

# Stigma Related to Leprosy—A Scientific View

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## Introduction

Leprosy is one of the oldest diseases known to man (see Chapter 11.1). Exclusion from society has been a feature of leprosy from its earliest descriptions onwards (e.g., Numbers 12:10–15, NIV Bible). In the times of the Old Testament, the exclusion was not just a social phenomenon but a divine institution, which served as a public health measure to contain an infectious disease (e.g., Numbers 5:1–3). A provision for re-entry into society also existed if the person was healed of their condition (see Leviticus 14:2–7). Potentially stigmatizing references to leprosy can similarly be found in Hindu and Muslim scriptures.

Social stigma has been a persistent feature of leprosy around the world, including in the U.S. and even countries where leprosy is not, or is no longer, endemic, such as the European countries. Tom Frist wrote a book titled, ‘Don’t treat me like I have leprosy’ (1). This title would be understood in very many languages and cultures, since the name ‘leprosy’ (or its translation in other languages) has become a synonym for exclusion and has even been used as a curse word. This usage has led the U.S. and Brazil to formally ban the term ‘leprosy’ and replace it with ‘Hansen’s disease’.

## PUBLICATIONS ON LEPROSY-RELATED STIGMA

Scientific work on stigma is relatively recent. A search in PubMed conducted on January 5, 2018, found only 220 articles in total addressing leprosy and stigma and/or discrimination. The first scientific paper listed dates back to 1946 (2). There were only 11 publications between 1940 and 1980. The number of publications gradually increased over the next two decades, with 20 between 1980 and 1990, and 25 between 1990 and 2000. In the new millennium, the number of publications has rapidly increased, with 59 between 2000 and 2010 and 105 between 2010 and 2017.

A large majority of the publications consist of reflections on stigma, often through anecdotal evidence, case studies, or descriptive studies. The latter include historical, anthropological, and sociological studies employing qualitative methods as well as research in the realm of public health employing quantitative surveys. The quantitative publications usually rely on knowledge, attitudes, and practice (KAP) questionnaires or, more recently, actual scales that measure aspects of stigma or aspects of life impacted by stigma, such as social participation, depression, or quality of life. There are very few intervention studies other than the only randomized trial on stigma interventions: the Stigma Assessment and Reduction of Impact (SARI) study conducted in Cirebon, Indonesia (3).

## CROSS-CUTTING ASPECTS OF STIGMA

### **Health-related stigma**

Leprosy-related stigma is perhaps the oldest form of disease-related stigma known to man and, along with stigma against persons with mental illness, epilepsy, and, more recently, tuberculosis and HIV, is also the most widespread around the globe. The etiology of stigma may differ among conditions and cultural settings. For example, leprosy is often stigmatized because of the notion that the person affected has committed a sin or broken a taboo, either in this or a previous life. The stigma may also be due to fear of the disfigurements it causes. In contrast, persons with schizophrenia suffer stigma because people perceive them to be unpredictable or dangerous, while persons living with HIV may be stigmatized because of the association with homosexuality and promiscuity or because of AIDS' characterization as a fatal and incurable disease. However, the manifestations and psychosocial consequences of stigma and discrimination are remarkably similar across conditions and cultures (4, 5, 6). The likely reason is that at the core of stigma is a common human response to difference.

Measurement methods and interventions shown to be effective in reducing stigma or mitigating its impact are also very similar across conditions and cultures (4, 7, 8, 9, 10, 11). Because of these similarities, the generic term 'health-related stigma' has been proposed (12). We suggest that the definition and characteristics of health-related stigma also fit with most aspects of leprosy-related stigma.

### Leprosy and other neglected tropical diseases

Leprosy has been classified as one of the neglected tropical diseases (NTD). Although not a typical tropical disease, its association with poverty means that leprosy is particularly prevalent in tropical countries with large population groups living in poverty. Besides the link with poverty and the visible signs of disease, such as skin lesions and chronic wounds, social stigma is another feature that many of the NTDs have in common. A systematic review found published evidence of stigma related to 10 of the NTDs (7). The association between NTDs and poverty may increase the existing stigma due to other factors.

## INTERSECTIONALITY OF STIGMA

Intersectionality is an approach to analyzing social relations that is concerned with inequalities that are played out and sustained when certain attributes operate simultaneously in a given context (13). For example, women with a low socioeconomic status are likely to have a different experience of stigma than men with a high socioeconomic status, even in the same area. The concept of intersectionality is particularly useful when addressing (leprosy-related) stigma, since it takes into account overlapping stigma conditions that might unfold in a given context, affecting persons differently. Discrimination due to racial identity, ethnic background, caste, documentation status, age, social class, or gender may also be operating in a given area.

### Racism and Xenophobia

Several studies on the history of leprosy provide evidence of racism and xenophobia. For example, studies have identified racism and xenophobia underlying discussions about migratory laws during The First Leprosy Conference in Berlin (14) and scientific investments in research on “Indian leprosy” (15). The building of isolated leprosy settlements to protect the race from the “scourge” (16) and the isolation of healthy children from leprosy-affected parents for eugenic reasons (17) and public policy (18) reflect similar biases.

### Gender

Other studies have addressed gender differences in leprosy-affected communities. Dijkstra et al. (19) reviewed evidence-based studies on leprosy stigma and gender, concluding that, of 18 papers, 12 indicated that women suffered additional stress in various aspects of life than men. Dijkstra et al. were interested in studies that produced data for both genders in order to assess possible inequities. Some of these factors affected the course of treatment. In Bahia, Brazil, Souza et al. (20) evaluated Hansen’s disease indicators over a 14-year period in terms of gender differences and noticed that males dropped out of treatment more frequently than females. Possibly this attrition was due to an interaction of stigma and gender, affecting men differently.

## Class and Social Status

Class and social status have also been shown to influence the treatment of people with leprosy. Staples, for instance, describes the effect of caste on people's responses to those affected with leprosy in India, and how, as a consequence, their lives take shape (21). In Nepal, Heijnders showed that, for some people who have a higher social status, the impact of stigma was less than for those of a lower status (22). Likewise, in Sierra Leone, persons in positions of authority who were affected by leprosy managed to retain their positions (23). Also, the work of White on migration in the U.S. is relevant in this context (24, 25). She suggests viewing stigma "as a fluid and multilayered phenomenon" and calls for a deeper look "at individual incidents that are understood as stigmatizing and at the narratives of those affected by the disease to determine what factors are working to complicate people's lives or to deepen an individual's social and economic exclusion" (25).

The consideration of intersectionalities in leprosy stigma research will help explain more accurately the various ways in which different groups are affected. Moreover, it may clarify interactions with other confounding stigmatizing conditions such as not being able to provide for one's family, belonging to a certain caste in India, or living in a certain stigmatized community, as Staples points out in his keen editorial on leprosy stigma (26). Dijkstra et al. (19) call for studies that "disaggregate data by gender", which will provide information that may contribute to gender-specific policies, approaches, and interventions. Gender is a good starting point for integrating an intersectional approach into leprosy stigma research, an approach that may be used for other factors also.

## DEFINITIONS OF STIGMA

Weiss and Ramakrishna have 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 health problem" (27). This definition is used in this chapter, since it emphasizes that stigma is a social process rather than a static phenomenon, as the meaning of the Greek word 'stigma' suggests. The latter characterization is reflected in the Oxford Dictionary definition of stigma as "a mark of disgrace associated with a particular circumstance, quality, or person" (28), for example, through pricking or branding, as was done to slaves to denote ownership. The notion that stigma is a process is more helpful, as it emphasizes the dynamic nature of stigma, highlighting the possibility of reducing or even eradicating stigma completely.

It is also worth noting that many languages do not have a term for 'stigma'. Often, words like 'prejudice' or 'discrimination' are used as synonyms. In the English language, the meanings of 'stigma' and 'prejudice' are similar but not the same—see Phelan et al. for a detailed discussion on the difference (29). In the above definition, discrimination is part of stigma, denoting the enacted or experienced part of stigma. Internalized stigma, often called 'self-stigma', is likely to be

the most common form of stigma in leprosy. Livingston and Boyd (30) have provided a definition of internalized stigma that is also very appropriate for persons affected by leprosy:

A subjective process, embedded within a sociocultural context, which may be characterized by negative feelings (about self), maladaptive behavior, identity transformation or stereotype endorsement resulting from an individual's experiences, perceptions, or anticipation of negative social reaction on the basis of their health condition.

## Etiology

As stated earlier, stigma against leprosy appears to be as old as the disease itself. References to this stigma can be found in the major religious scriptures of the Christian, Hindu, and Muslim faiths, which have contributed to the notion that leprosy was a punishment for sin and the persons affected should be avoided and excluded from the regular community. The latter exclusion may have been a divinely instituted protective public health measure at a time when no treatment or other measures were available, but it nevertheless inspired the belief that leprosy patients should be isolated. In the society of the Middle Ages, at a time when leprosy was highly prevalent in Europe, persons affected by leprosy were considered 'unclean' and were denied all civil rights. A liturgy for a mass existed in which a leprosy patient would be declared 'dead', even though s/he was still alive. Strong stigma against leprosy led to the formation of settlements where people expelled from their homes lived together, supporting each other. In India, the settlements are called 'leprosy colonies'; elsewhere, they are known as 'leprosaria' or 'leprosy villages'. Structural, government-instituted isolation practices fuelled the fear of leprosy and the notion that persons affected should be isolated. Examples include the exile of leprosy patients to Hawaii (Molokai) in the U.S. during the 19<sup>th</sup> century (31, 32), the public health measures that isolated leprosy patients in Norway (33, 34, 35); and the legislated, via the Lepers Act of 1898, isolation of leprosy patients in the British Empire at the end of the 19<sup>th</sup> century (36). The latter led to the exile of patients in South Africa to Robben Island. Similar examples exist in Indonesia, the Philippines, and Japan. Japan was one of the last countries to revoke mandatory isolation of patients, as late as 1996 (37).

By the 20<sup>th</sup> century, a deep-rooted fear of leprosy existed around the world. This fear continues up to the present time. Recent perception studies in India, Indonesia, and Brazil showed that people are afraid of catching leprosy through touch, e.g., shaking hands; ingestion, e.g., eating food prepared by affected persons; or absorption, e.g., sharing eating utensils, water for bathing, clothes, etc. (38, 39, 40, 41). This fear exists even if people do not know that leprosy is caused by bacteria and spread through droplets. The added belief that leprosy, or certain forms of leprosy, are incurable intensifies this fear (41, 42, 43, 44). The notion that leprosy is a divine punishment for sin or a result of 'bad karma' caused by misdeeds in a previous life is still current (45). In the Hindu religion, touching a person with leprosy is believed to cause ritual impurity, which is feared and thus avoided, especially by members of higher castes. In other cultures, such as in Indonesia, the predominant belief is that leprosy is hereditary (41, 46). Thus, people fear familial associa-

tion with affected persons, as that association may affect their offspring ‘for seven generations’ (44). People fear the disabilities that leprosy may cause, in particular, the disfigurements of face, hands, and feet that may affect persons in advanced stages of the disease. Perhaps the strongest fear is that of the social consequences of stigma and discrimination. People are usually aware of the negative attitudes and stereotypes associated with leprosy and of the possible severe repercussions on the social status of the family, marriage, friendships, work, etc.

Other beliefs regarding the cause of leprosy contribute to its stigma. For example, people may believe that leprosy is caused by bad or impure blood, sexual intercourse during menstruation, an unclean environment, immoral conduct, witchcraft, breastfeeding, or eating certain food items (shrimps, chicken) (39, 44, 47, 48). People often believe in multiple explanations, which are not seen as mutually exclusive.

A very practical issue that helps perpetuate the stigma of leprosy is that severely affected former patients can be seen begging in the streets and at places of religious worship in many endemic countries (49, 50, 51). Although begging is often more socially acceptable in these societies, it reinforces the belief that contracting leprosy will lead to ‘dehabilitation and destitution’ and cause a life of beggary (26, 52, 53, 54, 55, 56).

## Manifestations

The International Classification of Functioning, Health and Disability (ICF), published by the World Health Organization (WHO), classifies the consequences of health conditions (57). The conceptual framework of the ICF describes the dynamic interaction of different components of the disablement process. It also shows the interaction of impairments (difficulties at the physical level), activities (of daily living), and social participation with environmental and personal factors, which together produce an experience of disability. Most types of stigma, and the sources of stigma described above, are part of the Environmental factors domain of the ICF. In contrast, most manifestations of stigma occur in the Participation domain (57).

## SOCIAL STATUS AND REPUTATION

Goffman defined stigma as ‘an attribute that is deeply discrediting’ (58), a very apt description of what often happens when people are diagnosed with leprosy. They may lose their status and even part of their identity (59). Goffman referred to this condition as a ‘spoiled identity’. The loss happens most pointedly when the name or position of the person is replaced by the name of the disease, which happens regularly in communities where the level of stigma is high (41). The stigma may extend well beyond the person affected, negatively impacting his/her whole family and other caretakers (60). Thus, persons affected may be excluded from the family to protect its reputation. The same mechanism has been described very clearly by Yang et al. in relation to

mental health conditions in China (61). Not infrequently, affected persons isolate themselves, even to the extent of permanently leaving their own families, to mitigate the potential impact on family members or the marriage prospects of children and siblings (52).

## MARRIAGE AND OTHER RELATIONSHIPS

Leprosy often affects the marriage prospects of the persons affected or, through so-called ‘courtesy stigma’, the marriage prospects of children or siblings, especially in cultures and societies in which arranged marriages are common (46, 62, 63, 64, 65, 66). In studies using the EMIC stigma scale or the Social Distance Scale (SDS), questions about willingness to marry someone affected and likelihood of leprosy affecting marriage prospects are consistently among those receiving the strongest negative endorsement, indicating that these issues are a frequent manifestation of leprosy-related stigma (48, 67, 68, 69). Marital partners may seek divorce due to their partner contracting leprosy (65, 70), or the disease may negatively impact relationships and sexual health within a marriage (43, 65, 71). Spouses affected by leprosy may be denied sexual intercourse and may be required to sleep separately (72). In a study in southern Nepal, verbal and physical abuse of married women affected by leprosy occurred more frequently than abuse of women with other disabilities or community controls (71). In a study conducted in Indonesia on marriage and the sexual health of women affected by leprosy, spouses were much more supportive of their affected wives than those from Nepal, although some negative effects were experienced, such as using separate utensils at home or sleeping separately during treatment (73). Sexual relations were often affected, but sometimes at the instigation of the leprosy-affected wife. A diagnosis of ‘leprosy’ may also be grounds for divorce (41), an action that may still be supported by discriminatory legislation (see [ILEP – Zero Discrimination](#)). Other relationships, such as with friends and neighbors, can also be disturbed, leaving the affected person lonely and isolated (39, 43, 74).

## EDUCATION, WORK AND EMPLOYMENT

Children affected by leprosy, and even children whose parents are affected, have been refused entry into or have dropped out of school (39, 66, 75, 76, 77). In the past, when the prevalence of leprosy was much higher in many countries, separate schools were set up for leprosy-affected children. Even at the present time, special schools and vocational training centers for leprosy-affected persons still exist, e.g., in India.

Difficulties in finding work or in maintaining employment are among the most common manifestations of leprosy-related stigma (4, 64, 66, 67, 74, 78, 79). People may be fired from their jobs, unable to find work, or hired only for menial jobs. Some businessmen and women may lose their customers, because people refuse to buy from persons affected by the disease out of fear of contagion or because items touched by them are considered impure. This issue is particularly true for persons preparing or selling food items for a living (41, 56, 74, 80).

## USE OF PUBLIC PLACES AND FACILITIES

People have also been denied access to places of religious worship, medical care, public transport, restaurants, hotels, etc. (66, 74, 81, 82). Even in recent years, groups of leprosy-affected persons have been refused lodging at hotels in New Delhi, India, and Makassar, Indonesia, with the excuse that their presence might upset other hotel guests (Gopal, personal communication; Yosep, personal communication). Such manifestations of stigma are remarkably similar across different cultures and conditions (4, 64).

## CONCEALMENT

Because of the potentially negative social consequences, leprosy-affected persons very often seek to conceal their status. This concealment may occur before, during, or after the treatment of leprosy as a condition (22, 82, 83, 84). Heijnders (22) described the dynamics in detail, elaborating on the concealment cycle described by Hyland (85). In her study in Eastern Nepal, Heijnders showed that patients try to hide their status from the community, but that the community may also hide the fact that they know the person's leprosy status. A negative response or behavior is usually 'triggered'. Heijnders observed that if, during this 'wait and see' phase, nothing further happens, or if others know that the person is being treated, the process can reverse itself and social integrity may be regained. If, however, "the symptoms remain or become worse, or if the person discontinues his or her treatment, the disease can become publicly labeled and result in public discrimination." Persons affected use different strategies for concealment, such as withdrawal to hide visible signs or telling 'stories' to explain their signs or regular visits to a clinic. It should be noted that concealing one's condition is highly stressful and can lead to anxiety and depression (86, 87, 88).

The tendency of persons affected by leprosy to conceal their disease has very important implications for case finding and post-exposure prophylaxis strategies that rely on the screening and treatment of contacts. Patients are often willing to disclose their status to household and perhaps family members, but are much more reluctant to tell neighbors, social contacts, and others (89). In the recent LPEP project, most contacts in the pilot districts in India, Nepal, Myanmar, Cambodia, and Indonesia were willing to disclose their status to neighbors and often to social contacts as well (90). In Tanzania and Sri Lanka, disclosure was generally limited to household contacts. Contact-based interventions should be managed carefully and full consent from index patients is needed before their contacts are approached, either for screening only or for screening and post-exposure prophylaxis.

## HUMAN RIGHTS VIOLATIONS

Many of the manifestations involve discrimination and can be classified as human rights violations (66). Awareness of the latter has become much more prominent since the UN Convention for the Rights of Persons with Disabilities (CRPD) came into force in 2006. The CRPD applies hu-



man rights to the specific context of persons with disabilities, including persons affected by leprosy. Organizations of persons affected, such as the International Association for Integration, Dignity and Economic Advancement ([IDEA](#)), Movimento de Reintegração das Pessoas Atingidas pela Hanseníase ([Morhan](#)), Ethiopian National Association of Persons Affected by Leprosy ([ENAPAL](#)), and the Association of People Affected by Leprosy India ([APAL](#)), have been fighting for the equal rights of persons affected by leprosy for several decades now.

Stigma reinforces existing inequalities in social class, gender, and age. This reinforcement was confirmed by several researchers who studied the impact of stigma on the lives of persons affected by leprosy (46, 62, 65, 84, 91).

# Impact on Individuals and Their Families

The above manifestations of stigma may have a direct impact on, for example, relationships. However, their impact goes beyond relationships to affect three areas in particular: (1) mental wellbeing, (2) socioeconomic status and livelihood, and (3) quality of life. Beyond the individuals and their families, stigma also impacts leprosy control services and programs and their effectiveness.

## IMPACT ON MENTAL WELLBEING

The psychological impact of the diagnosis 'leprosy' can be severe and may lead to depression and even to suicide or attempted suicide, as documented by many investigators (52, 62, 86, 87, 91, 92, 93, 94, 95, 96). People who have been subjected to stigma for prolonged periods may internalize the negative attitudes (97, 98). Livingston and Boyd (30) defined internalized or self-stigma as a

subjective process, embedded within a socio-cultural context, which may be characterized by negative feelings (about self), maladaptive behaviour, identity transformation or stereotype endorsement resulting from an individual's experiences, perceptions, or anticipation of negative social reaction on the basis of their health condition.

Internalized stigma is perhaps the most widespread form of stigma among persons affected by leprosy. It impacts mental wellbeing, social participation, and quality of life in similar ways as stigma experienced in the form of discrimination (97, 99, 100).

## SOCIOECONOMIC IMPACT

People affected by leprosy often belong to a lower-income section of society. Thus, the work and employment-related manifestations of stigma have a strong economic impact on their livelihoods. In a study in India, a large number of leprosy-affected persons were interviewed, many of whom lost months or years of work time and thus income (101). The lost time may aggravate existing poverty or even drive people into poverty; such 'dehabilitation' may end with begging (50, 51, 52, 56, 102). The effects of stigma may also have an economic impact on the family members and caregivers of the persons affected (60).

## IMPACT ON QUALITY OF LIFE

The manifestations of stigma, and also the psychological and socioeconomic impacts, have been shown to have a significant impact on the quality of life (QoL) of persons affected by the disease. Joseph and Rao (103) demonstrated this impact in South India. Subsequent studies confirmed these findings in other parts of India (104, 105), Bangladesh (87), Nepal (106, 107), Indonesia (3), and Brazil (108, 109). Some studies compared the QoL reported by women and men and found that the level reported by women was significantly lower, confirming that women are disproportionately affected by the consequences of leprosy-related stigma (62, 66, 104). Similarly, persons with leprosy-related disabilities reported a lower quality of life than those without disabilities (87, 103, 106).

## IMPACT ON LEPROSY CONTROL EFFORTS

The perceived stigma and use of concealment as a coping strategy may cause patients to delay treatment, provided they suspect or know they have leprosy (82, 110, 111). Concealment may also result in patients opting to be treated at a distant clinic (83). If the risk of discovery becomes too large, patients may also discontinue treatment, thus resulting in poor adherence (22). Another consequence of leprosy-related stigma is that it is unpopular to work in leprosy services. Hence it is often difficult to attract quality staff members, especially for jobs that require them to spend a substantial proportion of their time on leprosy work.

# How To Measure Stigma

To describe and understand how stigma affects the lives of individuals or to assess whether interventions are effective, it is essential to obtain views from multiple participants using different methods. Stigma can be assessed from two major perspectives: that of the persons affected by the condition and that of the 'sources of stigmatization' (5). The latter may be persons, e.g., community members or health workers, but may also be structures, such as discriminatory laws, poli-

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cies, or practices. This assessment may include qualitative methods and ethnographic approaches, such as participant observations, interviews, and focus group discussions or Photovoice, or quantitative methods, such as knowledge, attitude, and practice questionnaires or scales (112). The main instruments available for assessing leprosy-related stigma or aspects of life directly affected by stigma, such as social participation and quality of life, can be found in Table 1.

**TABLE 1** Instruments used to measure stigma, manifestations of stigma, or impact of stigma

Name of instrument	Target group	Origin and aim	Items and domains	Validity
SARI Stigma Scale (SSS) (113)	Persons affected	The SSS assesses stigma and is based on the HIV Stigma Scale developed by Berger et al.	21 items (score 0–3) and four domains: experienced stigma, disclosure concerns, internalized stigma, and anticipated stigma	Alpha 0.88, ICC 0.75 (95%CI 0.64–0.83), SDCgroup* 1.37; no floor or ceiling effects
EMIC stigma scale affected persons (EMIC-AP) (100)	Persons affected	The EMIC-AP assesses perceived, internalized, and experienced stigma	15 items (score 0–3)	Alpha 0.88, weighted kappa 0.70; no floor or ceiling effects
5-Question Stigma Indicator Affected Persons (5-QSI-AP) (114)  The 5-QSI-AP was incorporated into the WHO Monitoring & Evaluation Guide 2017.	Persons affected	The 5-QSI-AP assesses perceived, internalized, and experienced stigma	5 items (score 0–2)	A first validation was performed in spring 2018
Participation scale (P-scale) (115, 116)	Persons affected	The P-scale assesses participation restrictions and is based on the ‘Participation domain’ of the ICF.	18 items (score 0–5); covers 8 of the 9 participation domains in the ICF	Original study: alpha 0.92, weighted kappa 0.80

TABLE 1 Instruments used to measure stigma, manifestations of stigma, or impact of stigma (cont'd)

Name of instrument	Target group	Origin and aim	Items and domains	Validity
		The P-scale was developed in English and 6 languages in Brazil, India, and Nepal		Nepal: alpha 0.93, ICC 0.90 (95%CI 0.85–0.94), no floor or ceiling effects
Participation Scale Short (PSS) (117, 118)	Persons affected	The PSS is the shortened version of the P-scale developed using a large international database of P-scale data	13 items (score 0–5); covers 7 of the 9 participation domains in the ICF	Alpha 0.85; criterion validity (against P-scale): $r=0.76$ ; sensitivity 0.76 (95%CI 0.56–0.89), specificity 0.93 (0.82–0.98)
WHO-Quality of Life scale abbreviated (WHOQOL-BREF) (119)	Persons affected	The WHOQOL-BREF assesses quality of life	26 items (score 1–5) that measure the following broad domains: physical health, psychological health, social relationships, and environment	This scale has been shown to have adequate validity in many countries in Asia
Social Distance Scale (SDS) (120, 121)	Community members	The SDS assesses social distance between the respondent and a person affected as described in a so-called vignette. Social distance is used as a proxy for attitudes.	7 items with a 4-option 'degree of willingness' scale: 'Definitely willing' (0), 'Probably willing' (1), 'Probably not willing' (2), 'Definitely not willing' (3)	Alpha 0.87, SD-Cgroup* 0.60, ICC 0.75 (95%CI 0.62–0.84); no floor or ceiling effects

**TABLE 1** Instruments used to measure stigma, manifestations of stigma, or impact of stigma (cont'd)

Name of instrument	Target group	Origin and aim	Items and domains	Validity
EMIC Community Stigma Scale (EMIC-CSS) (120)	Community members	The EMIC-CSS measures perceived attitude and behavior of the target group towards persons affected by the stigmatized condition.	13–15 items, with response scales containing 4 options: ‘Yes’ (2), ‘Possibly’ (1), ‘No’ (0) and ‘Don’t know’ (0)	Alpha 0.83, SD-Cgroup* 0.81, ICC 0.84 (95%CI 0.75–0.90); no floor or ceiling effects
5-Question Stigma Indicator Community Stigma (5-QSI-CS) (68)  The 5-QSI-AP was incorporated into the WHO Monitoring & Evaluation Guide 2017.	Community members	The 5-QSI-CS assesses perceived stigma and discrimination	5 items (score 0–2)	Alpha 0.52, weighted kappa 0.65, no floor effect; ceiling effect 22%.

\* SDC = smallest detectable change (in a group)

## Stigma Reduction Interventions

Insights into the wide range of negative effects of stigma on education, employment, marriage, and relationships and the corresponding violations of human rights underscore the fact that interventions for preventing or addressing stigma are essential.

Where stigma is an effect of disease, the treatment of that disease is incomplete if stigma is not addressed. Interventions to address stigma should not be considered optional; they are essential. (59)

Over the last few years, there has been a growing awareness among policy makers, NGOs, health professionals, and researchers of the importance of stigma reduction interventions. The UN Human Rights Council adopted resolution 15/30 endorsing principles and guidelines for the elimina-

tion of discrimination against persons affected by leprosy and their family members. The guidelines called for all forms of stigma and discrimination to stop and for any discriminatory legislation or policies to be repealed (122).

A wide range of health-related stigma reduction interventions have been developed and tested in different settings and contexts. Most of these initiatives take place in fields other than leprosy, such as mental health and HIV, for which many projects to reduce stigma have been initiated (10, 123, 124, 125, 126). Stigma reduction interventions can target a specific type of stigma (e.g., internalized stigma, enacted stigma), a specific actor (e.g., the stigmatized individual, health professional, family member), or a specific level at which the stigma manifests itself (e.g., intrapersonal, interpersonal). The latter categorization was used by Heijnders and Van der Meij (8), who identified five levels at which interventions can address stigma, each with its own aim, as illustrated in Table 2. Although targeted at a certain level, particular stigma reduction interventions often produce effects at multiple levels.

**TABLE 2 Stigma-reduction strategies at different levels (8, 121)**

<b>Levels for stigma reduction</b>	<b>Stigma-reduction interventions at this level aim to:</b>
Intrapersonal	Change individual characteristics such as knowledge, attitudes, behavior, and self-concept; improve self-esteem, coping skills, empowerment and economic situation
Interpersonal	Establish relationships between members of the patient’s interpersonal environment (family, work environment, friendship network)
Community	Increase knowledge regarding health conditions and stigma, increase community development skills, and develop support networks within specific groups
Organizational and institutional	Modify health and stigma-related aspects of an organization
Governmental and structural	Enforce the protection of rights of people affected with a stigmatizing illness.

In the field of leprosy, a few examples of stigma reduction interventions are described in the literature. Counseling is a good example of an intervention on the intrapersonal level. In Nepal, Floyd-Richard and Gurung developed a group counseling intervention in which a group of 5–7 persons affected met in five two-hour sessions (127). In Indonesia, Lusli et al. developed a peer counseling intervention (128, 129). Persons affected by leprosy were trained as peer counselors, then offered counseling to other persons affected. Three different types of counseling were offered: individual, group, and family. Raising awareness of human rights played an important role in this intervention.

On the interpersonal level, socioeconomic development initiatives such as those developed and implemented in Indonesia (3), Nepal (130), and Nigeria (131) are examples of interventions shown to be effective in reducing stigma. Dadun et al. used a so-called ‘twin-track approach’ in which an established microcredit bank became inclusive of persons affected by leprosy through the provision of a ‘security fund’, advocacy, and training of staff regarding leprosy (132). At the community level, the contact intervention described by Peters et al. is an evidence-based example (133). In this intervention, events were organized in the communities in which leprosy-affected persons lived. During the events, ‘contact’ between persons affected and community members was facilitated either directly through testimony or indirectly through, for example, video. Guides on making such videos and comics and organizing a community event can be found here ([SARI Project videos](#)). The premise is that establishing a more personal relationship through direct or indirect contact will demystify leprosy and provide correct information, invalidate stereotypes, and generate empathy, which, in turn, leads to improved attitudes and reduced prejudice (10, 134, 135).

Sustained social marketing campaigns have been shown to be effective to improve leprosy case detection and attitudes towards leprosy in Sri Lanka and India ([BBC Media Action](#)), although actual evidence of attitude change has not been published in the peer-reviewed literature as far as we could find (136, 137). We are not aware of any studies that tested the effectiveness of interventions addressing leprosy-related stigma at the organizational, institutional, governmental, or structural levels.

None of these interventions focus only on education, because the effect of education alone on stigma reduction is seriously questioned (8, 59, 138). A few studies have found positive effects of education on reducing leprosy-related stigma (75, 139), but, in general, the available evidence shows that knowledge is only of the determinants—and not a very strong one—of positive attitudes (23, 140). Education should be an element of a stigma-reduction intervention, but should not be the focus. There are a few other lessons that can be learned from studies on stigma-reduction interventions.

First, it is important that stigma-reduction interventions are not set up as one-off activities but are developed in such a way that they can be sustained (137, 138). Hence, the interventions should be low cost, use materials and methods that are available in and appropriate to local settings, and are designed such that they can be executed by health professionals and the staffs of non-governmental organizations (NGOs) and disabled people’s organizations (DPOs) in local settings.

Second, the participation, not merely consultation, of affected persons in the development and implementation of stigma reduction interventions is important (133, 141, 142). The principle of ‘Nothing about us without us’ applies from a rights-based perspective, but evidence shows their participation also enhances the effectiveness of the interventions (141). In the SARI project in Indonesia, people affected by leprosy co-designed the interventions and were involved in the implementation (128, 133). For example, persons affected served as lay counselors or made the videos that were screened in the community. The participatory nature of the project was perceived as important for its success.

Third, a thorough understanding of the local context, worldview, and knowledge, beliefs, and fears concerning leprosy is important for designing interventions and materials. The materials must be appropriate and effective to address the real needs of the people and to change their attitudes and behavior regarding leprosy (23, 143, 144, 145).

Fourth, stigma is a sensitive subject. For several reasons (e.g., because people have concealed their diagnosis from family members or neighbors, because of changes in power relations), there may be unexpected, unintended, and undesirable effects of stigma-reduction interventions. It is important to always ask for consent from the persons concerned when there is a risk that their status may be revealed. Furthermore, it is necessary to discuss very carefully how any materials such as photographs and video will be used. Having people and procedures in place that help deal with these issues in an appropriate and timely manner is very important (146).

Although several types of interventions to reduce leprosy-related stigma have been developed and implemented, so far only one study has tested their effectiveness in a randomized control trial. The SARI project tested the effectiveness of three interventions: counseling, contact development, and socioeconomic development. The project concluded that a measurable reduction in leprosy-related stigma can be achieved, both at the community level and among people affected by leprosy (3). It showed that strategically targeted interventions developed in a participatory manner with a thorough understanding of the local context are able to reduce stigma in the community. In addition, the targeted interventions have a potentially life-changing effect on people who live with the consequences of stigma and discrimination. There is an urgent need for more studies on the effectiveness of stigma-reduction interventions in other settings.

## Replacing the Term ‘Leprosy’ with ‘Hansen’s Disease’

In some countries, the term used for ‘leprosy’ is closely connected to stigma and may be connected to negative stereotypes and emotions. This negativity was the case with the term ‘*lepra*’ in Brazil. Therefore, in 1976, a Ministry of Health ordinance (no. 165 of May 14, 1976) prohibited the use of the terms ‘*lepra*’ or ‘leprosy’ in all its publications. Nineteen years later, another effort to change the terminology resulted in the issuance of Federal law no. 9010, which banishes the term ‘leprosy’ and its derivatives from official/government documents. The first initiative was orchestrated by a physician named Abraao Rotberg who led the leprosy services of Brazil. The second was led by the patient association MORHAN. One might wonder why the second initiative was necessary. Were the mass media campaigns and law enforcement insufficient enough that another ordinance was needed after almost two decades? Other pertinent questions might be whether the name change has contributed to disease control and patient adherence to treatment



and whether it has contributed to a reduction in stigma against and exclusion of those affected by it.

Before addressing these questions based on the scientific literature, let us consider what professor of semiotics and communications Umberto Eco says in his book, *The Name of the Rose*, "...the mystery of leprosy has continued to haunt us because we have not recognized the nature of the sign." And very specifically, he asserts that, "The lepers are a sign of exclusion in general" (147). Why resort to semiotics and literature when addressing terminology change? In the case of the Brazilian situation, a person affected by the disease does not like to be called a 'leper' (*leproso*) unless the person has a figurative meaning in mind, in the sense of 'being an outcast', as an exaggeration or figure of speech, not a disease. This expression is used by many in communications to refer to 'social exclusion', as Eco discusses in chapter "Third Day: Nones" of his book. The expression is used as a metaphor, a mythical image of a medieval practice of social exclusion of various outcasts, instead of as a reference to a Hansen's disease patient of modern times. In the case of Eco's novel, it serves the purpose of describing members of a group that is heretic from a theological perspective. His brilliant discussion of how heresies develop within the enlightened circles of high religion by the creation of circles of exclusion teaches us that this metaphorical use of the image of leprosy and its characteristics is here to stay, but the way it plays out is intriguing and not as easily understood as it appears to be at first sight.

We searched for scientific publications in Portuguese about the terminology change from leprosy to Hansen's disease in the Virtual Health Library (Biblioteca Virtual de Saude) in April 2018 and found only 8 entries with full text. Despite little being published, something can be learned from the Brazilian experience of 40 years of efforts to get rid of leprosy-related stigma through a name change.

At the time of the terminology change in Brazil, no validated instruments were available to assess stigma in longitudinal studies about stigma changes. Nonetheless, in recent years, qualitative studies point out that the stigma still exists (148) but that services delivery and care have improved (149). It is important to point out that the name change was accompanied by a change in service delivery whereby patients would be seen at regular health clinics and hospitals instead of the former segregated practices. After analyzing 50 interviews by people affected, Femina et al. (150) concluded that the terminology change did not eradicate the circulation of the term '*lepra*' and did little to reduce prejudice against the disease. Maia et al. (151) interviewed 134 nursing professionals and manual laborers about Hansen's disease. Eighteen percent (18%) of the manual laborers were familiar with the term 'Hansen's disease', in contrast to the 87% familiar with the term '*lepra*'. It is interesting to note that both groups were divided regarding the curability of either Hansen's disease or '*lepra*'. Both groups referred to physical deformities as a characteristic and to 'bad blood' as the cause of the disease. The results reveal that although nursing professionals are expected to know about diseases, including Hansen's disease, apparently their education did not convey a better understanding of the curability and causes of the disease than that of unskilled manual workers. The fact that manual workers were not very familiar with the term 'Hansen's disease' indicates that the new term needs more visibility.

A much larger qualitative study by Oliveira et al. in 2001 surveyed 800 non-affected housewives in the cities of Rio de Janeiro and Duque de Caxias (152). They concluded that the social representation of '*hanseníase*' (Hansen's disease) is anchored in the notion of '*lepra*' (leprosy). In other words, in order to understand the new term, people use the old one, which is available in dictionaries, the Internet, the Bible, and other literature. Because of a strong background rich in content and (negative) meanings that pervades common sense mentality, the social representation of Hansen's disease may only become significantly different from leprosy in the distant future, if at all, the authors conclude.

A study of the educational materials employed widely in health education activities in Brazil concluded that the new term '*Hanseníase*' was presented from a medical perspective (153). This perspective emphasized symptoms and treatment but failed to change the meaning of traditional knowledge and cultural expressions pertaining to '*lepra*'. Despite the characteristics of the regional culture, the language employed was text-book-like, which makes sense to educated adults. However, teens and uneducated adults have little to no comprehension of the information conveyed. As a result, the educational activity ended up creating a "new disease", another terrifying condition analogous to leprosy, also causing skin lesions and disabilities. One of the authors (ZBP) who spoke with patients in Brazil heard them say that they have a "kind of leprosy called '*hansenia*' (Hansen's disease), but it is not '*lepra*' (leprosy)".

Another study attempted to understand patient adherence to treatment in relation to the patient's knowledge about Hansen's disease. The study found no difference in behavior that could be attributed to the use of the term 'Hansen's disease' (*hanseníase*) vis-à-vis leprosy (*lepra*) (154). None of the patients interviewed used 'Hansen's disease', as they could not pronounce the word in Portuguese (five syllables long). However, they employed both '*lepra*' and a shortened version of Hansen's disease: '*hansenia*'. Patient adherence was influenced by certainty about the cure and affective bonding to a health service provider (physician, nurse, or other staff team member).

The problems reported by the studies reviewed above show the fragility of a terminology change. The change in language might sound nicer and 'politically correct', but to use it as a single measure for reducing stigma is questionable. Stigma is a multidimensional phenomenon that includes labeling, but also interpersonal exchanges, health practices, cultural values, shared knowledge about disease, and societal dimensions such as legislation, access to services, protection, and patients' rights (155). It therefore takes multi-level and multidimensional interventions to bring about the desired change (8). Nonetheless, the name change offered patients an alternative term to use in everyday exchanges. The change in terminology might have created other problems, but it blurred the direct connection between a patient and the awful connotations of mythical leprosy. From now on, s/he was affected by '*hanseníase*', "a kind of leprosy" but certainly not the mythical '*lepra*' described in Eco's novel as "Misshapen, their flesh decaying and all whitish, hobbling on their crutches, with swollen eyelids, bleeding eyes" (147).

# Future Research Needs Regarding Leprosy-Related Stigma

## INTERSECTIONALITY

Future research should take the intersectionality of stigma into account and collect data on factors that may intersect with leprosy-related stigma, such as disability status, gender, age, marital status, family support, ethnic background, socioeconomic status, etc. Further insights are needed into how these factors work together to shape the experience of stigma and to facilitate resilience.

## UNDERSTANDING POSITIVE EXPERIENCES

Many studies that have been conducted on health-related stigma have focused primarily on the negative effects of stigma and on experiences of exclusion by the persons affected. By only focusing on stigma and exclusion, researchers, policy makers, and health practitioners miss the positive attitudes and experiences in the daily lives of people affected (e.g., individuals who are not ashamed of their disease, families that provide understanding and support, health workers who behave respectfully, friends/colleagues who are supportive, etc.). These positive experiences need to be fostered; therefore, they should get more attention in future research.

## EFFECTIVENESS OF STIGMA REDUCTION INTERVENTIONS

Evidence of the effectiveness of interventions, particularly over the long term, is very scarce. Very few studies have attempted to compare methods or to examine the sustainability of the positive changes that have been documented. Such studies are not easy to conduct, but deserve attention. Proper data on the effectiveness and sustainability of stigma reduction interventions would greatly enhance the scientific credibility of those interventions and thus increase the potential funding opportunities for implementation.

## STIGMA IN CHILDREN

Very little is known about how children are affected by leprosy-related stigma. This deficiency is partly due to a lack of suitable instruments and approaches to assessing stigma in children. As

thousands of children are affected by leprosy every year, and because they are also affected by parents or siblings with leprosy, more research is definitely warranted.

## STIGMA AND HEALTH SECTOR

Anecdotal evidence suggests that persons affected by leprosy are often stigmatized or discriminated by the staff in health or social services. However, very few studies have tried to document these anecdotes. An instrument is needed to measure leprosy-related stigma among health professionals. Such instruments exist in the fields of mental health and HIV and can thus be adapted for use in the field of leprosy. Appropriate interventions should also be developed, tested, and implemented.

## STIGMA AND MENTAL WELL BEING

The fact that stigma has a severe impact on mental health and wellbeing has been recognized for many years. Studies are needed that examine how the mental health needs of persons affected can best be met by informal services, such as peer counseling, and formal mental health services, such as community mental health programs.

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