

## Stigma in leprosy: concepts, causes and determinants

SILATHAM SERMRITTIRONG\* &  
WIM H. VAN BRAKEL\*\*,\*\*\*

\**Raj Pracha Samasai Institute (RPSI), Department of  
Disease Control, Nonthaburi, Thailand*

\*\**Athena Institute, VU University, Amsterdam, Netherlands*

\*\*\**Netherlands Leprosy Relief, Amsterdam, Netherlands*

Accepted for publication 25 February 2014

### *Summary*

*Background:* Leprosy is a chronic infectious disease that has stigmatised people affected since ancient times until now. This has resulted in difficulties in the lives of those affected.

*Purpose:* This literature review was conducted to understand the concept, causes, and determinants of stigma in leprosy.

*Method:* Electronic searches were undertaken using PubMed (Medline), CINAHL and PsycInfo databases. The internet was searched through Google Scholar for papers not found in these databases. The main inclusion criteria were papers related to stigma or leprosy written in Thai or English.

*Results:* After searching the databases, 84 papers were identified, 3 were removed because of duplication and parallel publication, and 20 were removed on abstract screening. After reading 61 full papers, 7 were excluded. Finally, 54 were included in this review. It was found that the concept of stigma involves not only characteristics considered undesirable, but also the social context of the individual or group. Reported causes and determinants of stigma related to leprosy are the external manifestations of the disease, cultural and religious beliefs, fear of transmission, association with people considered inferior and public health-related interventions.

*Conclusion:* Stigma is a complex phenomenon that has multiple causes, often linked to the cultural context in which it occurs. Despite this, many similarities were found in leprosy-related stigma across countries and cultures, which would facilitate the development of interventions.

## Introduction

Infectious diseases can be grouped into two categories, acute and chronic. Chronic diseases often result in long-term physical and social effects. Leprosy is a chronic disease which can be traced back thousands of years. It was described in an Egyptian Papyrus document written around 1550 B.C.<sup>1</sup> Indian writings around 600 B.C. describe a disease that resembles leprosy. It is believed that leprosy was brought to Europe by the army of Alexander the Great after coming back from India.<sup>1</sup> At that time, neither the biological cause nor treatment of the disease was known. Thus leprosy patients developed severe skin conditions and disabilities that terrified people. It was believed that leprosy is caused by a curse or caused by sin.<sup>2-5</sup> This belief has been widespread until the present day as shown in the studies of Alubo in Nigeria, Burathoki in Nepal and Idawani in Indonesia. They showed that communities perceived leprosy as a disease from God, the will of God or as a punishment by God.<sup>2,3,6</sup> As a prominent social effect, stigma plays an important role in the lives of people affected and their families. Leprosy has been used as an excuse to segregate diagnosed individuals into colonies or leprosaria.<sup>7</sup>

At present, *Mycobacterium leprae*, which was discovered by Gerhard Henrik Armauer Hansen of Norway in 1873, is widely known as the cause of leprosy. Effective, relatively short-duration treatment is available nowadays in the form of multidrug therapy (MDT).<sup>1,8</sup> However, the stigma attached to leprosy still persists in most countries.<sup>6,9-11</sup>

Stigma is a serious obstacle to case finding and to the effectiveness of treatment, which are the major concern of disease control programs.<sup>2,3,6,10,12-15</sup> Many attempts have been made to reduce the stigma attached to leprosy. For instance, leprosy services have been integrated into the general health care system to reduce the differences between people affected by leprosy and those suffering from other health conditions. Alternative terms have been used instead of 'leprosy', such as 'numbing skin disease' or 'Hansen's disease'.<sup>16,17</sup> A large budget has been used in the effort to reduce stigma through information dissemination. Although it has been shown that this approach may help to address fear and consequent discrimination related to the biological realities of leprosy, it is unlikely to affect the rejection and alienation due to the attribution of blame.<sup>18</sup>

In Thailand, leprosy-affected people are still stigmatised by health providers and by their neighbours.<sup>19</sup> Some leprosy patients have been shunned and refused treatment of their ulcers by nurse aids, resulting in delay in diagnosis and poor compliance to treatment in many of them.<sup>11</sup> Before applying for certain types of work, an applicant needs confirmation from a doctor that he/she does not have leprosy.<sup>20</sup>

Most stigma reduction programmes have been applied in a blanket fashion, which contradicts the reality that the characteristics of stigma, in particular the determinants, may be different in one society from those in others. It was recommended by Dijker and Kooman that interventions aiming to reduce stigma should be tailored to the type of condition, type of society and type of individuals involved.<sup>21</sup> This is because these factors determine the major motivational systems that affect people's responses to perceived deviance. Gussow and Tracy suggested that it is also essential to understand the social history, current cultural meaning and the 'world-view' of the people involved.<sup>22</sup>

To provide information needed for health personnel and other professionals who wish to know more or to develop any stigma-related empirical research, this systematic review aims to make an inventory of what is currently known about the causes and determinants of stigma related to leprosy in different societies. We use the conceptualisations of stigma by Goffman and Link and Phelan as a frame of reference.<sup>23,24</sup>

## Methods

Electronic searches were undertaken using PubMed (Medline), CINAHL and PsycInfo databases with the search term ‘leprosy AND (discrimination or stigma or causes or beliefs)’. The internet was searched through Google Scholar for papers not published in these databases. Draft reports and instruments were retrieved from collaborating partners of the International Consortium for Research and Action against health-related Stigma (ICRAAS). Hand searching was also done for unpublished literature, newspapers, theses, conference proceedings and reports. Studies included were those written in Thai or English; related to stigma or leprosy; and using qualitative, quantitative, or mixed methods.

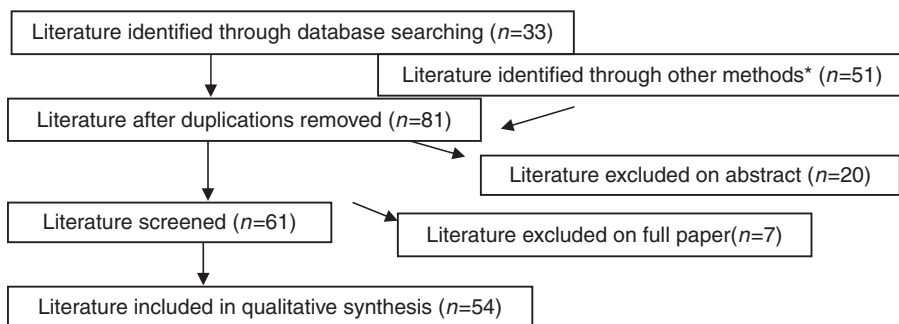
## Results

Figure 1 shows the process and numbers of publications identified, screened and eventually included in the review.

During the database searches, 84 papers were identified, 3 were removed because of duplication or parallel publication, and 20 were removed on abstract reading (not relevant). After reading 61 full papers, 7 were excluded as not relevant and only 54 were included in this review. Those included were papers written between 1963 and 2013. The findings are presented in narrative form under two main theme headings. The ‘concept of stigma’ is presented first, followed by ‘causes of determinants’.

### The concept of stigma

*Stigma* is a Greek word that in its origins referred to a kind of tattoo mark that was cut or burned into the skin of criminals, slaves or traitors, to visibly identify them as blemished or morally polluted people.<sup>25</sup> These individuals were to be avoided, particularly in public places. The word was later applied to other personal attributes that are considered shameful or discrediting. In relation to health, stigma was defined by Erving Goffman as an attribute that signifies that an individual is different from ‘normal’ people and, further, that the person is ‘of a less desirable kind—in the extreme, a person who is bad, or dangerous or weak.’<sup>23</sup>



**Figure 1.** Flow diagram of identified literature through database searching. \*Hand searching and searching through Google Scholar.

To increase the understanding of his definition, Goffman proposed three categories of attributes that are discrediting. They are 'abominations of the body' or stigma of physical disfigurement; 'aberrations of individual character' and/or personality, such as mental disorder, imprisonment, unemployment; and the 'tribal stigma' of race, nation and religion.

Goffman's definition has been cited by many investigators; however, it has not remained unopposed. Since studies in stigma have been carried out by different professionals in different circumstances, many definitions have been proposed as alternatives to or as an elaboration of Goffman's definition. Jones *et al.* defined stigma as "a mark or attribute that links a person to undesirable characteristics or stereotypes".<sup>26</sup> This definition implies that one group sees the other as abnormal. It introduces the concept of 'them and us'. Stafford and Scott proposed that stigma is "a characteristic of a person that is contrary to a norm of a social group or unit".<sup>27</sup> They defined 'norm' as a "shared belief that a person ought to behave in a certain way at a certain time". Crocker *et al.* said that "stigmatized individuals possess or are believed to possess some attributes or characteristics that convey a social identity that is devalued in a particular social context".<sup>28</sup> Link and Phelan referred to stigma as "a dynamic process that is linked to competition for power and tied into existing social mechanisms of exclusion and dominance".<sup>24</sup> Parker and Aggleton defined stigma as "a social process that involves identifying and using difference between groups of people to create and legitimise social hierarchies and inequalities".<sup>29</sup> Castro commented that stigma is "a result of structural violence perpetrated by the larger social forces that are rooted in historical and economic processes".<sup>30</sup> Jacoby pointed out that stigma is "a label associating a person to a set of unwanted characteristics that form a stereotype".<sup>31</sup>

Weiss and Ramakrishna defined stigma as "a social process or related personal experience characterized by exclusion, rejection, blame, or devaluation that results from experience or reasonable anticipation of an adverse social judgment about a person or group identified with a particular problem".<sup>10</sup> It is interesting to note that, while Goffman's definition focuses on individual attributes, the definitions created in the later years, such as those of Link and Phelan, Parker and Aggleton, Castro, and Weiss and Ramakrishna, focus more on the societal context. Link and Phelan further expanded the nexus between an attribute and a stereotype identified by Goffman with a wider set of meanings for the term.<sup>24</sup> They stated: ". . . stigma exists when the following interrelated components converge. In the first component, people distinguish and label human differences. In the second, dominant cultural beliefs link labelled persons to undesirable characteristics and negative stereotypes. In the third, labelled persons are placed in distinct categories so as to accomplish some degree of separation of 'us' from 'them'. In the fourth, labelled persons experience status loss and discrimination that lead to unequal outcomes".

Although their definition of stigma did not include societal issues, Stafford and Scott elaborated that society could create negative stereotypes to preserve the social structure or to permit exploitation of a group or its resource.<sup>27</sup> They also pointed out that social inequality dramatically influences the process of stigmatisation of certain individuals or groups. Those who have control in a society have the power to impose their norms, values and beliefs, including cultural meaning of an attribute and the stigma attached to it, on people who are powerless. This fits well with the views of Link and Phelan, and Parker and Aggleton with regard to the role of 'social power' in the process of stigma and discrimination. The suggestions of Stanford and Scott are also supported by the studies of Waxler, who reported that, because of racial prejudice and the perceived economic threat from the Chinese labourers among Hawaiians and others, the Chinese labourers employed in Hawaii were blamed for introducing leprosy into the country.<sup>32</sup>

It can be concluded that the current literature views stigma not as depending only on an undesirable characteristic of individual or group, but as constructed by the social context to which that individual or group belongs.

## CAUSES AND DETERMINANTS OF STIGMA IN LEPROSY

### EXTERNAL MANIFESTATIONS

At an early stage, leprosy may manifest itself only in mild skin lesions, but if left untreated, these lesions can become much more noticeable. At the same time, nerves may be damaged leading to impairments of eyes, hands and feet. Even while being treated, leprosy-affected people may have various skin conditions due to immunological reactions that may occur before, during or after treatment. These external manifestations are among the main reported causes of stigma.<sup>11,33</sup>

A case of a Polish immigrant who was diagnosed with leprosy in 1947 on English soil may well illustrate this statement. He was described as 'having an early leonine countenance' which would clearly mark him as different from the rest of society. This appearance evoked strong public reaction with street riots and questions in Parliament about him. He was then detained in the hospital against his will. In the present day, it has been reported that an unpleasant appearance still stigmatises people suffering from leprosy.<sup>6</sup> A study conducted in Indonesia between 1997 and 1999 reported that a negative reaction by the community towards leprosy patients depends mainly on the visibility of symptoms.<sup>6</sup> If the disease is still at early stage, without persistent visible patches or impairments, patients usually manage to hide their leprosy and there will be no stigmatising reactions from the others.<sup>6</sup> The results of two studies in Nepal in 1998 and 1999 support the findings of Idawani in Indonesia.<sup>3,35</sup> The first reported that community members discriminated most openly against leprosy patients with persistent visible symptoms and impairments, whereas the second recorded that those with leprosy-related impairments were more likely to experience negative community actions than those with the same disease without such signs. A recent study done by Rensen in India also found that people affected by leprosy who had visible signs suffered greater participation restriction than those who had not.<sup>36</sup>

Three studies in Thailand also yielded similar results as those in Indonesia and Nepal. Leeraphan found that visibility of deformity was positively correlated with the level of stigmatisation by the community.<sup>37</sup> Some patients perceived rejection from their families and voluntarily left their homes for treatment in hospitals or colonies. After treatment, the ex-patients with visible deformities faced difficulty in adapting when they were back in their home situation. This result is supported by the two studies from Thailand conducted by Predaswat and Poopook, which both reported that the most important attributes eliciting repulsion were the blood and puss from open wounds, and the disfigurement of the hands and feet.<sup>11,33</sup> They also recorded that even people with disability related to other health conditions and leprosy patients without disability, reportedly loathed people who had a leprosy-related disability.

In addition to these external manifestations, it was reported that some people with leprosy may have a distinctive odour caused by infected ulcers. This smell can be nauseating and was made worse in cases in which their communities did not allow people with leprosy to wash in communal water, as described in a report from Madhya Pradesh, India.<sup>14</sup> As well as making them outcasts, Predaswat and Poopook mentioned that bad odour can affect the patients' sense of worth and dignity.<sup>11,33</sup>

## RELIGIOUS AND CULTURAL BELIEFS

It was reported by different authors that since ancient times, leprosy has been interpreted as God's punishment of the sinful.<sup>3-5:38-40</sup> The Bible, particularly the book of Leviticus chapter 13, is usually quoted in that context. Leprosy may have been used as a metaphor for sin. 'Leprosy is like sin in many ways. There are some good reasons why many ancient rabbis considered a leper as someone already dead. Leprosy is like sin in that: it begins as nothing, it is painless in its first stages, it grows slowly, it often remits for a while and then returns, it numbs the senses - one cannot feel in the afflicted area, it causes decay and deformity, it gives a person a repulsive appearance.'<sup>38</sup> Guzik commented that 'These precautions were taken not merely for sanitary reasons, or to guard against contagion, for it is not certain that leprosy was contagious, but in order that the people might be taught through the parable of leprosy, what a fearful and loathsome thing sin is in the sight of God.'<sup>41</sup>

Volinn noted, however, that this particular stigma is not limited to Judeo-Christian religious traditions.<sup>39</sup> Entwistle describes how a belief which originated in Iran was transmitted to India. People afflicted with leprosy were considered to be sinners against the sun. Bathing in specified places like Suryakunds in Mathura was assumed to have healing power.<sup>40</sup> According to Try and Brown, Hindus believe that impairments resulting from leprosy are a result of misdeeds in a previous life that caused bad karma, or a divine punishment, and the Chinese believed that leprosy was sexually transmitted by contact with a prostitute, and therefore a punishment for immoral behaviour.<sup>4,5</sup> Try reported from a study in Nepal that communities held the belief that leprosy was a punishment from the gods for sins committed by patients or their relatives in present or previous lives.<sup>5</sup> According to Burathoki, this is usually attributed to failure to respect the gods by making appropriate offerings or by serious violations of social norms.<sup>3</sup> Predaswat recorded that, according to Buddhist belief, leprosy is a disease considered to be contagious and incurable.<sup>11</sup> A man with leprosy was not allowed to enter the monkhood because he was assumed to have a bodily disfigurement. The illness disqualified him from becoming a monk, a position regarded with high respect by the people. It was assumed that allowing a person with leprosy to join the monkhood would spread the disease to other monks. Predaswat reported that according to Buddhist doctrine, a person with leprosy suffers from the disease as a result of sinful acts committed during the previous life and is thus viewed as sinful and immoral.<sup>11</sup>

According to Gussow and Tracy, researchers ascribed stigma to religious beliefs that regard the disease as a punishment for sin, or to the massive involvement of Christian missionaries in the treatment of leprosy patients, which led to a perception of a disease so terrible that only God's servants are capable of tending to those affected by it.<sup>22</sup> However, Navon had a different view. Her study in Thailand reported that Buddhism did not assign a unique status to leprosy.<sup>42</sup> Although Buddhism officially forbade males affected by leprosy from fulfilling their traditional duty of joining the monastic order for a period 3 months, it was revealed that this prohibition was not strictly enforced and had no adverse effects on the image of the disease.

Other causes of leprosy which people have been reported to traditionally believe are witchcraft, a curse, trespassing of food taboos, contagion, and being hereditary.<sup>4,6,33,35</sup> Idawani mentioned that these beliefs tend to marginalise patients socially and bring shame upon them.<sup>6</sup> A study in Nigeria elaborated the belief that some think leprosy was inherited and that people with the same bloodline were more vulnerable to the disease.<sup>2</sup> People with different blood were therefore considered to have no risk. The same study also recorded that

this belief was also present among trained leprosy workers. One leprosy worker said that he was not afraid of contact with the disease as his blood was strong and the disease did not occur in his family. In Thailand, it was also reported that leprosy was thought to be hereditary, because the community often saw many cases of leprosy in one family. Villagers were thus proscribed from allowing their children to marry people with leprosy.<sup>11</sup> In the same country, many people with leprosy related disability were sent to a leprosy colony by their families as they were thought to be cursed and deserved social segregation.<sup>43</sup>

People believed that leprosy is not curable because of its persisting external manifestations. The studies in Thailand and Nigeria provide evidence to support this claim. They reported that patients with deformities were not perceived as cured, because their lost fingers and toes could not be restored. Nor was a patient considered cured who had any other symptoms such as a reaction or pain.<sup>2,11</sup> Alubo recorded that there was a general belief that for people with deformity, the symptoms will appear periodically during the hot season when the heat would make the disease flare up.<sup>2</sup>

#### FEAR

The fear of transmission is evidently one of the main reported causes of concern for people in a community.<sup>5</sup> This fear is enhanced by the visible signs that make people want keep a safe distance and especially take care that their children, considered most vulnerable to infectious, stay away from a 'patient'.<sup>2,15</sup> Fear has also been reported to be based on prevailing inaccurate beliefs. In Brazil, traditional notions that leprosy is an incurable, disabling and highly infectious disease widely prevail and lead to unnecessary fears and stigmatisation of patients.<sup>15</sup> Villagers in Thailand believed that once the person with leprosy was deformed, there was no cure and that the patient cannot return to a normal state.<sup>11</sup> In Nepal it was commonly believed that touch or close contact was the main cause of transmission.<sup>3,5</sup> In the same country, people also believed that transmission could occur through food, water, air, faeces, and patients' excreta, such as urine, sweat, pus from ulcers, semen, and vaginal fluid.<sup>3,5</sup>

However, the results of two studies from Thailand show that fear of transmission is not always the main cause of stigma.<sup>11,42</sup> Predaswat commented that leprosy was seen as a loathsome disease rather than a contagious disease because people in advanced stages of leprosy were characterised by bodily disfigurement, ulceration, excessive sweat, and bad odour.<sup>11</sup> Seclusion was voluntarily practiced by leprosy patients who were in such an advanced stage, because of the shame and fear of being repulsive. Navon recorded that fear of contagion did not arouse stigma against leprosy, since the Thai public considered it to be hereditary.<sup>42</sup> Furthermore, in the past, Thailand was still plagued by a number of epidemics even more terrifying than leprosy, such as malaria, smallpox, bubonic plague, and cholera, all of which took a heavy toll of the population.

#### ASSOCIATION WITH 'INFERIOR PEOPLE'

Seng recorded that in the past, leprosy was associated with people considered lower than others in all aspects.<sup>44</sup> During the Western colonial era in the nineteenth century, fears evoked by the high prevalence of leprosy among colonised populations gave rise to racist views that linked the disease with people perceived to the 'morally inferior'.<sup>44</sup> For example, the British colonial regime associated the Chinese working class with filth and social danger. Leprosy was viewed as an essentially Chinese problem brought into Singapore by migrants who

showed no visible signs of the illness and avoided detection at the point of disembarkation. This phenomenon was confirmed by Waxler, who reported that during the same era, to make a convenient excuse for excluding economic competitors and to confirm the Westerner's sense of superiority, Chinese migrants were blamed for importing leprosy to Hawaii and the Western United States.<sup>32</sup>

In her study in Thailand, Navon supported the view that being associated with inferior people contributed to leprosy stigmatisation.<sup>42</sup> She mentioned that in the past, when people affected by leprosy had disability, they did not have much choice to earn a living. Those who had supporting relatives lived separately nearby their families' home, while those who did not, earned their income as beggars, the most disgraced people in Thai society. However, Waxler argued that the association of leprosy with begging does not always cause stigma. For instance, begging in Nigeria is accepted and is not regarded as a stigmatised role among Muslims.<sup>32</sup>

Even nowadays, in a low-endemic situation and while effective treatment is available, this association still exists. People affected by leprosy are often poor, out of work, uneducated, or of a lower social class.<sup>45</sup> Some of them still earn a living as beggars. Nowadays, there is evidence that Thai people still use the terms – *khi ruan* and *khi thut*, which translate as 'leprosy' and 'leprosy with disability' – to degrade another person.<sup>46</sup>

#### PUBLIC HEALTH AND RELATED INTERVENTIONS

A different perspective holds that stigma is the product of the compulsory segregation of people affected by leprosy, practiced in many countries since the end of the nineteenth century.<sup>42</sup> This segregation policy was recorded as part of the attempt to control leprosy at a time when there was no effective treatment for the disease. Poorman reached the rather far-reaching conclusion that isolation of leprosy patients was introduced by scientists because they perceived leprosy as a threat to the healthy.<sup>47</sup> This while the general population did not tend to fear leprosy in the same way and resisted separation from their diseased family and friends. Eventually, people were taught to fear leprosy through the isolation and the propaganda campaign surrounding it. Later, as scientific knowledge advanced and leprosy was no longer feared among physicians as it once had been, they were unable to eradicate the fear that their predecessors had created, and leprosy remained stigmatized.

After the isolation policy was abandoned due to the availability of effective treatment, leprosy control programmes in most countries changed to promote a policy in which those affected remained in their own communities. This was often done through Information, Education, and Communication (IEC) campaigns. Predaswat reported that some IEC campaigns aroused public fear of leprosy with frightening educational images.<sup>11</sup> She further commented that this kind of intervention may help to encourage suspected cases to self-report early; however, at the same time it may reinforce stigma that was already present in the target area.

Another reported potentially stigmatising activity that is conducted for patients who are living in their own communities is a home visit, which is supposed to be done to follow-up patients who fail to meet an appointment. Visiting the house of leprosy patients may provoke stigma against them, if done carelessly. From her experience in Brazil, White reported feeling that the visits were invasive and capable of generating stigma for the patients her team were visiting.<sup>48</sup> Arriving in an ambulance may have alerted family members or neighbours that the people they were looking for had a health problem that was serious enough for health officials to come for them.



Frist mentioned in the context of promoting human rights, people affected by leprosy were encouraged by related organisations to establish their own associations.<sup>49</sup> Associations of people affected by leprosy are sometimes guilty of producing stigma when they go beyond the fight for justice, equal rights and integration to lobbying for special privileges denied to people with other diseases and to other disability groups.<sup>49</sup> When they do so, they unintentionally reinforce the stigma of leprosy as a separate disease in the mind of the public. Frist also commented that people should be helped because they are poor, handicapped, and/or old and have no other support base; not just because they once had a disease that has long since been cured.

## Discussion

The definition of the word 'stigma' has evolved over time. The definition originally focused on individual attributes that signify that an individual is different from 'normal' people. More recently, the definitions focus more on the societal context of stigma and the social process involved in the generation of stigma.<sup>24,29</sup>

The available evidence shows that stigma related to leprosy is caused by visible manifestations in people affected by leprosy, beliefs regarding causes of the disease and its treatment, fear of transmission, association of those affected with groups of people perceived as 'inferior', and public health measures that treated leprosy differently from other diseases.<sup>2-6,11,15,22,32-40,42-44,47-49</sup> These causal factors may be common or different in different societies or cultural contexts.<sup>32,42,44</sup>

Negative manifestations such as noticeable skin lesions and impairments cause affected people to look different from others. According to Link and Phelan, it is the starting point of stigma: 'people distinguish and label human differences'.<sup>24</sup> It is also one of the three categories of attributes that are discrediting as defined by Goffman.<sup>23</sup> This kind of stigma has not changed much over time as demonstrated by the case of a Polish immigrant who was diagnosed with leprosy in 1947, with visible signs of leprosy that evoked strong public reaction, and by the study of Rensen in 2011 that people affected by leprosy who had visible sign suffered participation restriction greater than those who had not.<sup>34,36</sup> It is common in many cultures or societies, for instance in England, Indonesia, Nepal and India, that individuals who have external manifestations of leprosy are stigmatised.<sup>3,6,11,33-37</sup> Leprosy is not the only disease that results in 'negative' manifestations. Such 'negative' manifestations also stigmatise people affected by other diseases, such as tuberculosis. Dodor recorded that the extreme weight loss seen amongst TB patients, coupled with a persistent cough, and sometimes coughing up blood makes people feel very uncomfortable around TB patients, heightening their fear of the disease.<sup>50</sup> Some TB patients also agreed that the features of the disease make them feel ashamed.

There is evidence from different cultures that leprosy is regarded as a punishment. For instance, among Christians, Hindus and Buddhists, leprosy may be regarded a punishment for sin or misdeed in this or a previous life.<sup>4,5,11,38,39</sup> Some beliefs may gradually change, such as the belief that leprosy is God's punishment for sin, as people begin to understand the biological cause of leprosy. Clearly, however, people may believe in several different causes operating at different levels. But it is a challenge to change the belief that leprosy is incurable as people recognise leprosy by its impairments that cannot be hidden, and the belief that leprosy is hereditary, because people know from experience that leprosy occurs in particular families or groups of people. The belief that leprosy is incurable and hereditary was found in

Thailand and Nigeria by Predaswat and Alubo.<sup>2,11</sup> It is interesting to know that in Nigeria even leprosy workers who are supposed to know leprosy better than others may hold the belief in hereditary. Also in the case of tuberculosis, another ancient disease, people in many cultures believe that TB is God-given as a 'punishment' for 'sins'.<sup>51</sup> In some circumstances, stigmatization arose from individuals' misperceptions of the aetiology of TB. Some people believed that smoking cigarettes, living in unhealthy lifestyle, drinking alcohol and the use of hard drugs such as cocaine, resulted in the development of TB.<sup>50,52</sup> According to Link and Phelan, these beliefs are the second components of stigma, the belief characteristics that link labeled people to undesirable negative stereotypes.<sup>24</sup>

Fear of transmission was considered as one of the main causes of stigma in many countries such as Nigeria and Brazil.<sup>2,5</sup> This is not the case for leprosy in Thailand, because leprosy was seen as hereditary, and a loathsome disease more than a contagious disease.<sup>11,42</sup> For tuberculosis, however, Thailand was similar to other countries in that fear of transmission was one of the main causes of stigma.<sup>50-53</sup>

Leprosy has been linked with 'inferior people' for many years. According to Seng and Waxler, the people in Britain and the United States in the colonial era linked leprosy with Chinese migrants who were regarded as 'inferior'.<sup>32,44</sup> In Asian countries such as Thailand, Navon reported that in the past leprosy was linked with begging, which is considered a disgrace in Thai society. This kind of link is still apparent in that Thai people continue to use the term 'leprosy' to disgrace another person. It is interesting to note the argument of Waxler who found that begging does not cause stigma among Muslims in Nigeria.<sup>32</sup> Empirical evidence will be needed to confirm Waxler's claim. In the authors' experience, even though people may resort to begging, and even though it may fulfil a social role in society, they do not do so voluntarily or as a chosen profession. The linkage between people affected by leprosy and the image of a beggar, the most inferior status of people in societies such as Thailand, fits well with the third component of stigma mentioned by Link and Phelan, namely, 'labeled persons are placed in distinct categories so as to accomplish some degree of separation of us from them'.<sup>24</sup> Government attempts to confine the transmission of leprosy by isolating people affected into leprosy colonies is likely to have helped to complete this separation of 'us' from 'them'. The linkage between tuberculosis patients and HIV/AIDS and between tuberculosis and poverty are also causes of stigma in tuberculosis, since HIV/AIDS and poverty have already been stigmatised by society.<sup>53,54</sup>

Information, Education and Communication (IEC) is the common intervention conducted by most countries to address stigma. However, IEC may result in more stigmatisation, if done carelessly.<sup>11</sup> Posting pictures of impairments related to leprosy to encourage people to get early treatment, and mentioning the transmission of the disease, without mentioning the small chance of being infected and effective drug treatment, may provoke a negative image of leprosy and a fear of transmission among the target population. Leprosy is not the only disease in which stigma may be increased by IEC interventions. IEC interventions in tuberculosis sometimes yield similar unintentional results.<sup>50</sup> Inaccurate health education messages by health professionals were mentioned by the community participants of Dodor's study in Ghana as the basis of their attitudes and behaviours towards TB patients.<sup>50</sup> The message commonly used reminds people to avoid sharing household items with TB patients. This makes people think that the patient should be isolated and his plates separated from those used by the rest of the household.<sup>50</sup>

The causes and determinants of stigma in leprosy fit well with the conceptualisations proposed by renowned stigma researchers such as Goffman, and Link and Phelan.<sup>23,24</sup>

They are similar to those of tuberculosis and may also be similar to those of other health conditions. This review may be used to guide the design of de-stigmatising interventions. A thorough knowledge of the cause(s) and determinants of stigma in a given context can provide important starting points for knowledge-based and interactive interventions such as education and contact between affected people and community groups. The causes and determinants may differ in different societies and cultural contexts. Research to help understand this context is therefore a necessity. Interventions should be tailored-made as much as possible and should take cultural differences into account.

## Acknowledgement

We would like to express our sincere thanks to Ms Jiske Erlings of Infolep, Netherlands Leprosy Relief, who provided valuable help in literature searches. Our thanks also go to Ms Ruth Peters and Ms Sarah Cummings for reading and commenting on the draft manuscript. Without their help, we could not complete this review effectively.

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