and their caregivers experienced exclusion and avoidance from the community, healthcare workers, their coworkers, and even their own families; be it at their neighborhood, workplace, hospital, and even public places. People were afraid to be near them,[30] excluded them from their home by the community and their family, banished them to live in the forest,[28] and were not inviting them to local events or parties.[24] The other manifestation of enacted stigma mentioned were difficulty and rejection in finding jobs, fired from their job solely because of their disease,[19,21-23,26-31] labelling and mocking,[21,23,25,27,28,31,32] and excluded by their families or spouse.[22,26-28,32]

There were 10 and 11 studies that mentioned anticipated and internalized stigma, respectively. People affected by leprosy experienced the fear of disclosing their condition due to the fear of other people's reaction and exclusion.[19,23,24,26,27,29,30] Adhikari *et al*. reported that 65.9% of the people affected by leprosy chose to conceal their condition, compared with only 40.7% that disclosed their condition to their closest relatives.[27] They also chose to isolate themselves from social activities because they have anticipated community responses towards them and their diseases and also because of their anxiety.[19,26,29-31] People with leprosy also reported having a feeling of shame,[19,26,27,29,31,32] normalize the stigma they have experienced,[21,28,31] and thinking less of themselves,[19,22,31,32] which ultimately led to having suicidal thoughts and attempted suicide.[22,26,28,32]

Impact of stigma

There was a minimum of two consequences of the stigma related to leprosy in all studies **(Table 4)**. In terms of social impacts, 12 studies mentioned social isolation as one of the social impact of stigma towards leprosy,[19,21-29,31,32] while marriage problems[19,21-23,26-28,32] and reduced employment opportunities were also emphasized.[19,21-24,26-29,31,32] Garbin *et al*. mentioned that 69% of the people affected by leprosy experienced problems at work, and even

Table 4 Impacts of the stigma towards leprosy.

Literatur (Tahun)	*Impacts of stigma**		
	Social	*Psychological*	*Health*
Adhikari *et al*. [2014]	O	O	X
Dako-Gyeke *et al*. [2017]	O	O	O
Dako-Gyeke [2018]	O	O	X
Garbin *et al*. [2015]	O	O	X
Goncalves *et al*. [2017]	O	O	O
Jung *et al*. [2020]	O	O	X
Lusli *et al*. [2015]	O	O	X
Lusti *et al*. [2016]	O	O	X
Marahatta *et al*. [2018]	O	O	O
Noordende *et al*. [2019]	O	O	X
Noordende *et al*. [2020]	O	O	X
Peters *et al*. [2015]	O	O	X
van Brakel *et al*. [2012]	O	O	X
Total	13	13	3

*O = Mentioned in the study; X = Not mentioned in the study.

12.3% fired from their job. One study also reported that the stigma has caused the leprosy patient's children experienced a delay in education. They were forced to work every day to financially support their family because their parent was unable to work anymore.[32] Decreased quality of life,[30] lowered self-esteem,[21,27,30,32] depression[25,26,30,31] and anxiety were the psychological impact highlighted.[26,32] Moreover, as stated above, suicidal thoughts and attempts were also reported.[22,26,28,32] Health consequences consist of poor health outcome caused by exclusion at the workplace, which made chronic leprosy-affected person had to undergo further distance to reach their workplace and felt pain from their deformity afterwards;[29] delayed health-seeking behavior[23] and delayed treatment due to prejudice from the healthcare workers.[28]

Discussion

The objective of this systematic review was to explain further the intensity of stigmatization towards leprosy from a broader scope and to elucidate the correlations and differences between different time and demographical settings. The results extracted from the 13 included studies in this review showed that stigma related to leprosy still widely experienced between different time stamps, across different regions and cultures. The similarity between all the studies is that the studies' locations were among the top 6 countries with the highest new case detection rate in 2018, except Ghana.[8] Adhikari *et al*. concluded that social discrimination and stigmatization towards leprosy would progressively decrease over time.[27] However, results in this study showed that within the range from 2012 to 2020, nine studies showed three forms of stigma manifestations, and all studies stated social and psychological impact altogether, indicated that within eight years, there were no remarkable changes that able to drastically reduce the occurrence of the causing factors yet. There is a need to address that there were studies indicated that there was a decreased intensity of stigma,[26,29,32] and there were community approval and support received by people affected by leprosy.[22,25,28,30,32]

This review showed that external manifestations were the most attributed cause of stigma, followed by fear of transmission, misconceptions of the disease, and burden on the family. One study included in this review stated a significant difference (p=0.008) in the severity of the stigma perceived between the uneducated and educated leprosy-affected people. Moreover, there was also a significant difference (p<0.001) between people with leprosy that have less or no knowledge regarding the cause and transmission method of the disease and assumed that leprosy is a dangerous, incurable disease, and the opposite[27] suggested that lack of education and knowledge regarding the disease could have made people with leprosy more prone to misconceptions, influencing not only the individual perceived stigma but also the community' fear of contagion, therefore led to more severe manifestations and impacts of stigma in general. Other studies endorse these findings.[16,28,30,33] Among all participants in the study conducted by Noordende *et al*., only 2% answered correctly regarding the disease transmission method. In contrast, the others answered the transmissions are from physical touch and sharing food with leprosy-affected people.[24] These findings were consistent with other studies that stated avoidance from people with leprosy due to fear of transmission still happened often.[22,34] Studies in this review stated that the most notable differences of the perceived stigma between deformed leprosy patients were that the deformed ones tend to presume that their conditions are permanently 'abnormal' even after they were cured of the disease and that they have more intense perceived stigma than the non-deformed ones.[27,31] These findings are corroborated by several studies that stated with more noticeable deformity and disability that leprosy-affected people had, the least amount of social interaction would be accomplished.[19,32,35-38] The misbeliefs reported in the included studies in this review were also stated in various and also recent other studies.[32,39-42]

There were high levels of either enacted, perceived, and self-stigma mentioned in all 13 included studies in this review. Eight of them reported all the stigma manifestations types concurrently **(Table 3)**. These results are supported by the reported high score in the Explanatory Model Interview Catalogue Scale[19,23-25,27] and Participation Scale.[19,26] People affected with leprosy in Nigeria[43,44] and Ghana[28,45] have also experienced high levels of stigma. Avoidance and exclusion were mentioned in all included studies, with one of the further manifestations was the community members refused to share food and drink with leprosy-affected people.[21,23,28] This phenomenon could have happened due to combined causing factors, such as the preexisting negative stereotypes of the disease and visible deformities, which led to an escalated community's fear of contagion. Another similar occurrence was reported from two other studies, mentioned that community members even refused to shake hands with leprosy-affected people.[10,31] eight studies stated fear of diagnosis disclosure as one of the major anticipated and internalized stigma manifestation,[19,21,23,24,26,27,29,30] which mirrors the most often form of anticipated and internalized stigma in this review, and are consistent with other studies.[46-48]

As stated above, marriage problems, reduced employment opportunities, and social isolation were the most frequent social impacts of the stigma stated in this study. The cultural aspects and stereotypes that are subject to different countries were believed to be one of the leading cause of relationship problems,[49] which could also lead to leprosy-affected people marrying other affected people.[20] Other study also stated that although leprosy-affected people were already cured, they have still experienced social exclusion and isolation,[50] indicating that cured people could severely face the impact of the stigma related to leprosy. Murder attempts towards people with leprosy were also reported in the recent studies that conducted in 2017 and 2020, which showed that although numerous interventions and awareness-raising regarding stigma related to leprosy were attempted since, at least, 20 years before this review, the expected outcome of drastic stigma reduction was yet to be achieved.[22,28] People affected by leprosy also reported to have experienced delayed education access,[33,51] whereas one included study in this review stated that it was the children that have experienced the delay instead,[32] suggested that the stigma related to leprosy could not only be able to affect leprosy-affected people but also their relatives. Studies included reported that people affected by leprosy often felt shame, anxiety, depression, and have lowered self-esteem, which were also stated by two other studies that are not included in this review.[52,53] Reported suicidal thoughts and attempts in the included studies are endorsed by the findings of two other studies, which concluded a correlation between stigma related to leprosy and self-hate and suicidal thoughts.[54,55] Among all the studies included, only three studies mentioned the health impacts of stigma related to leprosy. This finding might be caused by many of leprosy-affected people thought that physical pain was not the hardest to endure, but rather a psychosocial burden.[27,29] One of the health consequences reported in this review was the discrimination and prejudice from healthcare workers, which caused a delayed treatment that worsened the disease conditions, which are supported by two other studies.[56,57] Moreover, this condition also disrupted the professional relationship between healthcare workers and people with leprosy and extended the preexisted misconceptions towards the disease.[51]

There are a several limitations in this review that need to be stated. First, because of only studies with English language available were included, we may not have found all eligible and relevant literature for the review. Second, the findings in this review might need more data in various other regions to be able to provide a general context of the current state of stigma related to leprosy.

Conclusion

This systematic review found and adds further evidence of the leading causes, manifestations, and impact of stigma towards leprosy and its extent among different time and demographical settings. We found no drastic reduction of stigma related to leprosy within eight years across different regions of the world. We also found that the stigma towards leprosy is mainly caused by external manifestations of the people affected by leprosy, with the main manifestations of avoidance, social exclusion and concealment of the disease, and the main impact of social isolation from the community, reduced employment opportunities, and feeling of shame. Moreover, further multicentered research is needed to provide a more generalized context of this review. Further research is also needed to evaluate the implementation of currently existing intervention methods, considering that many recent studies still mentioned high levels of stigma. This systematic review can be used as the basic foundation of current conditions regarding stigma towards leprosy in innovating new intervention methods and as an eye-opener for every reader regarding this ongoing condition, which can hopefully eradicate the stigma towards leprosy for good.

References

1. World Health Organization. Leprosy [Internet]. 2019 [cited 4 May 2020]. Available from: https://www.who.int/news-room/fact-sheets/detail/leprosy
2. Aisyah I, Agusni I. Penelitian Retrospektif: Gambaran Pasien Baru Kusta. *Berkala Ilmu Kesehatan Kulit dan Kelamin*. 2018; **30(1)**:40-7.

3. Pusat Data dan Informasi Kementerian Kesehatan RI. Hapuskan Stigma dan Diskriminasi terhadap Kusta [Internet]. 2018 [cited 6 May 2020]. Available from: http://www.Kemenkes RI.go.id/resources/download/pusdatin/infodatin/infoDatin-kusta-2018.pdf
4. Centers for Disease Control and Prevention. Etiologic Agent | Hansen's Disease (Leprosy) | CDC [Internet]. 2017 [cited 5 May 2020]. Available from: https://www.cdc.gov/leprosy/health-care-workers/etiologic-agent.html
5. World Health Organization. Guidelines for the diagnosis, treatment, and prevention of leprosy. New Delhi: World Health Organization, Regional Office for South-East Asia; 2018.
6. World Health Organization. Global leprosy strategy, 2016-2020. 1st ed. New Delhi: World Health Organization, Regional Office for South-East Asia; 2016.
7. World Health Organization. Global leprosy update, 2017: reducing the disease burden due to leprosy. *Wkly Epidemiol Rec*. 2018; **93(35)**:445-56.
8. World Health Organization. Global leprosy update, 2018: moving towards a leprosy-free world. *Wkly Epidemiol Rec*. 2019; **94(35)**:389-412.
9. World Health Organization. Global leprosy update, 2015: time for action, accountability and inclusion. *Wkly Epidemiol Rec*. 2016; **91(35)**:405-20.
10. Tabah E, Nsagha D, Bissek A, Njamnshi T, Njih I, Pluschke G *et al*. Community knowledge, perceptions and attitudes regarding leprosy in rural Cameroon: The case of Ekondotiti and Mbonge health districts in the South-west Region. *PLoS Negl Trop Dis*. 2018;**12(2)**:e0006233.
11. Barrett R. Health-Related Stigma and Discrimination. *International Encyclopedia of Public Health*. 2008;269-272.
12. Weiss MG, Ramakrishna J, Somma D. Health-related stigma: rethinking concepts and interventions. *Psychol Health Med*. 2006;**11(3)**:277-87.
13. Weiss MG. Stigma and the social burden of neglected tropical diseases. *PLoS Negl Trop Dis*. 2008;**2(5)**:e237.
14. Brohan E, Slade M, Clement S, Thornicroft G. Experiences of mental illness stigma, prejudice and discrimination: a review of measures. *BMC Health Serv Res*. 2010; **10**:80.
15. Earnshaw VA, Chaudoir SR. From conceptualizing to measuring HIV stigma: a review of HIV stigma mechanism measures. *AIDS Behav*. 2009;**13(6)**:1160-77.
16. Sermrittirong S, Van Brakel WH. Stigma in leprosy: concepts, causes and determinants. *Lepr Rev*. 2014;**85(1)**:36-47.
17. Hofstraat K, van Brakel WH. Social stigma towards neglected tropical diseases: a systematic review. *Int Health*. 2016;**8**:i53-70.
18. Singh R, Singh B, Mahato S. Community knowledge, attitude, and perceived stigma of leprosy amongst community members living in Dhanusha and Parsa districts of Southern Central Nepal. *PLoS Negl Trop Dis*. 2019;**13(1)**:e0007075.
19. van Brakel WH, Sihombing B, Djarir H, Beise K, Kusumawardhani L, Yulihane R, *et al*. Disability in people affected by leprosy: the role of impairment, activity, social participation, stigma and discrimination. *Glob Health Action*. 2012;5.
20. Adhikari B, Kaehler N, Raut S, Gyanwali K, Chapman RS. Stigma in Leprosy: A Qualitative Study of Leprosy Affected Patients at Green Pastures Hospital, Western Region of Nepal. *J Health Res* [Internet]. 1 [cited 2020July.7];**27(5)**:295-00. Available from: https://he01.tci-thaijo.org/index.php/jhealthres/article/view/88694
21. Dako-Gyeke M. Courtesy stigma: A concealed consternation among caregivers of people affected by leprosy. *Soc Sci Med*. 2018;**196**:190-6.
22. Jung SH, Han HW, Koh H, Yu SY, Nawa N, Morita A, *et al*. Patients help other patients: Qualitative study on a longstanding community cooperative to tackle leprosy in India. *PLoS Negl Trop Dis*. 2020; **14(1)**:e0008016.
23. Marahatta SB, Amatya R, Adhikari S, Giri D, Lama S, Kaehler N, *et al*. Perceived stigma of leprosy among community members and health care providers in Lalitpur district of Nepal: A qualitative study. *PLoS One*. 2018;**13(12)**:e0209676.
24. van 't Noordende AT, Korfage IJ, Lisam S, Arif MA, Kumar A, van Brakel WH. The role of perceptions and knowledge of leprosy in the elimination of leprosy: A baseline study in Fatehpur district, northern India. *PLoS Negl Trop Dis*. 2019; **13(4)**:e0007302.

25. Peters RM, Dadun, Zweekhorst MB, Bunders JF, Irwanto, van Brakel WH. A Cluster-Randomized Controlled Intervention Study to Assess the Effect of a Contact Intervention in Reducing Leprosy-Related Stigma in Indonesia. *PLoS Negl Trop Dis*. 2015;**9(10)**:e0004003.
26. Lusli M, Peters R, van Brakel W, Zweekhorst M, Iancu S, Bunders J, *et al*. The Impact of a Rights-Based Counselling Intervention to Reduce Stigma in People Affected by Leprosy in Indonesia. *PLoS Negl Trop Dis*. 2016;**10(12)**:e0005088.
27. Adhikari B, Kaehler N, Chapman RS, Raut S, Roche P. Factors affecting perceived stigma in leprosy affected persons in western Nepal. *PLoS Negl Trop Dis*. 2014; **8(6)**:e2940.
28. Dako-Gyeke M, Asampong E, Oduro R. Stigmatisation and discrimination: Experiences of people affected by leprosy in Southern Ghana. *Lepr Rev*. 2017;**88(1)**:58-74.
29. Goncalves M, Prado M, Silva SSD, Santos KDS, Araujo PN, Fortuna CM. Work and leprosy: women in their pains, struggles and toils. *Rev Bras Enferm*. 2018;**71(suppl 1)**:660-7.
30. Garbin CA, Garbin AJ, Carloni ME, Rovida TA, Martins RJ. The stigma and prejudice of leprosy: influence on the human condition. *Rev Soc Bras Med Trop*. 2015;**48(2)**:194-201.
31. Lusli M, Zweekhorst MB, Miranda-Galarza B, Peters RM, Cummings S, Seda FS, *et al*. Dealing with stigma: experiences of persons affected by disabilities and leprosy. *Biomed Res Int*. 2015;**2015**:261329.
32. van 't Noordende AT, Aycheh MW, Schippers A. The impact of leprosy, podoconiosis and lymphatic filariasis on family quality of life: A qualitative study in Northwest Ethiopia. *PLoS Negl Trop Dis*. 2020;**14(3)**:e0008173.
33. de Stigter DH, de Geus L, Heynders ML. Leprosy: between acceptance and segregation. Community behaviour towards persons affected by leprosy in eastern Nepal. *Lepr Rev*. 2000;**71(4)**:492-8.
34. Seshadri D, Khaitan BK, Khanna N, Sagar R. The tangled web: a study of knowledge and attitude towards leprosy from a tertiary care hospital in India. *Indian J Lepr*. 2014;**86(2)**:27-41.
35. Lustosa AA, Nogueira LT, Pedrosa JI, Teles JB, Campelo V. The impact of leprosy on health-related quality of life. *Rev Soc Bras Med Trop*. 2011;**44(5)**:621-6.
36. Brouwers C, Van Brakel W, Cornielje H, Pokhrel P, Dhakal K, Banstola N. Quality of Life, Perceived Stigma, Activity and Participation of People with Leprosy-Related Disabilities in South-East Nepal. *Disability, CBR & Inclusive Development*. 2011;**22(1)**:16.
37. Crocker J, Cornwell B, Major B. The stigma of overweight: affective consequences of attributional ambiguity. *J Pers Soc Psychol*. 1993;**64(1)**:60-70.
38. Adhikari B, Shrestha K, Kaehler N, Raut S, Chapman RS. Community attitudes towards leprosy affected persons in Pokhara municipality of western Nepal. *J Nepal Health Res Counc*. 2013;**11(25)**:264-8.
39. Kaur H, Gandhi A. People's perception of leprosy--a study in Delhi. *Indian J Lepr*. 2003;**75(1)**:37-46.
40. John AS, Rao PS. Awareness and attitudes towards leprosy in urban slums of Kolkata, India. *Indian J Lepr*. 2009;**81(3)**:135-40.
41. Grewal I, Negi Y, Kishore J, Adhish SV. Knowledge and attitude about leprosy in Delhi in post elimination phase. *Indian J Lepr*. 2013;**85(3)**:123-7.
42. Mankar MJ, Joshi SM, Velankar DH, Mhatre RK, Nalgundwar AN. A Comparative Study of the Quality of Life, Knowledge, Attitude and Belief About Leprosy Disease Among Leprosy Patients and Community Members in Shantivan Leprosy Rehabilitation centre, Nere, Maharashtra, India. *J Glob Infect Dis*. 2011; **3(4)**:378-82.
43. Ibikunle P, Nwokeji S. Assessment of stigma among people living with Hansens disease in south-east Nigeria. *Leprosy Review*. 2017;**88(1)**:43-57
44. Ebenso B, Newell J, Emmel N, Adeyemi G, Ola B. Changing stigmatisation of leprosy: an exploratory, qualitative life course study in Western Nigeria. *BMJ Global Health*. 2019;**4(2)**:e001250.
45. Sottie CA, Darkey J. Living with stigma: Voices from the Cured Lepers' village in Ghana. *Soc Work Health Care*. 2019; **58(2)**:151-65.
46. De Groot R, Van Brakel WH, De Vries HJ. Social implications of leprosy in the Netherlands--stigma among ex-leprosy patients in a non-endemic setting. *Lepr Rev*. 2011;**82(2)**:168-77.

47. Barrett R. Self-mortification and the stigma of leprosy in northern India. *Med Anthropol Q*. 2005;**19(2)**:216-30.
48. Nishida M, Nakamura Y, Aosaki N. Prevalence and characteristics of depression in a Japanese leprosarium from the viewpoints of social stigmas and ageing. A preliminary report. *Lepr Rev*. 2006; **77(3)**:203-9.
49. van 't Noordende A, van Brakel W, Banstola N, Dhakal K. The Impact of Leprosy on Marital Relationships and Sexual Health among Married Women in Eastern Nepal. *J Trop Med*. 2016;**2016**:1-9.
50. Briden A, Maguire E. An assessment of knowledge and attitudes towards amongst leprosy/Hansen's disease workers in Guyana. *Lepr Rev*. 2003;**74(2)**:154-62.
51. Rafferty J. Curing the stigma of leprosy. *Lepr Rev*. 2005;**76(2)**:119-26.
52. van Brakel WH. Measuring health-related stigma--a literature review. *Psychol Health Med*. 2006;**11(3)**:307-34.
53. Litt E, Baker MC, Molyneux D. Neglected tropical diseases and mental health: a perspective on comorbidity. *Trends Parasitol*. 2012;**28(5)**:195-201.
54. Dako-Gyeke M, Dako-Gyeke P, Asampong E. Experiences of stigmatization and discrimination in accessing health services: voices of persons living with HIV in Ghana. *Soc Work Health Care*. 2015;**54(3)**:269-85.
55. Scott J. The psychosocial needs of leprosy patients. Lep Rev. 2000;**71(4)**:486-91.
56. John AS, Rao PS, Kundu R, Raju MS. Leprosy among adolescents in Kolkata, India. *Indian J Lepr*. 2005;**77(3)**:247-53.
57. Muthuvel T, Govindarajulu S, Isaakidis P, Shewade HD, Rokade V, Singh R, *et al*. "I Wasted 3 Years, Thinking It's Not a Problem": Patient and Health System Delays in Diagnosis of Leprosy in India: A Mixed-Methods Study. *PLoS Negl Trop Dis*. 2017; **11(1)**:e0005192
58. Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group. Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. *PLoS Med*. 2009:**6(7)**:e1000097. doi:10.1371/journal.pmed1000097.