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Illness perceptions of leprosy-cured individuals in Surinam with residual disfigurements – “I am cured, but still I am ill”

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Abstract

Objective: Leprosy has rarely been subject of health psychology research despite its substantial impact. Our aim was to explore illness perceptions in patients and their health care providers in Surinam. ~~We explored illness perceptions in patients and their health care providers in Surinam.~~ The Common Sense Model (CSM) was the guiding theoretical model.

Design: Patients with biomedically-cured leprosy and their health care providers completed the B-IPQ and took part in semi-structured interviews. The literature on illness perceptions in patients with leprosy was reviewed.

Main outcome measures: Patients' B-IPQ scores were compared with samples of patients with other (chronic) illnesses, and with health care providers completing the questionnaire as if they were visibly disfigured patients. Quotations from the semi-structured interviews were used to contextualise the illness perceptions.

Results: Patients' B-IPQ scores reflected the chronic nature of leprosy and were comparable with those with other chronic illnesses. Health care providers perceived leprosy to have a greater negative impact than did the patients. Perceived understanding of causes differed considerably between patients and health care providers.

Conclusion: Leprosy continues to be experienced as an illness with major psychological and social consequences such as stigmatisation, even after biomedical cure. Interventions that target patients, health care providers, and society at large may help reduce perceived shame and stigma. The CSM is a helpful theoretical model in studying this population.

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3 **Keywords:** leprosy; illness perceptions; chronic illness; stigma; Common Sense Model
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5 (CSM)
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For Peer Review

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3 Leprosy, also known as Hansen's disease, is an infectious disease caused by the bacteria
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5 *Mycobacterium leprae* which affects the skin and peripheral nerves. Leprosy is an important
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7 global health concern; early diagnosis and a full course of treatment are critical for preventing
8
9 lifelong neuropathy and disability.¹⁻³ In spite of the fact that nowadays leprosy can be cured
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11 with the help of a strict treatment schedule of multidrug therapy (MDT), it has not yet been
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13 eradicated. When leprosy is diagnosed and treated early, the disease results in few or no
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15 visible mutilations. However, if it is not diagnosed and treated early, outwardly visible signs
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17 of the illness, such as deformed fingers and toes, continue to influence the life of the leprosy-
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19 cured individual, even though they have completed a full course of medication. In this way,
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21 the leprosy-cured individual, and the people he or she is in contact with, will be constantly
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23 stigmatized due to~~reminded of~~ the presence of the mutilating disease.⁴ Rehabilitation, equal
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25 opportunities and social inclusion continue to be a considerable challenge for leprosy-cured
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27 individuals, who, often, are abandoned by their families and perceived as outcasts by
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29 society.^{5,6}

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35 For centuries the disfigurements of leprosy patients were a source of stigmatization for
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37 the sufferers of the illness.⁷ The stigma of leprosy can be so severe that people hide signs of
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39 onset, causing them to seek medical attention too late or not at all.⁸ Potential repercussions of
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41 these behaviours are disease progression and disease transmission as discontinuation of
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43 therapy may lead to drug resistance. Therefore, the psychological consequences of leprosy
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45 and onset of leprosy are not only the patient's problem, but also a problem for his or her
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47 families, caregivers and for ~~the~~ society at large; all experience the negative consequences.

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51 Illness perceptions are cognitive and emotional representations of the illness by the
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53 patient. Cognitive representations are the labels patients use to describe the disease (*identity*),
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55 the expected effects of the illness (*consequences*), the ideas about the cause (*cause*), the
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57 perception of how long it will last (*timeline*) and the thoughts about the ability to recover
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3 (control). The emotional representations incorporate the concern of the patients and the
4 emotional response. Illness perceptions, meaning of health, and illness behaviour affect
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6 stigma and behaviour relating to disease control. These concepts are outlined in the Common-
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8 Sense Model (CSM) in which cognitive and emotional representations of illness are described
9 as guiding the behavioural response of the patient. CSM research has shown that coping and
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11 illness perceptions are ~~seen as~~ determinants of outcome in illness.⁹ Kleinman's 'explanatory
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13 models' is another theoretical concept in studying how people make sense of an illness and its
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15 treatment.¹⁰ To date, only a handful of empirical studies considering illness perceptions and
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17 explanatory models of individuals affected by leprosy have been published in international
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19 journals (summarized in Table 1).¹¹⁻²⁰ For the most part, the few studies that have been
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21 published have focused on causal attributions. The relatively recent concept of illness
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23 perceptions appears not to have been explored in samples of persons with leprosy. Our study
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25 addresses this gap in the literature.²¹
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INSERT TABLE 1 ABOUT HERE

The present study aims to assess illness perceptions of individuals in Surinam who
have been medically cured of leprosy and who have visible disfigurement. Our aim is to
identify cognitive and emotional representations of illness to understand patient behaviour
and to contribute to patient-specific interventions. Illness perceptions of health care providers,
completing the questionnaire as being a patient, were also studied to detect possible
discrepancies between how they think about patients' illness perceptions and those of the
actual patients.

Methods

A mixed method design was used: patients and health care providers, completing the questionnaire as being a patient, filled out a validated questionnaire (B-IPQ) and responded to questions in a semi-structured interview. The B-IPQ assessed cognitive and emotional representations of illness by the patient. The common sense model was used to evaluate the identified cognitive and emotional representations of the illness. Previous research indicated that those representations were highly influential on patients' behaviour.⁹ In the semi-structured interview specific behaviour following the illness perceptions was explored. Narrative methodologies were used to understand the concept of stigma and the rituals of the patient.²²⁻²³

Our study sample comprised leprosy-cured individuals who were previously diagnosed with leprosy and have received successful treatment to eradicate the causative bacteria *Mycobacterium leprae*. The WHO classifies leprosy related impairment in three grades: Grade 0 (no impairment), Grade 1 (loss of sensation in hand or foot) and Grade 2 (visible impairment).³ People were eligible if they were affected by Grade 2 leprosy, able to give consent and were living in Surinam. All potential participants lived in a leprosarium, a center of accommodation for leprosy-cured individuals, under the auspices of the Esther foundation, Paramaribo, Surinam. The Esther foundation is a charity organization that supports the re-integration of leprosy-cured persons into society, for example, by using their Esther bus to make cultural trips and by organizing leprosy awareness education for surrounding primary schools. People with leprosy were approached by their social worker, employees of the Esther foundation, and were provided with information about the study and allowed time to consider participation. Ethical permission was granted by the Esther foundation ethics council. Study participation was based on free will, anonymity and confidentiality.

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3 Fifteen leprosy-cured individuals were approached; two refused to take part due to an
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5 intercurrent illness. In this paper pseudonyms are used to ensure anonymity of the
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7 participants. Health care professionals involved in medical care for leprosy-cured individuals
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9 in Surinam were invited to take part in the research. They included medical doctors from the
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11 Academic Hospital of Paramaribo and the Dermatological Service of Surinam, and nurses and
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13 social workers from the Esther foundation. The medical doctors were dermatologists and had
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15 experience of working with leprosy-cured patients; the nurses had specialized in leprosy
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17 nursing care. The social workers managed social activities such as excursions or religious
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19 meetings. Twenty health care professionals were approached; nine did not want to participate
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21 because they found the questionnaires too time-consuming.
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26 Data regarding sociodemographic and clinical characteristics of the patient
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28 participants were collected from the files in the Esther foundation. The Brief Illness
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30 Perception Questionnaire (B-IPQ) was used to assess illness perceptions.²⁴ The B-IPQ
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32 consists of eight questions, answered on a scale from 0 to 10, and one open question, which
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34 assesses three perceived causes of the illness. The Dutch version of the B-IPQ has been used
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36 in several populations with chronic illness.²⁵³ The questionnaire was given to both the
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38 leprosy-cured participants and the health care professionals. Health care professionals were
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40 asked to complete the questionnaire as if they were visibly disfigured leprosy-cured patients.
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45 Semi-structured interviews were used to explore participants' illness perceptions and
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47 their resulting behaviour, using the CSM. The topics included: origin and evolution of the
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49 illness, shame and concealment, punishment, impurity, and sexuality. Once informed consent
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51 had been obtained, interviews were conducted in participants' homes, by the first author. All
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53 interviews were conducted in Dutch and lasted approximately 90 minutes. They were
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55 recorded on audiotape for reasons of accuracy, and transcribed verbatim.
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Quantitative data were analyzed with SPSS version 20 software. Socio-demographic and illness characteristics were analyzed with descriptive statistics and frequencies. Independent *t*-tests were used to compare B-IPQ scores between leprosy-cured individuals and health care professionals, and between leprosy-cured individuals and reference data from patients with SLE (systemic lupus erythematosus) and asthma. Using Wordle™ a word cloud was created from answers to question 9 from the B-IPQ (“What are the three most important causes for your illness?”) to provide graphic illustration of the perceived possible causes.

Results

Participants

Fifteen leprosy-cured patients were approached, 13 participated. The mean age of the leprosy-cured individuals was 74.1 years (SD 7.2); mean age at diagnosis was 10.4 years (SD 3.8). Of the 13 participants 8 were Creole, 3 had mixed ethnicity, 1 was Caucasian, and 1 was from Eastern India. Full socio-demographic and illness characteristics are shown in Table 2. Twenty health care professional were approached. Two social workers, four nurses and five medical doctors agreed to participate.

INSERT TABLE 2 ABOUT HERE

Illness perceptions

The B-IPQ scores of the leprosy-cured individuals and health care professionals are shown in Table 3. The illness perceptions in the dimension Consequences, assessing the expected effects of the illness, were found to be significantly lower in leprosy-cured individuals than in health care professionals. The Concern experienced by leprosy-cured individuals was also

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3 overestimated by the health care professionals. Leprosy-cured individuals had high scores on
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5 the Timeline dimension, meaning that they perceived leprosy as an illness which has a long-
6
7 lasting impact on their lives. We compared our results with those from studies of two other
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9 chronic illnesses, i.e. systemic lupus erythematosus (SLE) and asthma (Table 4).^{11,253} We
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11 found similar response patterns across the studies; there were no significant differences
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13 among respondents with leprosy and the other two chronic illnesses.
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17 INSERT TABLE 3 ABOUT HERE

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20 21 22 Perceived causes

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25 In response to the open question of the B-IPQ: “What are the three most important
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27 causes for your illness?”, family curse, food, and heredity were most often reported by the
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29 patients (Figure 1 a) - the larger the font, the greater the number of responses. Bacterial
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31 cause was cited most often by the health care providers (Figure 1 b.).
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38 INSERT FIGURES 1 a and 1 b ABOUT HERE
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47 **Family curse.** The family plays an important role in the beliefs regarding the causes
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49 of leprosy. Actions of a family member, before the birth of the individual or during
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51 pregnancy, were thought to influence the health status of the child, as stated by Loretta, 79
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53 years old,
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56 *“It is hard to understand these things (possible causes), you will not understand but in*
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58 *Surinam we believe that when people do bad things ... this will result in having*
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3 *deficient children. For example, my grandfather had kicked a boa constrictor to*
4 *death, and my mother had beaten a fat frog to death.”*
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8 **Food.** Beliefs and behaviour related to eating were often mentioned during the
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10 interviews. The most striking belief was the fear of eating certain food products, for example
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12 animals such as unscaled fish, armadillo, snake or turtle. This symbolic belief is as also found
13 in Douglas’ description of dietary laws in a more religious context.²³ In Surinam this belief is
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15 called ‘*treef*’ (*plural: treven*). A ‘*treef*’ can be explained as a personalized ban on eating
16
17 specific food products. A patient explained that the thought behind the ‘*treef*’ is that the blood
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19 of the animal is ‘incompatible’ with the blood of the patient. When a leprosy-affected
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21 individual ignores the ‘*treef*’, the disease will become worse. Emma, 79 years old, describes
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23 her youth as leprosy patient:
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29 *“There were a thousand and one ‘treven’. My diet consisted of a little bit of rice and*
30 *dry fish. And so I grew weak. I lacked resistance, and became skinny and weak.”*
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37 **Hereditary.** The third cause is the belief that leprosy is hereditary, as is illustrated by
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39 Henri, 55 years old:
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42 *“When I came here (leprosarium), you know who were here too? My uncle and a*
43 *cousin.”*
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47 **Concealment**

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50 During the interviews it became clear that one of the coping mechanisms used by leprosy-
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52 cured individuals was to hide their deformities from public view (Figure 2). Many
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54 participants complained about being stared at by other people, i.e. people who did not have
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56 leprosy. In this way, patients perceived themselves as being an undesirable, rejected
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3 stereotype rather than a healthy normal person.²² It made them feel shy and uncomfortable.

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5 Peter, 71 years old, stated:

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8 *“I am cured, but still I am ill”*

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11 He did not want to draw attention to his mutilations and chose to conceal the outward signs of
12
13 his disease. This behavioural reflection of illness perception was observed using the CSM. A
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15 common method of concealment was to use clothing; wearing loose sleeves or using a scarf to
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17 lie over their hands.

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21 The woman in the picture, Maria, 73 years old, said:

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24 *“When they do not see it (her hands), they will not look at me And when people*
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26 *persistently stare at you, you become, as being a human, nervous and shy. To prevent*
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28 *this, I always do like this” (putting her hands under the cloth).*

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34 INSERT FIGURE 2 ABOUT HERE

35 36 37 38 39 **Discussion**

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46 Our findings show that leprosy-cured individuals in Surinam have culturally
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48 influenced beliefs about the perceived causes of leprosy. Leprosy is perceived as a chronic
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50 illness due to its enduring disfigurements. People with leprosy experience less negative illness
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52 perceptions than the Surinam health professionals expected. Compared to patients with other
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54 chronic somatic illnesses, patients with leprosy had similar scores on the B-IPQ. Using the
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56 CSM, Concealment was identified as the most common form of coping. Because of our
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3 semi-qualitative approach we were able to identify this belief of “still being ill”, and the way
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5 leprosy-cured individuals dealt with it in Surinam. Moreover, the identification of the origin
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7 of their perceptions only became apparent by listening carefully to their illness narratives
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9 using narrative methodologies. This supports the value of qualitative research in exploring
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11 these issues.
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15 We identified discrepancies between what health care professionals believe and what
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17 leprosy-affected people believe is the cause of leprosy. The current biomedical view is that
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19 the cause is mostly bacterial whereas the leprosy-affected participants believed it to be largely
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21 food-related. The finding that health care professionals have different views than the affected
22
23 individuals is well-known: patients seem to be more resilient than their partners and
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25 caregivers.^{275,286}
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29 The chronic nature of leprosy became apparent when using the B-IPQ. The timeline
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31 dimension was consistent with other chronic diseases, indicating that the effects of illness
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33 extend beyond the point of medical cure., in that its effects extend beyond the point of
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35 medical cure, is shown in the similarity of the B-IPQ scores of the participants in this study
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37 with those of patients with other chronic diseases. Leprosy Leprosy-cured individuals
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39 perceived their illness to be chronic, as did patients with more 'traditional' chronic illness.
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41 The notion that food is often perceived as a cause of leprosy illustrates the fascinating
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43 phenomenon of 'treef'. Food appears to be a specific perceived cause of the illness in
44
45 Suriname. This striking narrative is in line with Douglas' proposition that dietary laws
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47 intricately model the body.²⁵ The denial of infection as the cause of leprosy places
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49 Surinamese leprosy-cured individuals, metaphorically speaking, in the first half of the 19th
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51 century, when leprosy was seen as noninfectious more generally, i.e. by the medical
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53 profession and by society at large. Interestingly, the Surinam people may have correctly
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3 identified another potential, non-human, source of infection i.e. the armadillo (*Dasypus*
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5 *novemcinctus*) which appears to be a natural host of *M. leprae*.²⁹⁷
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8 Due to the small sample, the data from the questionnaires may not be representative of
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10 all Surinam people with leprosy, or of leprosy-affected individuals in other parts of the world.
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12 Social desirability may have been an issue in this study. This may be countered by listening
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14 respectfully to individual participants. In terms of recruitment, some potential health care
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16 participants declined to take part because the data collection methods were perceived to be too
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18 time-consuming. This limited our ability to further explore apparent discrepancies in greater
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20 depth.
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24 Implications for further research pertain to more in-depth exploration of illness
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26 perceptions and their determinants and consequences, from the perspective of key
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28 stakeholders, e.g., patients, their partners, relatives, health care providers, in a large multisite
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30 study. Within such work, enhanced understanding of the stigma associated with leprosy might
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32 be gained by drawing on HIV/AIDS research, as the public perception and personal
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34 experience of this infectious disease has improved dramatically in recent years.³⁰²⁸
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36 Additionally, artistic works, such as novels, films, paintings or music, may be useful in
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38 helping us to better understand the illness perceptions surrounding leprosy. A novel such as
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40 “*A burnt-out case*”³¹²⁹, the film “*Molakai*”³²⁰, the painting “*Walking corpses*”³³¹ or the song
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42 “*Leprosy*” by the hard rock group Death³⁴² may provide the researcher with perceptions of
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44 leprosy from a wide range of perspectives.
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50 Clinical implications of our study indicate that health care providers should aim to
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52 incorporate local ‘folk models’ of leprosy into their models of medical care. Such an approach
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54 may improve adherence to long-term medication use and improve illness control. On a
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56 societal level, improving the image of leprosy may improve the psychosocial experiences of
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58 stigma of people affected by the illness. Involving people affected by leprosy would help to
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ensure that such interventions reflect patients' experiences and address their needs and priorities.

For Peer Review

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Table 1 Studies on illness perceptions in (ex-) patients with leprosy¹¹⁻²⁰

First author year country	# Patients, Clinical characteristics	Assessment of illness perceptions	Results	Comments
Feliciano 1998 Brazil	64 leprosy patients, 119 controls who sought diagnostic services	Semi-structured interview	Patients had low frequency of spontaneous explanatory models re leprosy	The patients' social network is of crucial importance in the use of health services. Patients may not voice their thoughts about leprosy out of fear of social rejection
Heijnders 2004 Nepal	76 leprosy patients in a leprosy control project	Open qualitative interviews	Patients attributed meaning to their symptoms in CSM – dimensions: Identity; stigma; adherence; causes; treatment control. These were related to adherence to medication.	Explanatory models approach was used (Kleinman, year).
Mull 1989 Pakistan	59 outpatients, 69 inpatients with leprosy	Semi-structured interview	Denial was highly prevalent (~60%). Leprosy attributed to dietary causes (~50%), physical causes within the body (~25%), in the environment (~15%), emotional and magical causes (~10%)	Denial is understandable in a society that stigmatizes persons with leprosy. Public health interventions aimed at the society at large may be instrumental in addressing the image of leprosy and thereby improve the fate of persons with leprosy

Neylan 1988 Thailand	61 inpatients with leprosy	Explanatory model approach with open interviews	Causes for leprosy: sin, karma, humoral imbalances. Leprosy not perceived as chronic condition but as a series of acute disorders	Modern medical management needs to take explanatory models into account
Opala 1996 Sierra Leone	Not specified	Open interviews	Leprosy perceived as witchcraft; “lepers are witches”. Herbal medicines treatment of choice, despite availability of modern medication	Medical anthropology research
Stevellink 2011 India	95 leprosy patients (hospitals, charity projects, home visits)	questionnaires	Stigma dominant phenomenon; social participation severely restricted	Theory-driven empirical study
Tsutsumi 2004 Bangladesh	140 persons with leprosy	CES-D to assess depression in association with having leprosy	Higher scores in leprosy patients on ‘depression’, associate with more severe degree of leprosy	Plea for public health emphasis on reducing discrimination
van de Weg 1998 Nigeria	Key informants (e.g., folk healers); 60 persons with leprosy	questionnaire	Traditional beliefs dominant (e.g., God’s wish); related to help- seeking	Illness perceptions related to adherence and help-seeking
Weiss 1992 India	56 recently diagnosed leprosy out-patients	EMIC (Explanatory Model Interview Catalogue)	High levels of depression and anxiety; causal attributions: food/water; germs/dirt; magico-religious	Belief in a traditional cause of illness associated with clinic attendance
White 2005 Brazil	43 patients	In-depth interview	Folk models of illness and biomedical models of illness were observed	Explanatory models may be associated with adherence to treatment

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For Peer Review

Table 2. Socio-demographic and illness characteristics of leprosy-cured individuals

	Leprosy-cured individuals (n=13)
Percentage females	53.8%
Age, mean (SD)	74.1 (7.2)
Age at diagnosis of leprosy, mean (SD)	10.4 (3.8)
WHO, EHF sum score, mean (SD)	7.5 (2.5)
Ethnicity	
Creole	8 (62%)
Mixed	3 (18%)
Caucasian	1 (6%)
East Indian	1 (6%)
Marital status	
Married	4 (31%)
Unmarried	9 (69%)
Children, mean (SD)	3.9 (3.3)
Education	
Incomplete elementary school	13 (100%)
Elementary school or higher	0 (0%)
Work history	
Employed	11 (85%)
Unemployed	2 (15%)
Accommodation	
Leprosarium	8 (62%)
Private housing	5 (38%)

EHF = eye, hands and feet (0-2, for both eyes, hands and feet - six sites) (minimum 0, maximum 12). The

leprosarium mentioned was the Estherhof.

Table 3. Mean scores (SD) on the B-IPQ dimensions of leprosy-cured individuals and health care professionals who completed the questionnaire as if they were leprosy-cured individuals

Dimension	Leprosy-cured individuals (n=13)	Health care professionals (n=11)
Consequences ¹	4.8 (3.9)	7.5 (1.7)*
Timeline ¹	8.5 (2.4)	8.9 (2.0)
Personal control	6.2 (3.4)	5.6 (3.0)
Treatment control	6.9 (3.7)	6.4 (2.7)
Identity ¹	6.1 (3.3)	6.6 (2.4)
Concern ¹	3.3 (4.3)	7.9 (2.3)**
Coherence	5.7 (4.5)	7.3 (1.8)
Emotional response ¹	5.7 (3.9)	7.3 (2.2)

¹ Higher scores indicate more negative perceptions

*p<0.05, ** p<0.01

Table 4. Mean scores (SD) on the B-IPQ dimensions of leprosy-cured individuals versus two other chronic illnesses, i.e. systemic lupus erythematosus and asthma.^{11,25}

Dimension	Leprosy (N=13)	SLE (N=31) ²⁵	Asthma (N=309) ¹¹
Consequences ¹	4.8 (3.9)	6.5 (2.3)	3.5 (2.3)
Timeline ¹	8.5 (2.4)	9.2 (1.8)	8.8 (2.2)
Personal control	6.2 (3.4)	5.6 (2.7)	6.7 (2.4)
Treatment control	6.9 (3.7)	8.4 (1.6)	7.9 (2.0)
Identity ¹	6.1 (3.3)	6.0 (2.6)	4.5 (2.3)
Concern ¹	3.3 (4.3)	5.8 (2.7)	4.6 (2.8)
Coherence	5.7 (4.5)	6.8 (1.9)	6.5 (2.6)
Emotional response ¹	5.7 (3.9)	5.8 (2.7)	3.3 (2.9)

¹ Higher score indicate more negative perceptions

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Figure 1a. Perceived causes of leprosy in leprosy cured individuals
88x51mm (96 x 96 DPI)

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Figure 1b. Perceived causes of leprosy in health care professionals completing the questionnaire as if they were patients
88x51mm (96 x 96 DPI)

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Figure 2. Concealment of the disfiguring mutilations on the hands of leprosy cured Maria, a 73 years old woman (Source: Spapens & Stads, 2012)²⁶
914x682mm (72 x 72 DPI)

Abstract

Objective: Leprosy has rarely been subject of health psychology research despite its substantial impact. Our aim was to explore illness perceptions in patients and their health care providers in Surinam. The Common Sense Model (CSM) was the guiding theoretical model.

Design: Patients with biomedically-cured leprosy and their health care providers completed the B-IPQ and took part in semi-structured interviews. The literature on illness perceptions in patients with leprosy was reviewed.

Main outcome measures: Patients' B-IPQ scores were compared with samples of patients with other (chronic) illnesses, and with health care providers completing the questionnaire as if they were visibly disfigured patients. Quotations from the semi-structured interviews were used to contextualise the illness perceptions.

Results: Patients' B-IPQ scores reflected the chronic nature of leprosy and were comparable with those with other chronic illnesses. Health care providers perceived leprosy to have a greater negative impact than did the patients. Perceived understanding of causes differed considerably between patients and health care providers.

Conclusion: Leprosy continues to be experienced as an illness with major psychological and social consequences such as stigmatisation, even after biomedical cure. Interventions that target patients, health care providers, and society at large may help reduce perceived shame and stigma. The CSM is a helpful theoretical model in studying this population.

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3 **Keywords:** leprosy; illness perceptions; chronic illness; stigma; Common Sense Model
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For Peer Review

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3 Leprosy, also known as Hansen's disease, is an infectious disease caused by the bacteria
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5 *Mycobacterium leprae* which affects the skin and peripheral nerves. Leprosy is an important
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7 global health concern; early diagnosis and a full course of treatment are critical for preventing
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9 lifelong neuropathy and disability.¹⁻³ In spite of the fact that nowadays leprosy can be cured
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11 with the help of a strict treatment schedule of multidrug therapy (MDT), it has not yet been
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13 eradicated. When leprosy is diagnosed and treated early, the disease results in few or no
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15 visible mutilations. However, if it is not diagnosed and treated early, outwardly visible signs
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17 of the illness, such as deformed fingers and toes, continue to influence the life of the leprosy-
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19 cured individual, even though they have completed a full course of medication. In this way,
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21 the leprosy-cured individual, and the people he or she is in contact with, will be constantly
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23 stigmatized due to the presence of the mutilating disease.⁴ Rehabilitation, equal opportunities
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25 and social inclusion continue to be a considerable challenge for leprosy-cured individuals,
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27 who, often, are abandoned by their families and perceived as outcasts by society.^{5,6}
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33 For centuries the disfigurements of leprosy patients were a source of stigmatization for
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35 the sufferers of the illness.⁷ The stigma of leprosy can be so severe that people hide signs of
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37 onset, causing them to seek medical attention too late or not at all.⁸ Potential repercussions of
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39 these behaviours are disease progression and disease transmission as discontinuation of
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41 therapy may lead to drug resistance. Therefore, the psychological consequences of leprosy
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43 and onset of leprosy are not only the patient's problem, but also a problem for his or her
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45 families, caregivers and for society at large; all experience the negative consequences.
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50 Illness perceptions are cognitive and emotional representations of the illness by the
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52 patient. Cognitive representations are the labels patients use to describe the disease (*identity*),
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54 the expected effects of the illness (*consequences*), the ideas about the cause (*cause*), the
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56 perception of how long it will last (*timeline*) and the thoughts about the ability to recover
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58 (*control*). The emotional representations incorporate the concern of the patients and the
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3 emotional response. Illness perceptions, meaning of health, and illness behaviour affect
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5 stigma and behaviour relating to disease control. These concepts are outlined in the Common-
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7 Sense Model (CSM) in which cognitive and emotional representations of illness are described
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9 as guiding the behavioural response of the patient. CSM research has shown that coping and
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11 illness perceptions are determinants of outcome in illness.⁹ Kleinman's 'explanatory models'
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13 is another theoretical concept in studying how people make sense of an illness and its
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15 treatment.¹⁰ To date, only a handful of empirical studies considering illness perceptions and
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17 explanatory models of individuals affected by leprosy have been published in international
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19 journals (summarized in Table 1).¹¹⁻²⁰ For the most part, the few studies that have been
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21 published have focused on causal attributions. The relatively recent concept of illness
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23 perceptions appears not to have been explored in samples of persons with leprosy. Our study
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25 addresses this gap in the literature.²¹

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39 The present study aims to assess illness perceptions of individuals in Surinam who
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41 have been medically cured of leprosy and who have visible disfigurement. Our aim is to
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43 identify cognitive and emotional representations of illness to understand patient behaviour
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45 and to contribute to patient-specific interventions. Illness perceptions of health care providers,
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47 completing the questionnaire as being a patient, were also studied to detect possible
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49 discrepancies between how they think about patients' illness perceptions and those of the
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51 actual patients.
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Methods

A mixed method design was used: patients and health care providers, completing the questionnaire as being a patient, filled out a validated questionnaire (B-IPQ) and responded to questions in a semi-structured interview. The B-IPQ assessed cognitive and emotional representations of illness by the patient. The common sense model was used to evaluate the identified cognitive and emotional representations of the illness. Previous research indicated that those representations were highly influential on patients' behaviour.⁹ In the semi-structured interview specific behaviour following the illness perceptions was explored. Narrative methodologies were used to understand the concept of stigma and the rituals of the patient.²²⁻²³

Our study sample comprised leprosy-cured individuals who were previously diagnosed with leprosy and have received successful treatment to eradicate the causative bacteria *Mycobacterium leprae*. The WHO classifies leprosy related impairment in three grades: Grade 0 (no impairment), Grade 1 (loss of sensation in hand or foot) and Grade 2 (visible impairment).³ People were eligible if they were affected by Grade 2 leprosy, able to give consent and were living in Surinam. All potential participants lived in a leprosarium, a center of accommodation for leprosy-cured individuals, under the auspices of the Esther foundation, Paramaribo, Surinam. The Esther foundation is a charity organization that supports the re-integration of leprosy-cured persons into society, for example, by using their Esther bus to make cultural trips and by organizing leprosy awareness education for surrounding primary schools. People with leprosy were approached by their social worker, employees of the Esther foundation, and were provided with information about the study and allowed time to consider participation. Ethical permission was granted by the Esther foundation ethics council. Study participation was based on free will, anonymity and confidentiality.

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3 Fifteen leprosy-cured individuals were approached; two refused to take part due to an
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5 intercurrent illness. In this paper pseudonyms are used to ensure anonymity of the
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7 participants. Health care professionals involved in medical care for leprosy-cured individuals
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9 in Surinam were invited to take part in the research. They included medical doctors from the
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11 Academic Hospital of Paramaribo and the Dermatological Service of Surinam, and nurses and
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13 social workers from the Esther foundation. The medical doctors were dermatologists and had
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15 experience of working with leprosy-cured patients; the nurses had specialized in leprosy
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17 nursing care. The social workers managed social activities such as excursions or religious
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19 meetings. Twenty health care professionals were approached; nine did not want to participate
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21 because they found the questionnaires too time-consuming.
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26 Data regarding sociodemographic and clinical characteristics of the patient
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28 participants were collected from the files in the Esther foundation. The Brief Illness
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30 Perception Questionnaire (B-IPQ) was used to assess illness perceptions.²⁴ The B-IPQ
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32 consists of eight questions, answered on a scale from 0 to 10, and one open question, which
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34 assesses three perceived causes of the illness. The Dutch version of the B-IPQ has been used
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36 in several populations with chronic illness.²⁵ The questionnaire was given to both the leprosy-
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38 cured participants and the health care professionals. Health care professionals were asked to
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40 complete the questionnaire as if they were visibly disfigured leprosy-cured patients.
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45 Semi-structured interviews were used to explore participants' illness perceptions and
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47 their resulting behaviour, using the CSM. The topics included: origin and evolution of the
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49 illness, shame and concealment, punishment, impurity, and sexuality. Once informed consent
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51 had been obtained, interviews were conducted in participants' homes, by the first author. All
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53 interviews were conducted in Dutch and lasted approximately 90 minutes. They were
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55 recorded on audiotape for reasons of accuracy, and transcribed verbatim.
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3 Quantitative data were analyzed with SPSS version 20 software. Socio-demographic
4 and illness characteristics were analyzed with descriptive statistics and frequencies.
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7 Independent *t*-tests were used to compare B-IPQ scores between leprosy-cured individuals
8 and health care professionals, and between leprosy-cured individuals and reference data from
9 patients with SLE (systemic lupus erythematosus) and asthma. Using Wordle™ a word cloud
10 was created from answers to question 9 from the B-IPQ (“What are the three most important
11 causes for your illness?”) to provide graphic illustration of the perceived possible causes.
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18 19 **Results**

20 21 *Participants*

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24 Fifteen leprosy-cured patients were approached, 13 participated. The mean age of the leprosy-
25 cured individuals was 74.1 years (SD 7.2); mean age at diagnosis was 10.4 years (SD 3.8). Of
26 the 13 participants 8 were Creole, 3 had mixed ethnicity, 1 was Caucasian, and 1 was from
27 Eastern India. Full socio-demographic and illness characteristics are shown in Table 2.
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INSERT TABLE 2 ABOUT HERE

47 48 *Illness perceptions*

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3 overestimated by the health care professionals. Leprosy-cured individuals had high scores on
4
5 the Timeline dimension, meaning that they perceived leprosy as an illness which has a long-
6
7 lasting impact on their lives. We compared our results with those from studies of two other
8
9 chronic illnesses, i.e. systemic lupus erythematosus (SLE) and asthma (Table 4).^{11,25} We
10
11 found similar response patterns across the studies; there were no significant differences
12
13 among respondents with leprosy and the other two chronic illnesses.
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17 INSERT TABLE 3 ABOUT HERE

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20 INSERT TABLE 4 ABOUT HERE

21 22 Perceived causes

23
24
25 In response to the open question of the B-IPQ: “What are the three most important
26
27 causes for your illness?”, family curse, food, and heredity were most often reported by the
28
29 patients (Figure 1 a) - the larger the font, the greater the number of responses. Bacterial
30
31 cause was cited most often by the health care providers (Figure 1 b.).
32
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38 INSERT FIGURES 1 a and 1 b ABOUT HERE
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46 **Family curse.** The family plays an important role in the beliefs regarding the causes
47
48 of leprosy. Actions of a family member, before the birth of the individual or during
49
50 pregnancy, were thought to influence the health status of the child, as stated by Loretta, 79
51
52 years old,
53
54

55
56 *“It is hard to understand these things (possible causes), you will not understand but in*
57
58 *Surinam we believe that when people do bad things ... this will result in having*
59
60

1
2
3 *deficient children. For example, my grandfather had kicked a boa constrictor to*
4 *death, and my mother had beaten a fat frog to death.”*
5
6
7

8 **Food.** Beliefs and behaviour related to eating were often mentioned during the
9
10 interviews. The most striking belief was the fear of eating certain food products, for example
11
12 animals such as unscaled fish, armadillo, snake or turtle. This symbolic belief is as also found
13
14 in Douglas’ description of dietary laws in a more religious context.²³ In Surinam this belief is
15
16 called ‘*treef*’ (*plural: treven*). A ‘*treef*’ can be explained as a personalized ban on eating
17
18 specific food products. A patient explained that the thought behind the ‘*treef*’ is that the blood
19
20 of the animal is ‘incompatible’ with the blood of the patient. When a leprosy-affected
21
22 individual ignores the ‘*treef*’, the disease will become worse. Emma, 79 years old, describes
23
24 her youth as leprosy patient:
25
26

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28
29 *“There were a thousand and one ‘treven’. My diet consisted of a little bit of rice and*
30 *dry fish. And so I grew weak. I lacked resistance, and became skinny and weak.”*
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37 **Hereditary.** The third cause is the belief that leprosy is hereditary, as is illustrated by
38
39 Henri, 55 years old:
40
41

42 *“When I came here (leprosarium), you know who were here too? My uncle and a*
43 *cousin.”*
44
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46

47 **Concealment**

48

49
50 During the interviews it became clear that one of the coping mechanisms used by leprosy-
51
52 cured individuals was to hide their deformities from public view (Figure 2). Many
53
54 participants complained about being stared at by other people, i.e. people who did not have
55
56 leprosy. In this way, patients perceived themselves as being an undesirable, rejected
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1
2
3 stereotype rather than a healthy normal person.²² It made them feel shy and uncomfortable.

4
5 Peter, 71 years old, stated:

6
7
8 *“I am cured, but still I am ill”*

9
10
11 He did not want to draw attention to his mutilations and chose to conceal the outward signs of
12
13 his disease. This behavioural reflection of illness perception was observed using the CSM. A
14
15 common method of concealment was to use clothing; wearing loose sleeves or using a scarf to
16
17 lie over their hands.

18
19
20 The woman in the picture, Maria, 73 years old, said:

21
22
23 *“When they do not see it (her hands), they will not look at me And when people*
24
25 *persistently stare at you, you become, as being a human, nervous and shy. To prevent*
26
27 *this, I always do like this” (putting her hands under the cloth).*

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34 INSERT FIGURE 2 ABOUT HERE

35 36 37 38 39 **Discussion**

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45 Our findings show that leprosy-cured individuals in Surinam have culturally
46
47 influenced beliefs about the perceived causes of leprosy. Leprosy is perceived as a chronic
48
49 illness due to its enduring disfigurements. People with leprosy experience less negative illness
50
51 perceptions than the Surinam health professionals expected. Compared to patients with other
52
53 chronic somatic illnesses, patients with leprosy had similar scores on the B-IPQ. Using the
54
55 CSM, concealment was identified as the most common form of coping. Because of our semi-
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3 qualitative approach we were able to identify this belief of “still being ill”, and the way
4
5 leprosy-cured individuals dealt with it in Surinam. Moreover, the identification of the origin
6
7 of their perceptions only became apparent by listening carefully to their illness narratives
8
9 using narrative methodologies. This supports the value of qualitative research in exploring
10
11 these issues.
12

13
14 We identified discrepancies between what health care professionals believe and what
15
16 leprosy-affected people believe is the cause of leprosy. The current biomedical view is that
17
18 the cause is mostly bacterial whereas the leprosy-affected participants believed it to be largely
19
20 food-related. The finding that health care professionals have different views than the affected
21
22 individuals is well-known: patients seem to be more resilient than their partners and
23
24 caregivers.^{27,28}
25
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29 The chronic nature of leprosy became apparent when using the B-IPQ. The timeline
30
31 dimension was consistent with other chronic diseases, indicating that the effects of illness
32
33 extend beyond the point of medical cure. Leprosy-cured individuals perceived their illness to
34
35 be chronic, as did patients with more ‘traditional’ chronic illness. The notion that food is
36
37 often perceived as a cause of leprosy illustrates the fascinating phenomenon of ‘treef’. Food
38
39 appears to be a specific perceived cause of the illness in Suriname. This striking narrative is in
40
41 line with Douglas’ proposition that dietary laws intricately model the body.²⁵ The denial of
42
43 infection as the cause of leprosy places Surinamese leprosy-cured individuals, metaphorically
44
45 speaking, in the first half of the 19th century, when leprosy was seen as noninfectious more
46
47 generally, i.e. by the medical profession and by society at large. Interestingly, the Surinam
48
49 people may have correctly identified another potential, non-human, source of infection i.e. the
50
51 armadillo (*Dasybus novemcinctus*) which appears to be a natural host of *M. leprae*.²⁹
52
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56 Due to the small sample, the data from the questionnaires may not be representative of
57
58 all Surinam people with leprosy, or of leprosy-affected individuals in other parts of the world.
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60

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3 Social desirability may have been an issue in this study. This may be countered by listening
4 respectfully to individual participants. In terms of recruitment, some potential health care
5 participants declined to take part because the data collection methods were perceived to be too
6 time-consuming. This limited our ability to further explore apparent discrepancies in greater
7 depth.
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15 Implications for further research pertain to more in-depth exploration of illness
16 perceptions and their determinants and consequences, from the perspective of key
17 stakeholders, e.g., patients, their partners, relatives, health care providers, in a large multisite
18 study. Within such work, enhanced understanding of the stigma associated with leprosy might
19 be gained by drawing on HIV/AIDS research, as the public perception and personal
20 experience of this infectious disease has improved dramatically in recent years.³⁰
21
22 Additionally, artistic works, such as novels, films, paintings or music, may be useful in
23 helping us to better understand the illness perceptions surrounding leprosy. A novel such as
24 “*A burnt-out case*”³¹, the film “*Molakai*”³², the painting “*Walking corpses*”³³ or the song
25 “*Leprosy*” by the hard rock group Death³⁴ may provide the researcher with perceptions of
26 leprosy from a wide range of perspectives.
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41 Clinical implications of our study indicate that health care providers should aim to
42 incorporate local ‘folk models’ of leprosy into their models of medical care. Such an approach
43 may improve adherence to long-term medication use and improve illness control. On a
44 societal level, improving the image of leprosy may improve the psychosocial experiences of
45 stigma of people affected by the illness. Involving people affected by leprosy would help to
46 ensure that such interventions reflect patients’ experiences and address their needs and
47 priorities.
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