



Nuancing stigma through ethnography: the case of cutaneous leishmaniasis in Suriname



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ABSTRACT

Health-related stigma and its dramatic consequences for those stigmatized have long been a crucial concern for public health authorities globally. However, before concluding that stigma spoils the lives of people with a particular disease or disability and is a major obstacle to obtaining/providing adequate health care, it is necessary to first determine *whether* there is actual stigmatization related to the condition concerned. The purpose of this article is to nuance the concept of stigma through a detailed ethnographic exploration of the experiences and views of patients and others affected by the parasitic skin disease cutaneous leishmaniasis (CL) in Suriname, South America. Qualitative data on the perceptions, treatment and illness experiences of CL in Suriname was collected in 2009 and 2010 among 205 CL patients at the Dermatology Service in the capital city Paramaribo, and among 321 people in different rural hinterland villages. The exploration reveals the complex and sometimes confusing statements of patients and observers of social reactions to the disease. The authors conclude that – in contrast to other societies – CL is not generally a stigmatized disease in Suriname (though this is not to deny that stigmatization may occur occasionally). Over the past decades, the concepts of stigma and stigmatization have been abundantly theorized. But when theory drifts away from ethnographic evidence, it may turn into imprecise popular speech. In this article, we warn against inflation of the term stigma and show, through an in-depth qualitative description of reactions to symptoms of CL in Suriname, why negative reactions may not necessarily entail stigma.

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Just as there are iatrogenic disorders caused by the work that physicians do (which then gives them more work to do), so there are categories of persons who are created by students of society, and then studied by them.

Goffman (1963:167)

1. Introduction

Since Erving Goffman coined the term ‘spoiled identity’ in 1963 to describe the social significance of stigma for affected individuals or groups, the concept has been frequently used – perhaps over-used – by social scientists, in particular with regard to illness and

disability. The emergence of HIV/AIDS has probably been the most prominent case in the past few decades to which scholars have applied stigma as a concept to capture the desperation of many sufferers. Innumerable are the studies describing the plight of people living with HIV/AIDS, whose situations are so dire, more due to the social discrediting and exclusion they experience than to the disease itself (e.g. Gielen et al., 1997; Parker and Aggleton, 2002; Lugalla et al., 2012). Studies of disability have also repeatedly pointed out that the social consequences of a physical or mental disability may be worse than the disability itself (see Luka, 2010; Parry, 2013; Smart, 2012; Susman, 1994; Wright, 1983).

Goffman showed how stigma is attached to the social identity of an individual when s/he is found to possess attributes that mark him/her as deviant, and as a result is treated as a different person. Who you *are* is overshadowed by what you *have*: a particular religion or ethnic origin, a criminal past, an illness or disability (cf. Kwansa, 2013:10). This ‘deviance’ is viewed as “a negative construct, a mark of shame that communicates to others the fact

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that a person is not able to fulfill social and cultural role expectations” (Green, 2009:15). Stigma, according to Link and Phelan (2001:367), happens when “elements of labeling, stereotyping, separation, status loss, and discrimination” co-occur in a power situation that allows the components of stigma to unfold. It is a typical “social process, experienced or anticipated, characterized by exclusion, rejection, blame, or devaluation that results from experience or reasonable anticipation of an adverse social judgment about a person or group” (Weiss and Ramakrishna, 2004:13).

Stigma therefore has a drastic impact on people's lives at different levels. In this article, we explore the extent to which people with the parasitic skin disease cutaneous leishmaniasis (CL) in Suriname, South America, are stigmatized. How do patients experience the disease? Are the consequences of reactions to the disease in Suriname as dramatic and life changing as is often the case with stigma? Can we even speak of stigma when we look at the reactions of patients and members of the studied communities to the disease? This article addresses these questions and shows how negative reactions to a disease may not necessarily entail stigma in the sense outlined above.

1.1. Cutaneous leishmaniasis and stigma globally

Cutaneous leishmaniasis affects between 1 and 1.5 million people globally and is a growing health problem. It is a skin infection caused by parasites belonging to the genus *Leishmania*, transmitted via the bite of infected female sand flies (*Phlebotomus* or *Lutzomyia* species) (Hu, 2013:8). Depending on the infecting species, different clinical symptoms can develop, “ranging from localized CL with single to multiple skin ulcers, satellite lesions or nodular lymphangitis” (ibid.). CL is clinically considered “one of the most serious skin diseases in developing countries” (González et al., 2008:1) due to the potentially extensive ulceration and scar formation.

Detection, treatment, and prevention of CL are, however, not currently prioritized at a global level. The World Health Organization (WHO) has acknowledged it as a severely neglected ‘Category 1’ disease, which covers emerging or uncontrolled diseases (WHO, 2004:13). Studies investigating CL-related stigma are scarce and lack in-depth exploration. Nevertheless, it is commonly seen as a health condition causing aesthetic (Banuls et al., 2007:10; Desjeux, 2004:10), social, and psychological stigma (Kassi et al., 2008:1; Reitingger et al., 2005; Yanik et al., 2004), and because of its potentially disfiguring effects, health researchers and the WHO (2008:5) have increasingly highlighted the severity of CL-related stigma. These observations in the literature fed our assumption that the onset of our research in Suriname that CL causes stigma.

1.2. Types of stigma

Based on numerous published and unpublished discussions in the past two decades on the nature of stigma, particularly health-related stigma, social scientists and health professionals have categorized the concept into three main types: 1) experienced or enacted stigma; 2) anticipated, felt, or perceived stigma; and 3) internalized or self-stigma. We have also added a fourth type that potentially applies to a disease such as CL, namely: 4) aesthetic stigma.

Experienced or enacted stigma is evident in diseases such as leprosy, HIV/AIDS, and mental illness, where patients are confronted with overt acts of discrimination, name-calling, abuse, or negative attitudes because of their illness (Bharat et al., 2001:16; Van Brakel, 2003). When individuals fear encountering overt or enacted stigma, or when they feel shame about being associated with a certain illness (Scambler, 2004:32), anticipated, felt, or

perceived stigma occurs. This type of stigma, due to ‘hidden distress’ (Scambler, 1998), may possibly “disrupt people's lives even more than enacted stigma” (Van Brakel, 2003:194).

When the social or public stigma attached to an illness is internalized or accepted by those at whom it is targeted, it is called internalized or self-stigma (Herek, 2009:32). “In this sense, internalization refers to a process in which a person ... accepts perceived exclusionary views of society and self-stigmatizes himself or herself” (Weiss, 2008:e237). Self-stigma may not be easily identified but can cause as much or even more (psychological) distress than enacted or anticipated stigma.

When people are stigmatized because of bodily deformities, studies use the term ‘aesthetic’ (or ‘unaesthetic’) stigma (Desjeux, 2004:10; Bañuls et al., 2007:10). In this case, stigmatization is caused by visible marks on the body or visible physical deformities. In our study, we investigated stigma through exploration of the abovementioned categories.

2. Research program

Our research was part of a large multi-disciplinary five-year study called ‘Leishmaniasis in Suriname’ (2009–2014). Suriname is a thinly populated country in the northern part of South America, with about 550,000 inhabitants. The ethnic composition of the population is diverse, consisting mostly of Hindustanis (27.4%), Maroons (21.7%), Creoles (15.7%), Javanese (13.7%), people of mixed descent (13.4%), and other smaller groups of Indigenous peoples and others (7.6%) (Algemeen Bureau voor de Statistiek, 2013:42). Maroons and Indigenous peoples live mostly in remote areas, deep in the Amazon rainforest that comprises 80% of the country. They are also the groups most vulnerable to CL infection, since its vectors, sand flies, are mostly present in the dense vegetation of the rainforest. These hinterland populations and others visiting the rainforest, either for work (in the gold mining or timber sector) or social activities (tourists, vacationers), were therefore the target groups of our research.

CL is endemic in Suriname, with the first case reported in 1911 (Flu, 1911). Epidemiological data are, however, scattered, poorly collected, and hardly monitored. A total incidence of 66 cases per 100,000 inhabitants was reported between 1979 and 1985 (Van der Meide et al., 2008:192). In 2011, nearly 300 new cases were reported at the Dermatology Service in the capital city Paramaribo (Hu, 2013:13).

To contribute to improved treatment, prevention, and control, several national and international research and education institutes in Suriname and the Netherlands set up and executed the ‘Leishmaniasis in Suriname’ program. This integrated program comprised three projects—one clinical, one biological, and one medical anthropological—which provided insights into different aspects of CL in the country. This article on stigma is a result of the third project (see Ramdas, 2015), which focused on perceptions and treatment of CL.

3. Methods

Anthropological fieldwork was conducted between September 2009 and December 2010 at different sites: at the Dermatology Service in Paramaribo, and in the hinterland in different Maroon and Indigenous villages (Godo-olo, Brokopondo Centrum area, Donderskamp, Tepu) and the Brazilian gold diggers village of Benzdorp. All sites were selected in close collaboration with national stakeholders. Formal permission to carry out the study, both at the national and local levels, was obtained from Suriname's Medical Ethical Commission and the heads of the selected villages.

At the Dermatology Service, a total of 205 clinically diagnosed

CL patients participated in the study – with their written or verbal consent – through a short (structured) questionnaire, which contained open-ended questions concerning a range of aspects regarding perceptions and explanations of the illness, health seeking, self-treatment, stigma, disease contamination, and prevention. Each interview lasted approximately 30 min, and in some cases 45 min to 1 h. The answers of all patients were handwritten on a form, or in some cases (7) audio-recorded and then transcribed verbatim. Interviews were carried out with two to four CL patients per day. Follow-up conversations also took place when patients returned after one to three weeks to continue their treatment, which consisted of receiving at least two or three intra-muscular injections with the biomedical drug Pentamidine. Four medical doctors and two nurses involved in the treatment of CL patients at the Dermatology Service were also interviewed.

Our analytical emphasis was predominantly based on the 205 CL patients seeking treatment at the Dermatology Service, because they had received a laboratory confirmed diagnosis. Since the majority of the patients worked in the hinterland and had family and cultural ties with communities there, complementary research was carried out in the hinterland. Findings and analysis are therefore derived from both survey-type research (at the Dermatology Service) and qualitative ethnographic inquiries (in the hinterland).

In the hinterland, a further 321 people participated in the study. This number included one CL patient and eighteen ex-CL patients, all of whom had received a clinical diagnosis, while the remainder claimed either to have had CL themselves in the past or knew others with the illness. During the field research visits, which lasted between three weeks and three months, daily life was observed and casual conversations, focus group discussions, and in-depth interviews were carried out with community members, including key persons such as village Captains (4), their assistants known as *basiyas* (6), and ‘traditional’ healers (3). Additionally, interviews (individually or in a group) were carried out among sixteen health workers (three men and thirteen women) of the Medical Mission (MZ), a private, non-profit, primary health care organization providing medical care in 57 village clinics in the hinterland. Health workers of the hinterland study sites also initiated contact between the field researcher and the CL patients in the villages who had received a clinical diagnosis at one of the MZ clinics. Notes of all conversations, observations, and discussions were taken. Both Dutch and Sranan (the national formal and informal languages respectively) were the main languages used during interviews. In addition to Sranan, the Maroon language Aucan, the Indigenous language Trio, and Portuguese were also used in the hinterland villages. Audio-recorded interviews (50) were transcribed verbatim and translated; photographs were taken with the permission of those involved.

With the help of research assistants, the data was processed using computer software. All answers to the questionnaires were categorized and thematically entered into Excel spreadsheets, providing a practical overview of all themes. After coding, part of the data was also entered into SPSS. Data collected in the villages were transcribed using Word. The content of all transcripts was labelled and marked for key themes. By carefully going through the textual information per theme and according to what the content revealed about the different contexts (e.g. what was being said (and not), about which aspects, by whom, about whom), data was further broken down into sub-themes, allowing us to compare and contrast data in a detailed manner. In this way, thematic content analysis was used to analyse the data and extract relevant relationships between study results. Interpretation of the data was based on hermeneutic understanding through empathic contextualization and attention to verbal and non-verbal communication. The research was an attempt to capture emic experiences and ideas

and combine these with quantification in the analysis, in order to reach a true-to-life description of CL-related experiences that would also be convincing to policymakers. These formalized interpretations were always linked to the principal researcher’s observations and notes during the actual fieldwork.

All information collected during the research was treated as confidential and the identities of all CL patients and people living in the field sites have been anonymized. Literature research, secondary analysis of national statistics and other written texts, the study of patient files, and a personal diary were also part of the methodological package.

The term stigma was not used in the interviews. Indeed, the word stigma does not exist in the local languages that were used during the fieldwork, but even when Dutch or Portuguese was spoken, the term was not mentioned. The questions were open, inviting CL patients and others to talk about their experiences. For instance, CL patients were asked: “How do those in your social environment (family, neighbours, friends and others) react when they see your [CL] sore?” Or “How do you yourself feel about having these sores on your body?” When interviewing others (i.e. villagers) it was asked: “How, according to you, are people with CL treated in this community? How do you view someone with a CL sore?” These open questions led to follow-up questions, which revealed more information.

The qualitative approach made it possible to detect and limit the bias of social desirability in the conversations with respondents. In the section on research findings below, a few examples of conversations on the topic of stigma are also included. These examples clearly show how inquiries were made into (the different types of) stigma without using the term itself. Analysis of possible stigmatization was conducted afterwards based on the various experiences encountered during the field study.

4. Socio-demographic context of the study population

Of the 205 CL patients at the Dermatology Service, 183 (89%) were male and 22 (11%) female. Most of the patients (81%) were in the working age category 20–49 years. The majority (77%) lived in the capital city or surrounding districts, but originated mainly from or worked in the hinterland. This is shown in [Table 1](#) below, along with other socio-demographic statistics.

Most of the male patients worked in the gold or timber sector (79%) as gold diggers, machine operators, mechanics, security guards, taxi or truck drivers, woodcutters, coal sellers, or construction and technical workers. Most women were housewives, but also worked on plots as petty farmers (as is the custom in hinterland villages). Brazilian and Dominican women were mostly working as commercial sex workers in the goldfields deep in the rainforest.

In the hinterland villages, of the total of 321 people, 188 (59%) were men and 133 (41%) women, belonging to Maroon (Aucan, Saramacan) and Indigenous (Trio, Caraib) communities, and a small Brazilian gold diggers community. Maroons have lived in the hinterland for more than four centuries and are the descendants of African slaves brought to Suriname by the Dutch between the 17th and 19th centuries. Indigenous peoples are the first inhabitants of Suriname. The Maroon and Indigenous communities have a large geographical spread, and population density in the hinterland is very low. Villages differ from very small—about 200 people—to relatively large – more than 3000 people ([Van ‘t Klooster, 2011:251](#)). The Brazilian community of Benzdorp has an estimated population of between 1000 and 3000 Brazilians, most of whom work as (illegal) gold diggers.

In [Table 2](#), an overview is provided of some socio-demographic characteristics of the hinterland study population (n = 321).

Table 1
Socio-demographic statistics of all CL patients (n = 205).

Characteristics	Number and percentage of patients					
	Male		Female		Total (M + F)	
	#	%	#	%	#	%
Age (in years)						
≤19	16	7.8	4	2	20	9.8
20–29	58	28.2	4	2	62	30.2
30–39	59	28.7	8	4	67	32.7
40–49	32	15.6	5	2.4	37	18.1
≥50	18	8.7	1	0.5	19	9.2
Total	183	89	22	11	205	100
Ethnic background						
Maroon	94	45.8	13	6.3	107	52
Hindustani	32	15.6	0	0	32	15.6
Javanese	21	10.2	0	0	21	10.2
Mixed	16	7.8	0	0	16	7.8
Creole	10	4.8	1	0.5	11	5.3
Brazilian/Dominican	5	2.4	6	2.9	11	5.3
Indigenous	5	2.4	1	0.5	6	2.9
Other (Dutch)	0	0	1	0.5	1	0.5
Total	183	89	22	11	205	100
Educational level						
No formal education	16	7.8	6	2.9	22	10.7
Primary	61	29.7	6	2.9	67	32.6
Secondary	103	50	9	4.3	112	54.6
Tertiary	3	1.4	1	0.5	4	2
Total	183	89	22	11	205	100
Living area						
Capital city or surrounding districts	147	71.7	11	5.4	158	77
Hinterland	29	14	9	4.3	38	18.5
Both hinterland and capital city	5	2.4	2	0.9	7	3.4
French Guyana	2	0.9	0	0	2	0.9
Total	183	89	22	11	205	100

Table 2
Socio-demographic statistics of the hinterland study population (n = 321).

Characteristics	Number and percentage of the hinterland study population					
	Male		Female		Total (M + F)	
	#	%	#	%	#	%
Age (in years)						
≤19	11	3.4	2	0.6	13	4
20–29	43	13.4	28	8.7	71	22.1
30–39	48	14.9	46	14.3	94	29.2
40–49	51	15.9	28	8.7	79	24.6
50–59	17	5.3	11	3.4	28	8.7
≥60	18	5.6	18	5.6	36	11.2
Total	188	59	133	41	321	100
Ethnic background						
Maroon	83	25.8	41	12.8	124	38.6
Indigenous	34	10.6	36	11.2	70	21.8
Brazilian	71	22.1	56	17.4	127	39.5
Total	188	59	133	41	321	100
Educational level						
No formal education	97	30.2	67	20.9	164	51.1
Primary	63	19.6	50	15.6	113	35.2
Secondary	28	8.7	15	4.6	43	13.3
Tertiary	0	0	1	0.3	1	0.3
Total	188	59	133	41	321	100
Living in hinterland village						
Godo-olo	42	13.1	24	7.5	66	20.6
Brokopondo Centrum area	41	12.8	17	5.3	58	18.1
Tepu	16	5	21	6.5	37	11.5
Donderskamp	18	5.6	15	4.7	33	10.3
Benzdorp	71	22.1	56	17.4	127	39.5
Total	188	59	133	41	321	100

The Maroon men in the hinterland study population were mostly (63%) working in the gold or lumber sector as gold diggers

(58%) or wood cutters (5%). Others were hunters or fishermen, wood craftsmen, shopkeepers and boat makers. Some were working in government service, others were retired or jobless. Of the 34 Indigenous men, 17 (50%) were involved in small scale trade, such as selling meat and fish (18%), agricultural products (26%) or birds (6%). Others worked in airstrip maintenance, the civil service, as teachers or were jobless. Of the 71 Brazilian men, the majority (90%) worked in the gold sector.

Most women (80%) in both the Maroon and Indigenous communities of the hinterland study population said that they were housewives, but they also worked as petty farmers, sold agricultural products, were engaged in processing food and preparing and selling food products, or they traded in fish or embroidery. Some also owned small shops where they sold beverages and other 'luxury' products. Other women worked as teachers, school cleaners, or in the civil service. One was a nurse. Most of the Brazilian women in Benzdorp were working in the commercial industry (54%), as commercial sex workers, or selling food, clothing and beauty products. Others were cooks for gold diggers, housewives, or owned gold digging machines or motor taxis.

Among the 321 people in the hinterland study population, one 19-year-old Indigenous man, a bird seller, was being treated for CL at the time of the research, while 18 people were classified as ex-CL patients (i.e. those who had previously undergone biomedical treatment). The majority of these ex-CL patients were from Maroon communities (12 men, 4 women), and the remainder (one man, one woman) were from Indigenous communities. Of the 18 ex-CL patients, most (11) were in the age category 30–49 years. The men were mostly engaged as gold diggers, the women were involved in different activities (such as shop keeping, nursing, housewife or student).

5. Research findings

5.1. Patients' experiences with CL and the reactions of others: no enacted stigma

About patients' experiences concerning stigma, of the 205 patients, 125 (12 women, 113 men; 61%) mentioned having experienced no negativity due to the disease. Sixty-six patients (9 women, 57 men; 32%) did report having experienced unpleasant reactions from people in their social environment. The remaining 14 CL patients (one woman, 13 men; 7%) had no comments on the topic. Among the 66 CL patients who reported unpleasant experiences because of the disease, 47 (four of whom were women) reported having experienced no overt acts of hostility. When these latter respondents are considered together with the 125 CL patients who reported experiencing no negativity, the research supports the finding that most of the CL patients we talked with (16 women, 156 men; 84%) – did not experience enacted stigma due to their sores. Many patients even reacted with surprise to questions concerning stigma, while some laughed and others had little to say about it. The majority reported that they were mostly treated as "normal", "like usual", or "not differently" by those in their social environment. "People just advise us to go to the doctor", several CL patients (18%) remarked.

Inquiries in the hinterland villages support the finding that the people with CL whom we talked to said that they did not experience enacted stigma due to their sores. Many people in the hinterland villages explained that CL is not a disease for which people should be avoided, isolated, or discriminated. It is known as a sore that is curable with the right medication. In the following, a small selection of conversations with people in the hinterland villages, on how CL is considered in terms of stigma, is presented. These conversations capture the personal and general attitude of people in the various communities. The conversation in the [first box](#) took

place during a meeting between the researcher (I), a *basiya* (R1), and his sister (R2) at Godo-olo. The topic was enacted stigma (without using the term) towards a fictive person with CL.

Box 1

Conversation between field researcher (I) and a *basiya* (R1) and his sister (R2) about enacted stigma at Godo-olo

I: If someone has a sore in the village, how do you treat him?

R1: Just like that.

R2: Free.

R1: Normal, free, we are normal with him. ...

I: But if someone would have it, like I would, and I would be walking towards you folks here, what would you do?

R1: Be normal

I: But if I stand close to you, won't you tell me to move away?

R2: No, no.

I: No?

R2: No, no, I won't say it. I won't scold you. You're ill, right? That thing, I don't think it can fly over to me [laughing]. If I'd do anything, it would be about if it would smell. Then too I wouldn't shout at you, but I would move away. I will not scold you, because you're ill ...

I: But can he [fictive CL patient] invite people over to his house to cook and eat freely?

R2: Yes, he can.

I: You'll eat freely?

R1: Yes, yes, you eat freely with him, no problem.

I: Even if he has a sore on his arm?

R1: Yes, it's no problem.

I: So, it's not a kind of disease to be secretive about?

R2: No, no, you can't hide it.

Another in-depth conversation (see [box 2](#)) on the topic of self- and enacted stigma between the field researcher (I) and another *basiya* (R), who had experienced multiple CL sores on his body, revealed further social responses:

Box 2

Part of a conversation between field researcher (I) and another *basiya* (R) about self- and enacted stigma at Godo-olo

I: (...) did you feel ashamed of it [CL]?

R: No, no, no, no, no. I'm not a person that feels ashamed if illness takes me. You see. I wasn't ashamed of it. No.

I: Did it smell?

R: Yes, it did. Very strong.

I: How did people react to you then?

R: No, I shouldn't lie. The people didn't let go of me. The people came to me. Because if there are people who love you, talk every day with you, they will come to you even in illness ...

I: And did people sit around you in a similar way as we do now [on chairs opposite one another in relatively close proximity]?

R: Yes.

I: Would they eat and drink with you?

R: Yes.

I: Did people give you a handshake?

R: Yes, the people didn't have problems with those things.

I: Here in the village, people behave normally, the usual way like they do, if you have *Busi Yasi* [CL], or they -

R: - will they live with you a certain way? No, no, we don't have that way of living with someone here. No.

I: But how come? Because it's a sore that smells, leaks water, dirty looking, etcetera, and still people are not different with you?

R: Yes. I understand what you're saying. But if we would look at it like that, like ... we are here at Godo-olo, we are ONE, yes?

I: Yes.

R: That means they won't leave you, isolate you, you understand? Plus we are members of one family, here we live separately [in separate houses], but we are all one.

The Captain of the Indigenous village Tepu responded as follows to the question of how people in the village are viewed when they have CL:

There is no problem with *kaasa* [CL] here, it doesn't matter. When you have *kaasa*, it does not matter, you can eat and drink with everyone, it's normal. *Kaasa* is not contagious. There is no discrimination in the village here on *kaasa*.

At Donderskamp, a 59-year-old man, a hunter, who had experienced CL, said:

There is no one who will reject you or refuse you because you have *Busi Yasi* [CL] (...) besides, you don't see people with *Busi Yasi* that often, that's why there is no attitude against it. And it is really not a sore to be afraid of, because it is curable. It is also not contagious, because otherwise everybody in the village would get it, right?

In addition to the ethnographic interviews, observations provided more understanding about the reactions of people to CL. At Tepu, for example, it was observed that family members of a 19-year-old man, Rudi, sat in close proximity to him, despite the dollar-shaped sore on the tibia of his left leg. Rudi was lying in a hammock, and after he stood up other family members went to sit in it, without any reservations or fear of contamination. He filled his day making bird cages, off and on surrounded by other family members and children. On another occasion, the principal investigator met Rudi walking in close company with his mother on their way to visit other family members. Along the way – about 3 min' walk – they met several people who greeted them, some of whom stood for a few seconds to chat with them. Rudi seemed totally at ease, wearing shorts, with a birdcage in his hand. His sore was visible to everyone, but no one seemed to avoid him.

The selected ethnographic inquiries and observations above

provide a sound understanding of the general and personal attitudes of the study population towards CL. The particular conversation with *basiya* R sheds light on how a cured CL patient experienced the disease in terms of self-stigma and enacted stigma. Overall, analysis of both the (survey-type) inquiries at the Dermatology Service and the ethnographic exploration in the hinterland villages suggests that in Suriname, people with CL encounter hardly any enacted stigma solely on the grounds of having CL sores on their bodies. Of course, we do not conclude – on the basis of a mainly qualitative research study – that CL-related stigma does not exist at all in Suriname. But we do aim to draw attention to the fact that the evidence gathered from the conversations and observations that took place for this study indicates that there is very little or even no blame or rejection of CL patients, as has been reported in other countries or regions, such as Afghanistan, Pakistan, Middle East and Maghreb (Kassi et al., 2008; see Web reference; Reitingier et al., 2005; WHO, 2007). People with CL sores tend to emphasize that they remain who they are; their identity does not become ‘tainted’ or ‘spoiled’ (Goffman, 1963), or in Kwansa’s (2013:10) terms, they do not *become* their illness. People with CL are not isolated or hidden.

Medical doctors and health workers working in the hinterland and at the Dermatology Service called CL a “low stigmatized illness”, but their use of the term stigma still reflects the commonly ‘inflated’ terminology as we discuss it in this paper. Those in a CL patient’s social environment stay in touch with the person just as they did before he/she developed the disease. Rejection or social exclusion because of the disease seemed to occur only rarely. We encountered hardly any hidden distress (Scambler, 1998) related to CL. The research also revealed that talking about the sore or showing it to others was rarely taboo. On the contrary, most patients openly showed others their sore(s) in the hope of receiving advice on effective medication in order to avoid (costly or faraway) biomedical treatment (see also, Ramdas, 2012).

5.2. CL patients’ negative experiences

Of the 66 CL patients at the Dermatology Service who did report negative experiences, thirty mentioned strong and overt reactions from others after seeing the sores. Thirty-two CL patients said that they themselves kept a distance from others because of their disease. They noticed how others avoided them or hesitated when sitting next to them (e.g. on public transport). Some believed that people only pretended to act normally, but were in reality disgusted by the sore. A few patients avoided certain public places in anticipation of negative remarks. Some explained that they were treated “normally” or “not differently” by others, but had decided to keep their own distance.

Of these 66 CL patients who reported having experienced negative reactions related to CL, the majority (38 patients, 58%) expressed feeling bad about their looks. Some said they were “disgusted” by their sores, others reported feeling “shy” or “ashamed”. These feelings were experienced when sores became bigger, or when they had multiple sores. The gruesome appearance of CL sores contributed to patients’ fear of the disease. Aside from a sore’s appearance, the growth of a sore, the increase in number of sores, and their visibility could also cause overt negative reactions from those in a patient’s environment. Strikingly, of the 66 CL patients who reported negative experiences, 23 (35%) had two or more CL sores on their body. Some patients were seriously affected by disseminated forms of CL, as was the case for a 39-year-old woodcutter, who had many small, pimple-like sores all over his body. In this case, his colleagues urged him to stop working. In all of these cases, however, experiences that pointed to a loss or ‘spoiling’ of their identity were not mentioned.

Coinciding with the number of lesions, in some cases the size, visibility, and location of the sores – on the face, ears, hands – contributed to the experience of negative reactions. Especially when sores occurred on the face, negative attitudes from others were more recognized. The face is of “essential importance in interpersonal relationships” (Koster and Bergsma, 1990:569), being the first body part that is looked at in interactions and that expresses a person’s personality. Indeed “The face is (...) a pre-eminent symbol of the self” (Synnott, 1990:407), while facial beauty is a “highly valued, and powerful attribute, of the self” (Synnott, 2006:163). Having facial disfigurements can therefore cause profound distress and self-stigma. Facial CL sores are, however, rare in Suriname, as we will discuss in the next section.

6. Inflation of stigma?

So far, we have described the reactions of others (i.e. those in a patient’s social environment) to CL patients, as well as patients’ own illness experiences and whether they had experienced *enacted, perceived, self- and/or aesthetic stigma*. We have used the term ‘stigma’, but the question we are trying to answer here is this: can we actually categorize and view the negative reactions to CL in light of the theoretical discussions and empirical observations regarding the term ‘health-related stigma’, in a similar way as we would do in the case of leprosy, HIV/AIDS, and mental illness? The above-mentioned nuances of the processes of stigmatization have refined our understanding of its origins and mechanisms, but have not mitigated Goffman’s initial qualification of the ‘spoiled identity’ and its dramatic consequences. In his literature review on health-related stigma, Van Brakel (2006:310) remarks that “Stigma and its psychosocial consequences cause indescribable suffering” profoundly affecting an individual, mentally, socially, in terms of employment, education, and missed health-seeking opportunities, among others.

In the case of CL in Suriname, do the negative reactions of others to the illness ‘change’ the individual or does the illness overtake the individual’s identity? Or, using Reis’ terms (1996:237–238): are the CL sores signs or marks that communicate to others that the bearer is ‘different’ from others in a negative sense? The answer is that this is hardly the case. With the exception of a few cases perhaps (see below), we cannot say that CL patients are stigmatized.

Negative reactions to an illness do not necessarily imply stigmatization. As Dijker and Koomen (2007:8), in line with Goffman (1963) and Crocker et al. (1998), have written:

stigma refers to an attribute or symbol (e.g. a word referring to that attribute) that is known to be negatively evaluated by a social group or society, in such a way that individuals or social groups associated with that attribute tend to be denigrated and socially excluded and hence stigmatized.

Our research shows that despite the ‘more serious’ cases of CL-related negativity, and without trivializing CL patients’ unpleasant experiences, these accounts cannot be labelled as (enacted) stigma. Indeed, several emphasized explicitly that they had never felt excluded or humiliated by others. Thus, in spite of open negative reactions and physical avoidance by others, patients’ lives in most cases went on as before. They kept working, as much as possible, fishing, planting, and doing their day-to-day activities.

The strong reactions of those upon seeing a large and/or raw CL sore can be understood as ‘natural’, in the sense that people tend to be initially frightened by serious bodily injuries. But such reactions also imply that they are cautious about infection. Lack of knowledge of the biomedical explanation for and aetiology of CL may lead to fear of contamination and to cautiousness, but not necessarily to

(enacted) stigma. These reactions do not devalue or socially isolate a person with CL. Follow-up conversations with a few (11) CL patients at the Dermatology Service, conversations with ex-CL patients in the hinterland and observations of their lives showed that as sores healed, other people's negative attitudes disappeared and they could continue to live normally, as they had done prior to the disease.

In terms of aesthetic stigma, CL scarring did not present itself as a problem among the study population. It is possible that because most of the CL patients were men, working in harsh professions where cuts and bruises are daily experiences, scars are less important to them than trying to survive and earn money. Maybe the outcome would be different if more women and children were affected, or if the type of CL experienced in Suriname was contagious, as is the case in other parts of the world.

One crucial explanation concerning the absence of (enacted) stigma is that CL in Suriname rarely causes facial disfigurements. While in some parts of the world, such as Afghanistan and Turkey, facial disfigurement from CL sores on the cheeks, nose, lips, and forehead is common and severe – due to the prevalence of harsher types of CL as well as muco-cutaneous leishmaniasis (WHO, 2002; Diniz et al., 2011; Cattand et al., 2006; WHO, 2007) – in Suriname this is hardly the case (Hu, 2013). The main causative agent for CL in Suriname is *Leishmania (Viannia) guyanensis*, which clinically manifests in a less extensive and destructive form (Hu et al., 2012).

It also seems likely that patients would have experienced more painful – stigmatizing – reactions if the lesions on their face had been bigger and more disfiguring. Proof of this assertion can be seen in the case of a 17-year-old patient who had attended the Dermatology Service prior to this study, and who from the age of five had suffered from a severe and mutilating form of CL (Van der Meide et al., 2008). He was diagnosed as having been infected with a very serious – but rare for Suriname – form of CL caused by *Leishmania (Leishmania) amazonensis*. For the years-long duration of his illness, he had lived in his hinterland village (ibid.) and, according to a dermatologist at the Dermatology Service (personal communication, 2010), had experienced intense social exclusion, being avoided by most people in his community.

It is not difficult to understand why deformities of the face have far reaching stigmatizing consequences for a CL patient. As mentioned above, the face represents a person's identity, and we know people by their faces. A 'spoiled' face is therefore easily (mis) taken as a sign of a spoiled identity. Stigmatization is thus arguably almost unavoidable if a person shows a marred face to the world, even if the viewer rationally knows that the disfiguring marks have nothing to do with the person's character and identity; it is, simply, impossible to ignore. A further complication is that, with some exceptions, the face is a part of the body that is generally the least covered (and coverable). As Goffman (1963:64–68) contends, a crucial element in stigma management is its visibility and perceptibility. Jones et al. (1984) refer to this as the 'concealability' of stigma. Hiding a bodily mutilation is therefore, in this case, most difficult where it would be most necessary: the face.

We must emphasize, however, that this interpretation of the stigmatizing effect of facial disfigurement is not directly based on our ethnographic data, but rather on logical reasoning and comparison. The large majority of the research participants were unfamiliar with this type of CL and did not mention facial mutilation when asked about what worried them most. They related the question to their livelihood and responded that wounds on their legs were the most troublesome as they hindered their daily activities. Indirectly, their association with work also confirms our conclusion about the absence of stigma.

Findings from a clinical study on health-related quality of life (HRQL) within the 'Leishmaniasis in Suriname' program (Hu et al.,

2013) also seem to support this conclusion. Hu and colleagues measured the HQRL among 163 CL patients using Skindex-29 questionnaires and the EQ-5D/visual analogue scale (VAS) prior to treatment. The majority of patients (86%) had sores on their upper and lower limbs and trunk. The study concluded that patients with lesions on the head/face, trunk, and upper limbs had a higher quality of life compared to those with lesions on the lower limbs. Lower quality of life of the lower limb group were related to the dimensions of "self care, mobility, usual activities, and pain/discomfort" (Hu et al., 2013:82) rather than to anxiety or depression, as is more likely in cases of stigmatization (Yanik et al., 2004).

7. Conclusion

Dijker and Koomen (2007:6) point out that stigmatization happens:

(...) when a deviant condition is increasingly perceived and responded to as a defining or essential attribute of the "whole" person or social group, or of the person's or group's reputation, character or identity. It goes at the cost of discovering the individual's or group's *non-deviant* and useful attributes, and treats the victim as "essentially" or morally bad, thereby withholding giving him or her a "second chance".

But as the authors go on, the term stigma may be too often and too easily applied. The question we therefore set out to ask is whether people with CL in Suriname are stigmatized. Does the fact of bearing CL sores on the body spoil one's identity?

This research concludes that there is hardly any (enacted) stigma related to CL in Suriname, and suggests that the term stigma may be an exaggeration when used for the case of Surinamese people infected with CL. The study has shown that most CL patients did not experience any negativity due to their illness, while only a relatively small number (66) did. We could perhaps describe the experiences of the latter group as bordering on stigma (mostly anticipated, internalized, or self-stigma). Stigmatization, in the sense of "exclusion, rejection, blame, or devaluation" (Weiss and Ramakrishna, 2004:13) as a result of the illness, did not occur and CL sores are not a "deeply discrediting" attribute (Goffman, 1963:12), nor do they mark patients as "essentially or morally bad" individuals (Dijker and Koomen, 2007:6).

We have been as clear as possible in presenting the sometimes confusing and even contradictory statements of our respondents in relation to their experiences of CL, and have explained how we reached our interpretation of these statements. The ethnographic methods, based on free discussions and conversations, combined with direct observations, made this interpretation possible. As mentioned, we did not enter the field with a prior intention to prove the 'absence' of stigma; rather, this impression developed based on the data as the study progressed, and eventually became our conclusion.

Our detailed ethnographic exploration of the experiences and views of CL in Suriname is relevant for theory debates on stigmatization far beyond the borders of this country. The study uncovers the complex and sometimes confusing statements of patients and observers of social reactions to the disease. We conclude that – in contrast to other societies – CL is not generally a stigmatized disease in Suriname, although – obviously – some cases of stigmatization do certainly occur. Our in-depth qualitative description of reactions to symptoms of CL has shown why negative reactions do not necessarily entail stigma.

When theory drifts away from ethnographic evidence, it may turn into imprecise popular speech. What we warn against is a gradual 'inflation' of the concept of stigma, particularly in health-

related and policy-directed reports that tend too easily to label unpleasant reactions to people with certain disease symptoms as stigmatizing. Other researchers in the field of neglected tropical diseases also warn against a too “euphoric use of stigma” (Ribera et al., 2009:1), which leads to the allocation of (often limited) resources to overcome this perceived obstacle, to the neglect of other aspects of health care provision that may be of higher priority. For public health authorities in Suriname, our conclusion undoubtedly contributes to lifting at least one ‘burden’ in the fight against CL. Efforts can instead be focused on other aspects requiring attention, such as improving case detection, treatment adherence, and prevention of CL.

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References

- Algemeen Bureau voor de Statistiek, 2013. Definitieve Resultaten Achtste Algemene Volkstelling, vol. 1. Algemeen Bureau voor de Statistiek/Censuskantoor, Paramaribo.
- Bañuls, A., Hide, M., Prugnolle, F., 2007. *Leishmania* and the leishmaniasis: a parasitic genetic update and advances in taxonomy, epidemiology and pathogenicity in humans. In: Baker, J.R., Muller, R., Rollinson, D. (Eds.), *Advances in Parasitology*. Academic Press, Amsterdam.
- Bharat, S., Aggleton, P., Tyrer, P., 2001. India: HIV and AIDS-related Discrimination, Stigmatization and Denial. UNAIDS, Switzerland.
- Cattand, P., et al., 2006. Tropical diseases lacking adequate control measures: dengue, leishmaniasis, and African trypanosomiasis. In: Jamison, D.T., Breman, J.G., Measham, A.R., Alleyne, G., Cleason, M., Evans, D.B., Jha, P., Mill, A., Musgrove, P. (Eds.), *Disease Control Priorities in Developing Countries*. World Bank, Washington, pp. 451–466.
- Crocker, J., Major, B., Steel, C., 1998. Social stigma. In: Gilbert, D., Fiske, S.T., Lindzey, G. (Eds.), *The Handbook of Social Psychology*. McGraw-Hill, New York, pp. 504–553.
- Desjeux, P., 2004. Leishmaniasis: current situation and new perspectives. *Immunol. Microbiol. Infect. Dis.* 27 (5), 305–318.
- Dijker, A.J.M., Koomen, W., 2007. *Stigmatization, Tolerance and Repair*. Cambridge University Press, Cambridge.
- Diniz, J.L.C.P., Rocha Costa da, M.O., Gonçalves, D.U., 2011. Muco-cutaneous leishmaniasis: clinical markers in presumptive diagnosis. *Braz. J. Otorhinolaryngology* 77 (3), 380–384.
- Flu, P.C., 1911. Die Ätiologie der in Surinam vorkommende sogenannten “Boschyaws” einer der aleppobeule Analogen. *Centralblatt für Bakteriologie, Parasitenkunde und Infektionskrankheiten* 60, 624–637.
- Gielen, A.C., et al., 1997. Women’s disclosure of HIV status: experiences of mistreatment and violence in an urban setting. *Women & Health* 25 (3), 19–31.
- Goffman, E., 1963. *Stigma: Notes on the Management of Spoiled Identity*. Prentice Hall, Englewood Cliffs, NJ.
- González, U., et al., 2008. Interventions for old world cutaneous leishmaniasis (Review). *Cochrane Libr.* 4, CD005067.
- Green, G., 2009. *The End of Stigma? Changes in the Social Experience of Long-term Illness*. Routledge, New York.
- Herek, G.M., Gillis, R.J., Cogan, J.C., 2009. Internalized stigma among sexual minority adults: insights from a social psychological perspective. *J. Couns. Psychol.* 56 (1), 32–43.
- Hu, R.V.P.F., 2013. *Treatment, Quality of Life and Cost-aspects of Cutaneous Leishmaniasis in Suriname*. Doctoral thesis. Dermatology Service, Paramaribo.
- Hu, R.V.P.F., et al., 2012. First case of cutaneous leishmaniasis caused by *Leishmania (Viannia) braziliensis* in Suriname. *Am. J. Trop. Med. Hyg.* 86 (5), 825–827.
- Hu, R.V.P.F., et al., 2013. The effect of body location of “New World” cutaneous leishmaniasis lesions on the quality of life in Suriname. Doctoral thesis. In: Hu, R.V.P.F. (Ed.), *Treatment, Quality of Life and Cost-aspects of Cutaneous Leishmaniasis in Suriname*. Dermatology Service, Paramaribo, pp. 71–86.
- Jones, E., et al., 1984. *Social Stigma: The Psychology of Marked Relationships*. Freeman & Company, New York.
- Kassi, M., et al., 2008. Marring leishmaniasis: the stigmatization and the impact of cutaneous leishmaniasis in Pakistan and Afghanistan. *PLOS Neglected Trop. Dis.* 2 (10), e259.
- Koster, M.E.T.A., Bergsma, J., 1990. Problems and coping behaviour of facial cancer patients. *Soc. Sci. Med.* 30 (5), 569–578.
- Kwansa, B.K., 2013. *Safety in the Midst of Stigma*. African Studies Centre, Leiden.
- Link, B.G., Phelan, J.C., 2001. Conceptualizing stigma. *Annu. Rev. Sociol.* 27 (1), 363–385.
- Lugalla, J., et al., 2012. Social context of disclosing HIV test results in Tanzania. *Cult. Health & Sex.* 14 (S1), S53–S66.
- Luka, E.E., 2010. Understanding the stigma of leprosy. *South Sudan Med. J.* 3 (3), 1–3.
- Parker, R., Aggleton, P., 2002. HIV and AIDS-related stigma and discrimination: a conceptual framework and implication for action. *Soc. Sci. Med.* 57 (1), 13–24.
- Parry, J.W., 2013. *Mental Disability, Violence, Future Dangerousness: Myths behind the Presumption of Guilt*. Rowman & Littlefield, Plymouth.
- Ramdas, S., 2012. *Cruel disease, cruel medicine: self-treatment of cutaneous leishmaniasis with harmful chemical substances in Suriname*. *Soc. Sci. Med.* 75 (6), 1097–1105.
- Ramdas, S., 2015. *Perceptions and Treatment of Cutaneous Leishmaniasis in Suriname: A Medical-anthropological Perspective*. Doctoral thesis. University of Amsterdam.
- Reis, R., 1996. *Sporen van ziekte: medische pluraliteit en epilepsie in Swaziland*. Het Spinhuis, Amsterdam.
- Reitinger, R., Aadil, K., Kolaczinski, J., Mohsen, M., Hami, S., 2005. Social impact of leishmaniasis in Afghanistan. *Emerg. Infect. Dis.* 11 (4), 634–636.
- Ribera, J.M., Grietens, K.P., Toomer, E., Hausmann-Muela, S., 2009. A word of caution against the stigma trend in neglected tropical disease research and control. *PLOS Neglected Trop. Dis.* 3 (10), 1–4.
- Scambler, G., 1998. Stigma and disease: changing paradigms. *Lancet* 352 (9133), 1054–1055.
- Scambler, G., 2004. Re-framing stigma. Felt and enacted stigma and challenges to the sociology of chronic and disabling conditions. *Soc. Theory & Health* 2 (1), 29–46.
- Smart, J., 2012. *Disability across the Developmental Lifespan*. Springer, New York.
- Susman, J., 1994. Disability, stigma and deviance. *Soc. Sci. Med.* 38 (1), 15–22.
- Synnott, A., 1990. The beauty mystique: ethics and aesthetics in the Bond genre. *Int. J. Polit. Cult.* 3 (3), 407–426.
- Synnott, A., 2006. The beauty mystique: ethics and aesthetics in the Bond genre. *Facial Plast. Surg.* 22 (3), 163–174.
- Van Brakel, W., 2003. Measuring leprosy stigma – a preliminary review of the leprosy literature. *Int. J. Lepr. other Mycobact. Dis.* 71 (3), 190–197.
- Van Brakel, W., 2006. Measuring health-related stigma – a literature review. *Psychol. Health & Med.* 11 (3), 307–334.
- Van der Meide, W., De Vries, H., Pralong, F., Van der Wal, A., Sabajo, L., 2008. *Leishmania (Leishmania) amazonensis* infection, Suriname. *Emerg. Infect. Dis.* 14 (5), 857–859.
- Van ’t Klooster, C.I.E.A., 2011. Het belang van medicinale, aromatische en cosmetische planten voor de Saramaccaners in het binnenland van Suriname. *OSO Tijdschrift voor Surinamistiek en het Caraïbisch gebied* 30 (10), 248–266.
- Web reference** <http://www.irinnews.org/Report/78674/AFGHANISTAN-No-medicine-for-leishmaniasis-in-Badakhshan-Province> (accessed 11.19.2014).
- Weiss, M.G., 2008. Stigma and the social burden of neglected tropical diseases. *PLOS Neglected Trop. Dis.* 2 (5), e237.
- Weiss, M.G., Ramakrishna, J., 2004. Health-related Stigma: Rethinking Concepts and Intervention. Background Paper. Royal Tropical Institute (KIT), Amsterdam.
- World Health Organization, 2002. *Cutaneous leishmaniasis, Afghanistan*. *Wkly. Epidemiol. Rec.* 77 (29), 241–248.
- World Health Organization, 2004. *Report of the Scientific Working Group Meeting on Leishmaniasis*. World Health Organization on behalf of the Special Programme for Research and Training in Tropical Diseases, Geneva.
- World Health Organization, 2007. *Cutaneous Leishmaniasis: Why Are You Neglecting Me? a WHO Initiative to Control Cutaneous Leishmaniasis in Selected Old World Areas*. WHO Document Production Services, Geneva.
- World Health Organization, 2008. *Report of the Consultative Meeting on CL*, Geneva, Headquarters 30 April to 2 May 2007. WHO Document Production Services, Geneva.
- Wright, B.A., 1983. *Physical Disability: A Psychosocial Approach*. Harper & Row, New York.
- Yanik, M., Gurel, M.S., Simsek, Z., Kati, M., 2004. The psychological impact of cutaneous leishmaniasis. *Clin. Exp. Dermatol.* 29 (5), 464–467.