

## **Social implications of leprosy in the Netherlands - stigma among ex-leprosy patients in a non-endemic setting**

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### *Summary*

*Background:* In the Netherlands, leprosy is a rare and non-endemic disease, still occurring as an ‘import disease’. Moreover a considerable group of people affected by leprosy, originating mainly from the former Dutch colonies, suffer from neuropathic complications. This study investigates the social implications of leprosy for those affected in the Netherlands.

*Methods:* Thirty-one people affected were interviewed as well as six medical leprosy experts. The social implications were measured by means of semi-structured interviews and the Participation Scale.

*Results:* Self-stigma, shame and secrecy were often reported. Discrimination and stigmatisation of ex-leprosy patients by people around them seems a less frequent problem. Yet, people affected by leprosy seem to be a forgotten group with a high social burden due to low self-esteem and reduced social participation. Medical experts do not seem to be aware of the severity of leprosy-related forms of stigma in their patients. Ex-leprosy patients lack sound disease-related information and support groups. Due to the low incidence and as a consequence, the lack of awareness among doctors, leprosy patients in the Netherlands are faced with substantial diagnostic delay (mean delay 1-8 years).

*Conclusions:* Leprosy and its stigma affect the social lives of patients, even in a non-endemic area such as the Netherlands. Almost all respondents were affected by self-stigma. There is a need for 1) more information and support groups for patients, and 2) increased awareness among professionals.

## Introduction

Leprosy is associated with extreme prejudice, fear, aversion and social exclusion.<sup>1,2</sup> Throughout history, it has been considered one of the most terrifying and stigmatising diseases. Even nowadays, leprosy places a considerable social disease burden on affected people. This burden includes restrictions in social participation and emotional distress caused by feelings of shame and of being different. Several studies from endemic countries confirm this social burden.<sup>3–6</sup>

Stigma leads to social consequences such as participation restriction. It can be defined as ‘the coexistence of the following components: labelling, stereotyping, isolation, status loss and discrimination in a context where power is present.’<sup>7,8</sup>

Feelings of fear, shame, low self-esteem, isolation or feeling ‘different’ are all considered signs of self-stigma. Self-stigma can occur when people affected by a stigmatising condition become ashamed of their illness because of the attitudes of others towards the disease and/or the deformities they might have. Because of this process, the affected person may start applying the negative stereotype that people hold to themselves and develop a negative self-image.<sup>9</sup> Often a correlation exists between actual discrimination and self-stigma at an individual level.<sup>10,11</sup>

Stigma and exclusion of leprosy patients does not only occur in leprosy-endemic regions. Little information is available on the social consequences of leprosy patients living in a non-endemic area. One of the very few studies done in a non-endemic setting (United Kingdom), shows that leprosy patients are affected by diagnostic delay, since the disease is not recognised by medical workers due to the low disease prevalence in the area.<sup>12</sup>

The Netherlands is a non-endemic leprosy area, and among most laymen, leprosy is associated with ancient times, and with fiction.<sup>9</sup> According to a market research on familiarity with leprosy in the Netherlands, people lack disease-specific information and some of them don’t have any specific thoughts regarding leprosy.<sup>1</sup> Someone affected by leprosy is sometimes referred to as ‘melaatse’ in Dutch, nowadays this term is sometimes used as a metaphor for stigmatisation.<sup>ii,iii</sup> Since the Second World War no cases of indigenous transmission of leprosy have been reported in the Netherlands. Approximately five to 10 new leprosy diagnoses are made annually in patients that have contracted the disease in endemic regions, mainly in the former Dutch colonies Suriname and Indonesia. Leprosy is considered an ‘import disease’ in a non-endemic country such as the Netherlands.<sup>iv,12</sup> Diagnostic delay is a serious problem for leprosy patients, especially in non-endemic settings where doctors are unfamiliar with the condition. Often only after many consultations, a doctor with knowledge of leprosy diagnosis and treatment may be reached. Not infrequently, patients have already developed irreversible nerve damage by this time.<sup>12</sup>

In the current study we investigated the social impact of leprosy in the Netherlands.

<sup>i</sup>Van Rooijen I. Kennis en houding lepra: Onderzoek in opdracht van de Leprastichting. Marketresponse. 2009.

<sup>ii</sup>Trouw. Wilders voelt zich behandeld als melaatse. 2010. Available at: <http://www.trouw.nl/tr/nl/4492/Nederland/article/detail/1111648/2010/06/29/Wilders-voelt-zich-behandeld-als-melaatse.dhtml>

<sup>iii</sup>De Telegraaf. De nieuwe melaatsen. 2009. Available at: [http://www.hivnet.org/index.php?option=com\\_content&view=article&id=7942&Itemid=672](http://www.hivnet.org/index.php?option=com_content&view=article&id=7942&Itemid=672)

<sup>iv</sup>Steenjens M. Immigrant leprosy patient’s view of their illness and its influence on their position in Dutch society; an emic view. Thesis 2001; University of Amsterdam, the Netherlands.

## Methods

### DESIGN

This is an observational, descriptive study with a focus on the patients' view.

### STUDY SAMPLE

The study sample comprised people affected by leprosy; both patients still under medical care, as well as former patients. People were eligible when they were affected by leprosy, living in the Netherlands, able to give consent and willing to participate. People under medical surveillance were invited to participate in the study by their medical specialist. Also, medical doctors with experience in leprosy treatment and/or research were interviewed. Some of the experts and other medical doctors that were known for treating people affected by leprosy in the Netherlands were key informants.

### DATA COLLECTION AND INSTRUMENTS USED

Upon gaining permission, the interviewer approached the participants for an interview session of approximately 90 minutes at their own home or in the hospital, after consent was obtained. All interviews were conducted in Dutch, as all participants were comfortable with this. Also, specialists in the field of leprosy were interviewed.

These specialists all have experience in leprosy treatment and/or have performed research in this field. By using the snowball-method other leprosy experts came up and were contacted.

### ANALYSIS

Qualitative data was obtained with validated semi-structured interviews.<sup>13</sup> The following items were included in the interview-guideline: basic knowledge on leprosy, social participation, self-care, discrimination, social relationships, exclusion, restrictions and self-esteem. The interview used in this study was an adapted version of a validated interview guide.<sup>14</sup> The interviews were recorded for reasons of accuracy after consent of the interviewees had been obtained. The interviewer transcribed the recordings and secured the anonymity of the interviewees. A word cloud was made in order to graphically display the first association to come up into the interviewees' minds. Analysis of the qualitative data was done by connecting codes and identifying and clustering themes for all transcripts.

Quantitative data was derived from the Participation Scale, based on the terminology and conceptual framework of the International Classification of Functioning, Disability and Health (ICF).<sup>15</sup> This scale was used to measure the impact of stigma, as participation is an important aspect of stigma experience.<sup>11,16</sup> It has been validated for use with people affected by leprosy and for use in the Netherlands.<sup>16</sup> The scale contains 18 questions on experienced participation restriction, and interviewees are asked to compare themselves with peers who are not affected by leprosy. The Participation Scale has a total score on a scale from 0 to 90; a score of less than 13 means *no significant participation restriction*, 13 – 22 equals *mild restriction*, 23 – 33 *moderate restriction*, 34 – 53 *severe restriction* and more than 53 is classified as *extreme restriction*.<sup>16</sup> To test equality of population medians among groups for the variables age, sex, country of origin, disability grade, and being under medical care, the Mann-Whitney U test was used. A multivariate analysis with quantile regression on the

75th quantile of the participation score was used to test the association of determinants of severe participation restriction.

In this study, disability was graded according to the WHO grading system and diagnostic delay was defined as 'a point of consultation along the referral pathway where no diagnosis or misdiagnosis is made.'<sup>12,17</sup>

#### ETHICAL CONSIDERATIONS

Data were collected from July 2010 to January 2011 after a letter of no objection was obtained from the ethical committee of the Academic Medical Centre of the University of Amsterdam. The interviewer had taken into consideration the sensitivity of the subject and carefully handled the potential stress of retrieving bad memories by emphasising the anonymity of the participants, choosing her words carefully and by alternating general and personal questions. All eligible subjects were asked for verbal informed consent prior to the interview. No incentives were paid.

### Results

#### STUDY SAMPLE

In total, 96 ex-leprosy patients were invited to participate (three by telephone, 17 during regular consultation hours and 76 by a letter of invitation since they were not under medical care at that moment). All candidates invited during a consultation or by telephone were willing to participate. Of the 76 mail invitations, only 17 returned the response slip and 11 accepted the study invitation. No letters were undeliverable and were returned to sender; 65 out of 76 people did not respond. Of those that declined, but sent in the response slip, the main reasons mentioned were 'being afraid of negative feelings' and 'unwilling to recollect bad memories'. From the six people who declined the invitation three were reluctant to recollect unpleasant memories as reason. Thirty-one invitees participated in the study. All interviews were performed in Dutch as all participants spoke and understood this with sufficient fluency.

Twelve men and 19 women were interviewed. The mean age was 58 years (median 56). The youngest participant was 27 and the oldest 93. The majority were born in Suriname ( $n = 17$ ), followed by Indonesia ( $n = 5$ ), the Netherlands ( $n = 3$ ), and Brazil, Philippines, Angola, Morocco, Curacao and Paraguay (all  $n = 1$ ). The mean age of the participants at onset of leprosy-related symptoms was 25.

#### SELF-STIGMA

The majority of the participants ( $n = 25$ ), including the ones without visible signs, kept their diagnosis of leprosy a secret. They concealed their condition at work, among friends and family and in some cases even from their partners, children and spouses. Participants masked disease signs or told people they were affected by another disease such as rheumatism, when asked about the cause of their complaints and symptoms. Being ashamed of their condition and the fear of being treated differently was mentioned as reasons for secrecy. This is illustrated by a man (54) from Surinam who lost some of his fingertips due to leprosy. He tells nobody about his disease because he knows what the reactions can be like, since he experienced this when living in Surinam:

“The less people know about me and my disease, the better”, and “I always tell people I had an accident when they ask about my handicap”

A substantial group ( $n = 12$ ) admitted to sometimes feeling ‘different’ or ‘odd’ because of leprosy, including participants without visible signs of leprosy. A woman (27) from Angola, for example, has no visible signs of leprosy but nevertheless feels stared at very often and therefore only occasionally visits public places. Self-stigma is also confirmed by the negative associations ex-patients have when thinking of leprosy. The word cloud in Figure 1 shows the links that first come into the participants mind when asked to think of leprosy.

*“My life is one big lie” (Woman 69, Surinam)*

*“I felt like a prisoner of my own mind” (Woman 27, Angola)*

#### REACTIONS OF OTHERS

A minority of the respondents ( $n = 7$ ) gave examples of being stigmatised in the Netherlands, mainly by people originating from a leprosy endemic area ( $n = 6$ ). Examples of experienced stigmatisation are: people keeping physical distance, exclusion and calling names. Despite only a few of these negative responses, almost every participant said they were afraid of rejection and therefore don’t take the risk of telling others.

*“I was more afraid of the prejudices than the disease itself” (Woman 38, Brazil)*

#### DIAGNOSTIC DELAY

Participants mentioned experiences with doctors and specialists that had no clue about the nature of their complaints and symptoms. Diagnostic delay was observed in 24 participants (77%). All of these late diagnoses occurred in the Netherlands. A mean diagnostic delay of 1.8 years was found for people diagnosed in the Netherlands ( $n = 27$ ). For patients diagnosed outside the Netherlands ( $n = 4$ ) no diagnostic delay was reported by the interviewees.

*“Nobody was able to diagnose, not even the dermatologists” (Woman 46, Surinam)*



**Figure 1.** Word cloud of associations with leprosy of people affected by it when asked what came to mind first when the word leprosy was mentioned. Words that were mentioned more frequently are greater in size.

#### INFORMATION NEED

The need for practical and patient-oriented information was often mentioned (20 out of 31) during the interviews. Information about the route of infection and the disease process seemed to be especially lacking. For a lot of participants it is not clear what leprosy does to the body, when it is gone and if it can reoccur. A woman (46) from Surinam said she is afraid of the future because of the unpredictability she experiences with her leprosy.

“Even though the doctor says I am cured, I can still feel the disease bubbling below the surface”

The lack of (ex) patient support groups in the Netherlands was mentioned by eight people. Many respondents did not know any other person affected by leprosy, which enhanced the feeling of being ‘different’ and isolated.

*“It’s like I am the only one . . .” (Man 31, Curacao)*

*“You never read or hear anything about leprosy in the Netherlands, it is like it does not exist” (Woman 54, Surinam)*

#### SOCIAL PARTICIPATION

Study participants ( $n = 12$ ) mentioned that they continuously had to consider their actions to prevent (deterioration of) neuropathy-associated complications. Visible disease signs of leprosy (amputations, deformities and signs of paresis) were an important obstacle in social participation. People with visible complications were less mobile, more often house-bound and frequently had to give up hobbies and social pursuits. A man (65) from Holland is in a wheelchair because of wounds on his feet and a lack of sensation in his legs. He feels very restricted in his movement:

*“Feet are like tyres, when they are flat you won’t get far”*

*“My biggest handicap is not doing things, to prevent me from getting more sick” (Man 55, Surinam)*

This man lacks sensation in his hands and feet. Because of this handicap infections due to burns or sharp objects are more likely to occur.

Reasons mentioned for being house-bound ( $n = 3$ ) were:

*“It is too exhaustive to leave the house,” and “I am afraid that my condition could aggravate or lead to complications” (Man 54, Surinam)*

Twenty-two out of 31 participants (71%) reported experiences of some form of participation restriction. Fifteen people (48%) reported restrictions in the ability to find or keep work and having problems with social activities, mostly because of their physical disabilities and shame concerning their condition. Eleven participants (35%) confessed having difficulty meeting new people. The most common reason for this difficulty was the fear of questions concerning their condition and the fear of rejection.

The median participation score was 16 (0–33) points (mild restriction) with a minimum of 0 and a maximum of 65. As shown in Table 1, the highest level of participation restriction was found among men, and among respondents of Surinamese origin, patients under medical

**Table 1.** Determinants of participation restriction in people affected by leprosy in the Netherlands

Variable		N	Median	Interquartile range (25%–75%)	P-value
Sex	Men	12	30.5	11–38.5	0.096*
	Women	19	10	0–22	
Origin	Surinamese	17	29	0–29	0.003*
	Non Surinamese	14	1.5	0–16	
Disability grade	Grade 0	7	0	0–10	0.001*
	Grade 1	6	0	0–13	
	Grade 2	18	29	16–41	
Medical surveillance	Medical surveillance	21	29	16–41	<0.001*
	No medical surveillance	10	0	0–0	

\* Kruskal-Wallis test.

care and among those with a Grade 2 disability. Age was not associated with the participation score. The univariate analysis shows significant differences in medians between groups for origin, disability grades and medical surveillance. As shown in Table 2, further statistical testing with quantile regression on the 75th centile, indicates an independent statistically significant association for land of origin and medical surveillance. These two variables explained 42% of the variance in participation score ( $R^2 = 42\%$ ). The regression coefficient of  $-15$  at the 75th quantile indicates that people originally from Surinam, had a 15-point higher participation score (more participation restriction) than people who are not. People who are under medical surveillance, had a 29-point higher participation score compared to those not under medical surveillance for their leprosy.

#### EXPERTS

The group of six experts consulted for this study comprised four dermatologists, a physician/researcher in the field of leprosy and a professor of public health and infectious diseases. All of them have worked with leprosy patients, either in or outside the Netherlands. The experts estimated that in 2010 approximately 300–400 ex-leprosy patients resided in the Netherlands. They assumed that stigmatisation and social exclusion of leprosy patients rarely occurs. This assumption was based on their own professional experience with people affected by leprosy. The difficulty (ex-) patients experience in talking about leprosy is acknowledged by the experts, as well as the fact that patients can be ashamed of their affliction or unwilling to be confronted with it.

*“We have to be very careful when using the word ‘leprosy’, as this word alone can cause a lot of stress for the patient” (Prof. Dr. de Vries)*

**Table 2.** Multivariate analysis of determinants of social participation among persons affected by leprosy in the Netherlands

Characteristic	Coefficient	Standard Error	95% confidence interval	P-value
Surinamese origin	$-15$	6.208	$-27.7 - -2.28$	0.022
Medical surveillance	$-29$	5.803	$-40.9 - -17.1$	<0.001

This sense of shame can also be found in patients who keep their condition a secret.

*“Some patients did not want their family to be informed about their leprosy”* (Prof. Dr. Faber)

All experts agreed that most people in the Netherlands wouldn't easily recognise someone affected by leprosy and therefore wouldn't be able to stigmatise. However, according to the experts, stigma can occur when patients internalise the stigma they may have experienced in their country of their birth or when people from the same origin who are familiar with stigmatisation of leprosy treat them differently.

The possibility of diagnostic delay in the Netherlands was also acknowledged. Lack of attention to leprosy during the medical curriculum and lack of knowledge about leprosy among doctors were mentioned as factors contributing to diagnostic delay.

## **Discussion**

In contrast to what is believed by experts, stigma, exclusion and restricted participation is an everyday reality of many ex-leprosy patients in the Netherlands. Moreover, as substantial diagnostic delay occurs, people affected feel a need for support groups, and better access to relevant information about leprosy is needed.

Rather than experiencing stigmatisation from their surroundings, most ex-leprosy patients reported suffering mainly from internalised forms of stigma. This is likely to be related to the concealment of their affliction, the social isolation in the majority of the participants, and the fact that leprosy is a rare disease in the Netherlands. Professionals that deal with (ex) leprosy patients need to enquire actively for signs of these hidden forms of self-stigma. Self-stigma is also common in other stigmatising conditions in developed countries, such as HIV, epilepsy and mental illness.<sup>18–20</sup> A study performed in the Netherlands on the functioning of people affected by leprosy revealed the physical problems they encounter and the way this affects their social participation.<sup>21</sup>

Our study shows that stigma adds to this burden, also causing considerable emotional suffering, even long after their leprosy has been cured as a disease. This emotional suffering is caused by the feeling of being different or ashamed due to the disease and sometimes by actually being treated differently by others.

Very little is known about the social impact of this disease in a non-endemic area. The statistical outcomes of the Participation Scale confirm the participation restrictions reported by people affected in the qualitative interviews. Surinamese origin and being under medical surveillance both predict variance in participation score independently. The fact that visible disability did not have an independent effect as predictor for participation restriction may be explained by the fact that people more easily mask their disability or lie about the cause, than that they conceal seeing a doctor for their condition. Medical consultations also remind people of their disease and of being 'different' that way. The social participation restrictions experienced by Surinamese people were illustrated by examples of non affected Surinamese people in the Netherlands that stigmatise, and by the patients' own memory of leprosy being a shameful disease when living in Surinam. The effect of culture on stigmatisation has been acknowledged by many authors.<sup>7,22–28</sup> The causes and manifestations of stigma may differ among different cultures, but effects of stigma on individuals and families are remarkably similar across cultures.<sup>26</sup> The same is true for stigma reduction interventions,<sup>29</sup> although these may need to be culturally adapted to local context before implementation (Cross *et al.*, in preparation).



The participation scores indicated some moderately severe restrictions, which may warrant psycho-social interventions. Due to the small sample size, the study had little statistical power to detect statistical differences between groups. Our findings should therefore be interpreted with caution. Any future research should attempt to include a larger group of people affected by leprosy. Even though the Participation Scale is a validated tool to measure the effects of stigma, self-stigma can be measured more specifically using an instrument like the ISMI scale.<sup>26</sup> This tool was not used in this study because, as far as we know, it has not yet been validated in the Netherlands.

Other studies on leprosy in non-endemic countries reported on the diagnostic delay people face.<sup>3,12,30</sup> Important causes of delay are misdiagnoses, because dermatological and neurological conditions such as leprosy can be difficult to recognise and diagnose in non-endemic areas. Our findings of diagnostic delay match these findings.

The findings of this study ask for action to reduce self-stigma and diagnostic delay. Future research should investigate the importance and impact of self-stigma for people affected by leprosy elsewhere. It would be interesting to find out in what way leprosy is stigmatised in other non-endemic areas and whether internalised stigma is more common in developed countries than public stigma. Self-stigma can be challenged by interventions that encourage the development of personal identity through interaction with peers, proper information distribution, psycho-social support as well as general empowerment.<sup>29,31</sup> Increased and continuing awareness among doctors is necessary to minimise continuing damage and disability. Leprosy should be brought more often to the attention of medical specialists most likely to be consulted by leprosy patients, such as dermatologists and neurologists. The diagnosis of leprosy should be considered in cases of chronic dermatitis with peripheral nerve involvement in foreign-born individuals, as well as in those who have undertaken protracted travel abroad. Leprosy can be a complicated and challenging disease to manage. If suspected, referral to a tropical disease expert or a dermatologist with expertise in leprosy is warranted.<sup>3,12</sup>

A limitation of this study concerns the study sample. The majority of people invited by letter did not respond. Due to patient confidentiality regulations, we do not have information of those who did not respond. Therefore, we were not able to compare profiles of people who did not respond to those who did participate. We assume that the findings in our survey are an underrepresentation of the actual problems faced by ex-leprosy patients in the Netherlands. Moreover, the group of potentially affected people not under medical care, like illegal immigrants, were not included in our survey. This may have resulted in selection bias. Future research should involve a larger sample, incorporate self-stigma as a matter of priority and use a comprehensive assessment of self-stigma.

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